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From Confusion to Clarity: Exploring the Diagnostic and Retraining Challenges for Dystonic Musicians

by

David Edward Gardner

A thesis submitted in fulfilment of the requirements for the degree of Doctor of Philosophy

to

Trinity Laban Conservatoire of Music and Dance

Research & Knowledge Exchange

Date of Submission

September/ 2025

DECLARATION

I, David Edward Gardner, declare that this PhD entitled: From Confusion to Clarity: Exploring the Diagnostic and Retraining Challenges for Dystonic Musicians, is my own original work and has not been submitted for any other degree or qualification at this or any other institution. I confirm that all sources have been properly cited and acknowledged, and that I have not engaged in plagiarism or any other form of academic dishonesty.

ABSTRACT

This PhD investigates how musicians with Musicians' Focal Dystonia (MFD) navigate and experience rehabilitation, with particular focus on journeys of retraining from pre-diagnosis to post-retraining. The research design combines three, mixed-methods studies to investigate MFD awareness and discourse surrounding MFD within UK conservatoires, musicians' utilisation and perceptions of retraining practices and the strategies, motivations, and perceived outcomes of self-developed retraining (SDR).

The research shows that low and inconsistent awareness of MFD amongst stakeholders, (instrumental teachers and students at UK conservatoires) contribute to diagnostic delays and poorly informed rehabilitation choices and decisions. Medical guidance provided to musicians following a diagnosis of MFD remains limited including inconsistent and infrequent signposting to non-pharmaceutical options. Retraining pathways lack structure and are marked by unclear goals and objectives, varied theoretical grounding and declining support systems over time. Retraining outcomes are mixed across methods, and progress typically occurs after extended period of time (often exceeding more than five years). The results demonstrate the complexity of the retraining process together with the significant psychological demands of recovery.

Over half of dystonic musicians that choose to retrain adopt self-developed approaches to retraining that are tailored to iteratively address problem-solving, experimental learning, and peer-informed exploration. The personalised retraining pathways combine both sensorimotor retraining methods with psychological approaches (e.g., stress regulation, trauma-informed methods) which reflects the multifactorial nature of MFD. SDR is frequently associated with increased agency and a redefinition of success, and in addition to symptom reduction, musicians report changes in identity, priorities, and practice culture including greater self-care, non-judgemental awareness, and attention to the mind–body connection.

The PhD proposes a patient-focused multidisciplinary framework to improve the retraining experience that includes prompt and clear signposting to evidence-based choices and the integration of neurological playing health principles into standard teaching practices. It also advocates for continued, structured support that connects instrument-specific needs to general retraining principles and clear retraining goals. The research suggests that MFD and performance health literacy should be included in conservatoire curricula, including teacher development programmes. Referral and communication pathways require clarification and accessible, accurate, and accredited information concerning MFD, and rehabilitation should be provided to all musicians, working towards reducing delay and confusion throughout the process.

The research reframes rehabilitation for dystonic musicians as a longitudinal and transformative learning process. It delivers useful and practical guidance to educators, clinicians and retraining professionals concerning the immediate enhancement of timely access, the customisation of retraining processes, and improving dystonic musicians' long-term wellbeing.

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TABLE OF ABBREVIATIONS

Abbreviation	Definition
AAF	Altered Auditory Feedback
ABO	Association of British Orchestras
AEIMS	Le Association Europénne des Illustrateurs Médicaux et Scientifiques
ASPAH	The Australian Society for Performing Arts Care
BAPAM	British Association of Performance Arts Medicine
BMC	British Medical Council
BMJ	British Medical Journal
CANS	Complaints of the Arm, Neck and/or Shoulder
CD	Cervical Dystonia
CMFD	Cranial Mandibular Dysfunctions
CNS	Central Nervous System
DCS	Direct Current Stimulation
DGFMM	Deutsche Gesellschaft für Musikphysiologie und Musikermedizin
DS	Dynamic Stereotype
ECR	Extensor Carpi Radialis
ED	Embouchure Dystonia
EEG	Electroencephalogram
EMG	Electromyography
FAM	Frequency of Abnormal Movements Scale

FCR	Flexor Carpi Radialis
FD	Focal Dystonia
FFI	Five-Factor Inventory
FOA	Focus Of Attention
GT	Grounded Theory
HPE	High Psychological Effects
IPA	Interpretive Phenomenological Analysis
ISME	Instrument-specific Movement Exercises
LPE	Low Psychological Effect
LTAD	Long-Term Athlete Development
MCT	Motion Capture Technology
MFD	Musicians' focal dystonia
MEG	Magnetoencephalography
MEP	Motor-Evoked Potential
MMR	Mixed-Methods Approach
MPA	Musicians Performance Anxiety
MPPA	Medical Problems of Performing Artists
MRI	Magnetic Resonance Imaging
MSKP	Musculoskeletal Problems That Affect Playing
MPC	Music Performance Capability
MU	Musicians' Union
NEO	Neuroticism Extraversion Openness

NVDMG	The Dutch Performing Arts Medicine Association
OCD	Obsessive Compulsive Disorder
PAM	Performance Arts Medicine
PAMA	Performance Arts Medicine Association
PRHP	Performance Related Health Problems
PRMD	Performance Related Musculoskeletal Disorders
RSI	Repetitive Strain Injury
SD	Spasmodic Dysphonia
SDE	Slow-down exercises
SDR	Self-Developed Retraining
SMO	Sensorimotor Organisation
SMR	Sensory motor Retuning
TA	Thematic Analysis
TMS	Trans-magnetic Stimulation
WD	Writers Dystonia
WMSD	Work-Related Musculoskeletal Disorders

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DEDICATION

I would like to dedicate this PhD firstly to my wife, Lilian, and my three-year-old son, Thomas, who have kept me sane when I needed a calming voice. I would also like to thank my lovely mum for her unwavering support over a lifetime.

I also acknowledge the courage of my younger self who had substantially less grey hair at the beginning of the process.

CHAPTER 1 - Introduction to the Research.

This chapter introduces the PhD and its research field, Musicians' Focal Dystonia (MFD). It then presents an overview of the research – a three-study examination of how musicians navigate rehabilitation, with a particular emphasis on their retraining journeys from pre-diagnosis to post-retraining. Relevant gaps in the literature are discussed, followed by an outline of the theoretical framework, its practical applications and implications, and the conceptual framework. The aims and objectives of the PhD are then presented together with the research questions for each of the three studies.

1.1 OVERVIEW OF THE RESEARCH FIELD

MFD is a task-specific neurological movement disorder that affects an estimated 1% of professional musicians worldwide (Altenmuller & Jabusch, 2010). Its symptoms include involuntary muscle contractions and tremor when playing an instrument causing reduction in the ability to control intended fine motor actions (Jabusch et al., 2005; Konczak & Abbruzzese, 2013). It is a multifactorial condition involving a combination of physiological, psychological, and psychosocial factors (Détári, 2023; Ioannou et al., 2016a; J Leijnse et al., 2015). In the absence of a cure, and the often-limited effectiveness of standard treatment protocols for the condition (including botulinum toxin injections and anticholinergic medications), the subject has received considerable interest from researchers across a variety of fields, each approaching the condition from a particular viewpoint. This, in turn, has contributed to the formation of a more integrative and holistic investigation of the condition, that integrates the following areas:

1. **Neurophysiology:** Maladaptive plasticity altered cortical excitability, and sensorimotor mechanisms in task-specific motor control.
2. **Genetic Studies:** Genetic variants and phenotypic heterogeneity associated with focal dystonia.
3. **Rehabilitation Techniques:** The evaluation of retraining strategies including constraint-induced movement therapy, sensory re-education, and neuromodulation in managing symptoms.

4. **Psychological/Psychosocial:** Performance anxiety, stress, trauma, personality traits and their involvement in symptom onset and recovery.

Scope of the PhD

The PhD focuses on instrumental musician stakeholders and their experiences with MFD. The first study (Study 1) examines instrumental teachers and students within UK conservatoires. Studies 2 and 3 investigate dystonic musicians' retraining experiences and practices. The term "retraining" refers to non-pharmacological, sensory re-education techniques, "rehabilitation" refers to the broader recovery process, and "self-developed retraining" (SDR) refers to the personalised retraining approaches utilised and developed by musicians.

1.2 RESEARCH OVERVIEW

The search for rehabilitative techniques for MFD has led to the development of a variety of retraining methods for the condition, several of which have been shown to potentially improve symptoms or even reverse them in some cases, making them an attractive alternative to pharmacological interventions (Catellani et al., 2024). Exactly how dystonic musicians navigate and experience these processes over time remains largely unexplored within the literature. To expand knowledge within the field, this PhD addresses the lack of evidence in three areas. Firstly, awareness and discourse about MFD amongst instrumental teachers and students. Secondly, the experiences of dystonic musicians as they navigate diagnosis and the retraining process, and finally, how and why dystonic musicians develop and utilise SDR.

The PhD investigates this question from three distinct perspectives that follow a chronological progression from initial awareness to action. Study 1 investigates awareness and PRHI discourse in UK conservatoire teaching. Study 2 examines dystonic musicians' retraining utilisation, outcomes and support, and Study 3 explores the motivations, methods, and implications of SDR. Together, the studies generate evidence to inform educational strategies, clinical suggestions, and rehabilitation practices that are more musician centred.

Having presented an overview of the research landscape, the details of each of the studies conducted for the PhD are introduced.

1.3 RESEARCH QUESTIONS

The principal aim of this PhD is to address the following over-arching research question.

“How do dystonic musicians navigate and experience the process of retraining in their rehabilitation from MFD?”

To achieve this, each of the three studies addresses parts of this question from a particular position or point along a timeline of MFD rehabilitation. The following section clarifies the research questions for each of the three studies:

Study 1.

1. What is the current level of awareness and understanding of MFD amongst conservatoire teachers and students?
2. How are performance-related health issues (PRHIs), including MFD, discussed, and addressed within the one-to-one teacher-student setting in conservatoires?
3. What are the barriers and enablers to the effective communication and understanding of PRHIs, including MFD, within the conservatoire environment?

Study 2.

1. How do musicians with MFD approach and navigate the retraining process in their journey to rehabilitation from focal dystonia?
2. How do they evaluate and perceive the outcomes of their retraining?
3. What are their perceptions of their retraining experiences, and to what extent were their expectations met?

Study 3.

1. How do dystonic musicians develop and navigate self-developed retraining (SDR)? What are their motivations for doing so?
2. What are the common barriers and enablers to SDR?
3. What are the common experiences of SDR amongst dystonic musicians?
4. What insights can be gained from musicians that have utilised SDR? What are the implications for general retraining and rehabilitation practices?

1.4 STUDY OUTLINES

The PhD follows a three- paper design, with each study building upon the findings of the previous one, creating a developing exploration of the central research theme. By connecting these studies, the PhD addresses the aforementioned research gaps and presents a novel appraisal of how musicians experience MFD and retraining.

The following section provides a concise outline of the three studies that comprise the research:

1. **Exploring Musicians' Focal Dystonia Awareness, and Performance-related Health Discourse Within the One-to-one Conservatoire Teaching Environment – A Comparative Survey Analysis:**

Focus: This initial study examines current MFD awareness and the broader subject of performance-related health issue (PRHI) discourse amongst instrumental teachers and students within UK music conservatoires. It considers how they are currently addressed and how the roles and responsibilities of both stakeholders are perceived within the one-to one lesson setting.
Contribution: The study identifies specific knowledge gaps and patterns of communication between stakeholders. It also supports requirements to improve early awareness of MFD and efficient signposting to appropriate sources of help.

2. **Perspectives of Dystonic Musicians Undertaking Retraining for Focal Dystonia: Utilisation and Insights:**

Focus: The second study examines how dystonic musicians identify, select and engage with approaches to retraining. It reports the functional and psychosocial outcomes of retraining and the barriers and enablers to moving towards recovery.
Contribution: Retraining journeys are examined from the musicians' standpoint revealing important moments of decision, issues surrounding retraining support, and common pinch points that influence retraining outcomes and experiences.

3. **From Understanding to Implementation: Self-developed Retraining for Musicians' Focal Dystonia: A Thematic Analysis:**

Focus: The final study examines the motives of dystonic musicians in utilising SDR, how they develop and adapt their approaches, and what SDR-specific challenges affect retraining effectiveness and sustainability.
Contribution: The study extracts transferable insights and observations, informing patient-centred rehabilitation, educational practice, signposting for musicians with MFD.

1.5 THEORETICAL FRAMEWORK

The theoretical framework of the PhD adopts a multidisciplinary lens to reflect the multifactorial nature of MFD. It combines constructs from neuroscience, psychology, rehabilitation science, and music education to formulate the research questions, interpret the results, and to develop recommendations that appear, based upon the findings from the research. The following five theoretical constructs are identifiable throughout the research process:

1. **Neuroplasticity and sensorimotor integration:** MFD is considered to occur as a result of maladaptive plastic changes in the brain. This construct explains the reorganisation of cortical representations and degradation of fine motor-control due

to repetitive and highly demanding focused practice. It provides a clear explanation of how repetitive motor activities can lead to dysfunctional neural pathways.

2. **Motor Learning and Principles of Retraining:** Non-pharmacological approaches to rehabilitation are comprised of approaches to retraining including neuromuscular re-education (Enke & Poskey, 2018), constraint exercises (Berque et al., 2013), and sensory discrimination exercises (Butler et al., 2018). Within these approaches are fundamental retraining concepts including graded exposure, differential practicing, and attention-re-focusing.
3. **Integrated Neurology:** The neurology of MFD is frequently associated with simplistically defined boundaries that describe a separation between organic and non-organic processes. In fact, MFD reflects a unified system in which neural processes affecting attention, expectation, emotion, and learning, act together upon the same sensorimotor networks affected by MFD. Stress, perfectionism, trauma, and self-efficacy concerns,(Gowling, 2020; Ioannou et al., 2016b; Jabusch et al., 2004; Schneider et al., 2021) shape autonomic and cortical states, which also modulate plasticity, sensorimotor integration, and motor output. Motor control feeds back to beliefs, mood, behaviour, cognition and context, manifesting in both symptom and recovery (Latash, 2024; Schmidt et al., 2018). Unified assessments and interventions that simultaneously target sensorimotor retraining and cognitive-affective, are therefore essential.
4. **Educational Theory:** Constructivism and tertiary level music pedagogy reinforce the co-constructed nature of teaching within the one-to one context. PRHIs, including MFD, are understood, discussed and acted upon in accordance with teachers' opinions and beliefs. Student autonomy and the one-to one setting also play a significant part in these decisions. Each of these factors contributes to an understanding of "role expectations" between stakeholders when addressing PRHIs and channels of communication within conservatoires.
5. **Patient focused care:** Self-developed retraining is reliant on both shared decision-making and bespoke, self-directed learning. The alignment of strategies to fit the individual context of the musician, guide the needs and responses across larger, heterogeneous groups.

The role of the framework within this PhD is to facilitate clarity when developing the central constructs of the research including help-seeking, awareness, barriers and enablers, retraining decisions and both physiological and psychosocial outcomes. It permits the collection of accounts of interactions between psychosocial elements of MFD, including awareness, and with neuro-physical effects of neuroplastic change and motor learning. The framework also informs the development of both the survey instruments and the coding frameworks for qualitative data collection.

1.6 CONCEPTUAL FRAMEWORK

This section presents a brief outline of the conceptual framework of the PhD. A pragmatic worldview is adopted in which the chosen methods are considered a “best fit” for answering the research questions, rather than following a specific paradigm. Therefore, a sequential mixed-methods programme of research links the three studies together, with each study responding to its research questions whilst also informing the next.

The following conceptual map of the PhD introduces the progression of concepts addressed during the timeline of the research.

Starting Conditions

- To what extent do musicians know what MFD/PRHIs are, and do they know where to get help?
- What are the current standard beliefs within one-to-one instrumental teaching?
- Are trustworthy sources of information and referrals easily accessible?

Moving Through the Retraining Process

- Interpreting symptoms.
- Seeking appropriate sources of help.
- Navigating diagnosis and interpreting external advice.

- Choosing to undertake retraining utilising formal approaches/and or self-developed retraining.

Enablers and Barriers

- Information quality and clarity of retraining aims and objectives
- Support from clinicians/ retraining professionals/ teachers
- Time limitations, financial commitments and practice resources
- Psychological state. The influence of stress, anxiety or self-efficacy.

Short-term Changes

- Changes in perceived movement quality, consistency and control.
- The influence of psychosocial factors including confidence, distress and changes in performer identity.

Long-term Changes

- Sustainable levels of perceived recovery following retraining.
- Sustainability of retraining gains.
- Preventive practice as part of a normal routine.

Feedback Loops

- Retraining outcomes inform changes in attitudes and beliefs towards MFD, influencing adherence to retraining and seeking further help.
- Insights from SDR can inform the development of formal retraining and influence future PRHI training.

Connecting the Studies

The three studies connect the narrative of navigating MFD rehabilitation through retraining in the following sequence. Study 1 utilises a quantitative survey approach that compares instrumental teachers and students within UK conservatoires to discover what they know, and how they discuss PRHIs and MFD. It also questions the

role of teachers as health sign posters, producing concepts and ideas that inform the design, measures and sampling for Study 2. Study 2 then adopts an explanatory sequential mixed-methods approach (QUAN - QUAL). The quantitative survey phase examines patterns and associations whilst the qualitative interview phase explains mechanisms and contexts. The identification of the prevalence of SDR and questions surrounding motivation and challenges then inform the content of the final Study 3.

1.7 PERSONAL MOTIVATION

Whilst embarking on my career as a professional cellist I began to experience problems in the fine motor control of the fingers of my left hand. At the age of 27, I was confronted with my own diagnosis of MFD, forcing me to acknowledge that my personal performance goals and musical career path would need to change somewhat. I could no longer play the cello to the level that I was accustomed to, and the condition would now be a part of my everyday life.

Prior to my MFD diagnosis in 2005, like many musicians, I had never heard of dystonia. I struggled to find information about the condition, and after acquiring some rudimentary knowledge, I went in search of treatment, haphazardly lurching between doctor's appointments looking for answers. After more than a decade of modest success using standard medical treatments including oral medications and botulinum toxin injections, and whilst constantly fighting against my symptoms, I finally sought help from Joaquin Farias in Toronto, Canada. In 2016, I undertook his programme of "neuroplastic" re-education for MFD, during which I discovered the significance of retraining in the treatment of the condition and how my practice habits, physical health, personality traits and genetic pre-dispositions may have contributed to its initial onset. Although I do not claim that I am "cured" or have been able to regain my own pre-dystonic level of playing, I have acquired a more comprehensive understanding of the multifarious roles that the brain plays in instrumental music making, and the importance of developing and practicing good habits during our musical development. As a further, positive consequence of MFD, I now focus upon, and instinctively prioritise, the healthy development of the instrumental students that I teach, guided by a personal understanding that through the neglect of physical and psychological signs

of discomfort, debilitating and chronic problems related to instrumental playing may emerge, and possibly progress. The question, “could my MFD have been avoided if I’d known about it previously and understood the risks?” has never been far from my thoughts.

1.8 RESEARCH AIMS AND OBJECTIVES

The principal aim of this PhD is to establish and examine the barriers and enablers that dystonic musicians experience when encountering and navigating MFD along a timeline from pre-diagnosis to post-retraining. The research advances knowledge in the field by examining awareness, the diagnostic experience, and retraining utilisation from the musicians’ standpoint. The results of these enquires provide a novel perspective, highlighting points of action for improving understanding of MFD amongst musicians and medical professionals, reducing delays in achieving diagnoses and initiating retraining, and improving retraining outcomes.

The principle aims and objectives are:

1. **Investigate Awareness:** To examine current levels of awareness amongst non-dystonic musicians and suggest ways to enhance knowledge dissemination and preventive measures.
2. **Investigate Diagnostic Challenges:** To analyse the challenges and delays that are experienced by musicians during the diagnostic process and determine the causes of diagnostic confusion and inefficiencies.
3. **To Identify Common Barriers to Retraining**: To explore the common issues that are encountered by musicians during retraining for MFD.
4. **To Identify Common Enablers to Retraining:** To establish the factors that help musicians to succeed in their retraining.
5. **Investigate Self-Retraining Practices:** To examine the motives and strategies of musicians that implement self-developed retraining, assessing aspects that can enhance official rehabilitation programmes.

These objectives are intended to advance the current understanding of the condition from the musicians' perspective, enhance the effectiveness of retraining practices, and ensure that the rehabilitation practices are more musician centred.

1.9 SIGNIFICANCE OF THE RESEARCH

The PhD addresses gaps in knowledge concerning current stakeholder awareness of MFD and subjective understanding of the condition. It achieves this by questioning the importance of awareness, the diagnostic process, retraining utilisation, and the experience of retraining, each from the musicians' standpoint.

It contributes to the field in the following ways:

1. **Educational Initiatives:** The study of current awareness levels of MFD advocates for amplified PRHI education programmes and professional development programmes of PRHI education within tertiary music education institutions. By increasing the dissemination of knowledge and raising awareness, it enables musicians, educators and healthcare providers to work together to encourage earlier detection of MFD, to increase awareness of potential risk factors, and to take measures to reduce risk through healthy practice strategies, when possible. The development of programmes of MFD awareness that combine neurological and psychological knowledge to educate musicians about risk factors, early warning indicators, and prevention strategies, aiding both early diagnosis and neurologically healthy practice techniques.

2. **Improved Diagnostic Practices:** The research highlights the challenges and delays faced by musicians when searching for a diagnosis of MFD. It recommends improvements to current diagnostic procedures including better MFD awareness for health providers, clear signposting to non-pharmaceutical treatment options, and referral to psychological support options at the time of

diagnosis. By reducing confusion and delay during the diagnostic phase, musicians can receive prompt medical help, which in turn, works towards reducing rehabilitation times and increasing positive outcomes of retraining.

3. **Improving Rehabilitation Strategies:** The research also provides important insight into the retraining experiences of musicians by uncovering the current barriers and enablers common to the retraining process. Findings from the study can guide retraining professionals in developing increasingly personalised, support focused retraining strategies that meet dystonic musicians' specific requirements, improving the efficacy of retraining methods and contribute to better long-term outcomes.

4. **Psychological Support:** Understanding the emotional challenges that musicians face following a diagnosis of MFD, particularly as they begin the process of rehabilitation, is crucial in guiding and informing medical professionals during the diagnostic process. Clear signposting to mental health support at the time of diagnosis could significantly improve the retraining experiences of musicians, potentially improve outcomes, and encourage a more holistic approach to diagnosis and treatment.

5. **Policy and Practice Recommendations:** The research provides new knowledge which can guide music conservatoires and tertiary education institutions to develop their health policies concerning PRHIs and neurological playing health. The implementation of health signposting protocols and support structures that recognise the importance of the one-to-one teacher student relationship, could create an environment that increases health safe-guarding for musicians whilst also developing health communication channels for both performance and academic faculty, in equal measure.

6. **Empowering Musicians:** The focus on SDR strategies highlights the resilience and adaptability of musicians in overcoming MFD. By documenting and analysing these personal approaches, the study provides valuable guidance for other musicians facing similar challenges, promoting a sense of agency and empowerment within the community.

The PhD establishes links between existing research and the lived experiences of musicians and other stakeholders as they encounter and rehabilitate from MFD. It offers recommendations for the promotion of early interventions that include raising awareness and improving early management of the condition. It also centralises the importance of improving the retraining journeys of musicians by reducing confusion and delay, and by implementing proactive measures to streamline the retraining process, including improving the diagnostic process and delivering clear signposting.

Each study is built upon the collaboration between stakeholders and the personal narratives of musicians. Central to this collaboration is understanding that the three main components of the PhD (awareness within education, individual experiences of retraining, and insights gained from personalised retraining) complement each other, rather than offering stand-alone recommendations. The framework of the PhD highlights the complexities of navigating a diagnosis of MFD and the continuous interaction between musicians, educators and healthcare providers that is required to effectively manage the condition. It identifies the importance of recognising musicians' neurological playing health and seeks to contribute significantly to improving the long-term health and safeguarding playing careers of both healthy, and dystonic musicians.

The following chapter provides a comprehensive view of the literature across the field of MFD. The multifaceted nature of the condition is reflected in the wide range and depth of research that has been consulted to inform the development of the PhD.

CHAPTER 2 - Review of the Literature.

MUSICIANS' FOCAL DYSTONIA

2.1 INTRODUCTION

Performing music to a high standard is one of the most exhilarating and demanding activities that we undertake as human beings. It involves the precise execution of very fast, and in many instances, extremely complex physical movements that must be structured and coordinated with continuous auditory, visual, and somatosensory feedback (Altenmüller & Ioannou, 2016). The clockwork precision with which we are required to execute these skills within musical performance is also a consequence of intensive practice requiring more than 10,000 hours to achieve mastery (Ericsson et al., 1993). In addition to the physical and motor demands of musical performance, the complex psychological and emotional requirements that shape expressive performance must also work harmoniously and allow artistry to emerge. For many, the results of years of intensive training culminate in a successful career as a performing musician, yet for a significant number of musicians, the music making process is corrupted by focal dystonia. What was once automatic, becomes a brain-driven, whole mind/body chain reaction that can seriously disrupt, or even terminate, a musical career.

Dystonia is a neurological movement disorder characterised by sustained muscle contractions, repetitive twisting movements, and abnormal postures of the trunk, neck, face, or arms and legs (Tarsy & Simon, 2006). The etymological meaning of dystonia comes from the Latin prefix 'dys 'meaning abnormal and the Greek root 'tonos ' meaning tone (HarperCollins, 2019). During the 19th Century, the German neurologist Hermann Oppenheim attributed the word to the condition that he named *dystonia musculorum deformans*, more commonly known as torsion dystonia, a type of generalised dystonia affecting the whole body. It is now used to describe a group of dystonic conditions that vary in severity from the physical disabling and debilitating to the mildly inconvenient, all of which involve a state of disordered tonicity of tissues.

MFD is classified as a 'focal', task-specific form of dystonia, associated with occupations, most commonly affecting professional musicians (Butler et al., 2021). In task-specific focal dystonia the most prominent characteristic is the degradation and loss of voluntary control of highly over-learned complex and skilled movement patterns in a specific sensory-motor task (Altenmüller & Müller, 2013). However, motor symptoms, that involve activities away from the instrument may also be present. In their 2007 study, Rosset-Llobet et al. reported that 53.5% of patients experienced secondary motor disturbances, suggesting that MFD may be considered more movement than task-specific (Rosset-Llobet et al., 2007). The condition produces joint sustained and involuntary contractions of agonist and antagonist muscles which often cause torsion, involuntary and repetitive abnormal movements, and abnormal posture (Aránguiz et al., 2015). Classification of symptoms is related to the instrument played, for example, embouchure dystonia may affect coordination of the lips, tongue, facial and cervical muscles, and breathing in brass and wind players, whereas pianist's cramp and violinist's cramp may affect the control of finger, hand, and arm movements (Altenmüller & Jabusch, 2010). However, amongst woodwind players either hand or embouchure dystonia may be present (Rosset-Llobet et al., 2007). Additionally, although less common, other forms of MFD are also observed, including lower limb dystonia in drummers, and singers dystonia (SD), a form of laryngeal, spasmodic dysphonia only activated through singing (Ray & Pal, 2021).

The epidemiology of MFD also differs significantly amongst musical populations. Male musicians appear to be significantly more affected than female musicians, with ratios ranging from 2:1 to 6:1 (Lederman 1991; Brandfonbrener 1995; Lim et al 2001; Butler, 2006). Musical genre is also a significant potential factor. In their 2006 long-term MFD study of 144 musicians, Jabusch and Altenmüller reported that 95% of participants were classical musicians, whilst only 1% were jazz musicians and 4% were pop musicians (Jabusch & Altenmüller, 2006). Aránguez and colleagues also reported significantly more classical musicians in a similar 2015 study, although they also argue that many studies report more than 90% of participants as being classical musicians, and this may be due to the fact that samples are drawn directly from institutions that train [classical] musicians (Aránguiz et al., 2015). In their large cohort study of Brazilian

musicians with MFD Moura and colleagues calculated that popular musicians are in fact 2.5 times less prone to the condition than classical musicians (Moura et al., 2017). Research has confirmed that motor impairments are less frequently seen in jazz musicians, as a certain flexibility of note and tempo is intrinsic to this music form (Altenmüller et al., 2014; Sadnicka et al., 2018). Prevalence amongst professional musicians also appears to be higher compared to other musical populations, although music students are also at substantial risk. The mean age of MFD onset has been estimated to be 35.7 years, (SD = 10.6) (Conti et al., 2008), but range has been calculated from between 17-63 (Jabusch & Altenmüller, 2006). A 2017 study of 1468 Japanese college music students revealed an MFD prevalence of 0.7%, similar to the estimated 1% seen amongst professional musicians, with 71.5% of participants reporting to have had no prior knowledge of the condition (Konaka & Mochizuki, 2015).

2.2 THE ROLE OF PERFORMING ARTS MEDICINE

Many musicians suffer for their art, and health is often compromised during training (Matei et al., 2018). Injuries described as ‘playing-related’ in musicians have a prevalence rate of up to 87% although healthcare consultations remain low (Guptill, 2008). Due to the physical demands of instrumental playing, musicians are at high risk for developing painful musculoskeletal problems, including pain and overuse injuries, entrapment and peripheral neuropathies, and focal dystonias (Dommerholt, 2009). They are also similar to athletes, as both require superior sensory-motor integration (Altenmüller et al., 2000), but unlike athletes, there has traditionally been little or no health education or services to support musicians (Ackermann et al., 2012).

Awareness of musicians’ health problems has increased considerably with the growth of Performance Arts Medicine (PAM). PAM focuses on the medical needs of performing artists from across the various disciplines including theatre performers, dancers, vocal/instrumental musicians and visual artists (Sataloff, 2005). The field came to prominence in the 1980’s following the “Conference on the Medical Problems of Musicians” in Aspen, Colorado, in 1983 organised by leading expert in the field at the time, Alice G. Brandfonbrener MFD. Brandfonbrener went on to become the first director of the journal, Medical Problems of Performing Artists (MPPA), the premier

organ for reporting clinical and research knowledge in the field (Lederman, 2014). She was subsequently selected to be the first president of The Performing Arts Medicine Association (PAMA), formed in 1989. During the same period, studies in over-use injuries in musicians were becoming more frequent, (Brandfonbrener, 1986; Fry, 1987; Owen, 1985) including the first large-scale survey of overuse injury within 48 orchestras comprising the International Conference of Symphony and Opera Musicians (ISCOM).

During the following three decades, as research into PAM has expanded further, organisations like PAMA, have been created in more than 19 countries (as of 2020). They include: The British Association of Performance arts Medicine in the UK (BAPAM), Le Association Européenne des Illustrateurs Médicaux et Scientifiques, based in France (AEIMS), (DGFMM) in Germany, The Dutch Performing Arts Medicine Association (NVDMG) in Holland, and The Australian Society for Performing Arts Care (ASPAH) (S.-H. Lee et al., 2020). Each of the organisations promote research and/or publish peer reviewed research papers whilst also facilitating access to medical specialists and treatments for performing artists that may not be offered by standard models of healthcare.

Developments in PAM have improved methods of diagnosis and treatment, an awareness of the specialised problems of artists related to their occupation and lifestyle, and the establishment of an interdisciplinary approach to health programmes (Ostwald et al., 1994). The number of health programmes has increased significantly, especially within mainstream music education, but tend to focus on the incidence and severity of problems rather than the potential influence of health awareness and attitudes to injury (Rickert et al., 2015). In the UK, recent initiatives that address this problem include ‘Healthy Conservatoires’, a 2015 project initiated by Conservatoires UK, dedicated to understanding the ways in which musicians’ health is safeguarded and how musicians are trained to look after their health and wellbeing (https://healthyconservatoires.org/about). Known previously as, ‘Musical Impact’, the project involves partnerships between The Association of British Orchestras (ABO), Musicians’ Union (MU), BAPAM and the International Health Humanities Network. It was initially aimed at developing knowledge and understanding musicians’ chronic and

acute health problems and has now grown into an inter-disciplinary network that is recognised both nationally and internationally as promoting good practice in the performing arts.

However, after four decades, leading commentators have noted that we continue to offer very little in terms of injury prevention (Ackermann et al., 2012). In addition, access to programmes of prevention and health-related support is both erratic and dependent upon geographical location, and further research, development and implementation is needed in both educational and professional contexts (Parry, 2004). Challenges associated with participant adherence to studies into injury prevention are also apparent. In a 1997 study of orchestral musicians' response to a specific exercise programme for health awareness, the author noted a high attrition rate (Brandfonbrener, 1997). Further studies have shown that health intervention participants are also likely to be musicians already suffering from playing-related disorders, whilst those considered healthy may be more reluctant to participate (Chan et al., 2013; Foxman & Burgel, 2006). Amongst music student populations, research suggests a disconnect between students' perceptions and beliefs of performance-related health versus their actions (Spahn et al., 2004) and that an "over-reliance" of instrumental teacher advice (Williamon & Thompson, 2006) may contribute to lower adhesion to programmes of prevention, and possible resistance to participate when technical recommendations overlap.

A cultural shift has been identified as necessary amongst musical populations to encourage engagement towards health education, awareness, and programmes of injury prevention. Health interventions for musicians, particularly those aimed at injury prevention, are under-represented in current research and well-designed prospective research is needed to identify causal relations in the aetiology of [playing-related] musculoskeletal disorders in instrumental musicians (Baadjou et al., 2016). Stanhope and colleagues confirm the need for investigation of a wider range of interventions – ideally based on the risk factors determined with this [musician] population (Stanhope et al., 2019). Theoretical framework models for arts health interventions are not yet musician specific due to a lack of any specific health-literacy tool (Baadjou et al., 2019) and existing models such as long-term athlete development (LTAD) models are

adapted to fit educative programmes for musicians' health. Proactive prevention of injury in musicians is limited largely to attempts to manage practice and performance in ways that will cause the least amount of strain (Clark & Lisboa, 2013). Recent interventions that focus upon awareness and prevention strategies for performing related health problems (PRHPs) have revealed positive health outcomes using educative programmes (Baadjou et al., 2021; Wolff et al., 2021) as well as development of a comprehensive injury prevention framework (Rousseau et al., 2021). The following section broadly defines PRHPs, their prevalence and risk factors amongst professional and student musicians and outlines key studies and interventions that have guided the field of injury prevention in musicians' health in recent years.

2.3 DEFINING PERFORMANCE-RELATED HEALTH ISSUES IN MUSICIANS

When defining musicians' health issues within the literature, the nomenclature is slightly ambiguous. "Performance-related health problems" (PRHPs) is a broad term used to describe all musicians' occupational health problems, whilst the term, "performance-related musculoskeletal disorders" (PRMDs) refers specifically to musculoskeletal conditions, although this distinction is not always clear and can appear somewhat confusing. Several studies propose additional terms for PRMDs. For example, Fjellman-Wiklund and Sundlund (1998) describe, "work-related musculoskeletal disorders" (WMSD's), whilst Abréu-Ramos and Michio (2007) describe, "musculoskeletal problems that affect playing" (MSKPs). More "area-specific" definitions are also offered including, "complaints of the arm, neck and/or shoulder" (CANS) (Kok et al., 2015), and "cranial mandibular dysfunctions (CMFDs) (Steinmetz et al., 2009; Steinmetz et al., 2014). What is clear throughout the literature, is that musculoskeletal problems in musicians are significant, and of similar aetiologies across contrasting musical populations.

The landmark International Conference of Symphony and Opera Musicians (ISCOM) study in the 1980's reported a PRMD prevalence of 76% amongst orchestral musicians (Fishbein et al., 1988). Subsequent national and international surveys have documented the lifetime prevalence of PRMDs in professional orchestral musicians as

anywhere between 39% to 87%, depending on the survey methodology (Chan et al., 2013). Ackermann and colleagues (2012) have found that 70-80% of orchestral musicians suffer from PRMDs, whilst Steinmetz and colleagues report a prevalence as high as 89% (Steinmetz et al., 2015). Amongst music student populations, epidemiological studies also confirmed a high prevalence of PRMDs (Araujo et al., 2020; Brandfonbrener, 2009; Kreutz et al., 2009; Spahn et al., 2002; Spahn et al., 2004; Williamon & Thompson, 2006). In a 2015 study of 180 Czech conservatoire students, 89% of participants reported that they experienced pain whilst playing (Ioannou & Altenmüller, 2015). Both point prevalence and incidence of PRMDs differ significantly between studies, in part due to the heterogeneity of research groups and methods (Baadjou et al., 2016), and also due to the variation in working definitions of PRMDs. A further consideration is in the concentration of studies involving classical, formally trained, professional or student musicians. Stanhope et.al draw attention to under-investigated groups including non-orchestral professional musicians, amateur musicians and children and suggest the need for more studies that compare prevalence of musculoskeletal disorders between musicians and non-musicians to substantiate claims that musicians are at higher risk (Stanhope et al., 2019). Clearer terminology and more precise definitions of aetiologies surrounding PRMDs, together with improved methods and less heterogeneity between studies are required, to improve the overall quality of research in the field. More attention also needs to be given to less studied groups of musicians, especially children, that may benefit most from precocious treatment interventions or programmes of PRMD prevention.

PRHPs amongst musicians vary according to instrument type, gender, years of performing, repertoire, hours of practice, age, or genetic predisposition (Altenmuller & Jabusch, 2010; Kenny & Ackermann, 2015; Stojanović et al., 1995). They are personal, chronic and disabling health problems that affect the whole person, physically, emotionally, occupationally, and socially, causing pain, weakness, lack of control, numbness, tingling, or symptoms that interfere with the ability to play an instrument at an accustomed level, (Zaza et al., 1998). An association can also be established with increased time and intensity of practicing, a predisposing musculoskeletal condition at baseline, and overly tense technique (Liu & Hayden, 2002). Most musicians report symptoms lasting more than 1 year and many report symptoms lasting more than 5 years (Foxman & Burgel, 2006) with approximately 50%

of over- use cases involving the hands and wrists (Fry, 1987). An association with increased practice time, intensity, and symptom duration, is also a hallmark of PRMDs, although in contrast to PRHPs, they are associated more exclusively with musculoskeletal conditions, being broadly split into three categories, musculoskeletal disorders, entrapment neuropathies, or focal dystonias (Altenmuller & Jabusch, 2009; Ioannou & Altenmuller, 2014; Pirio Richardson et al., 2017).

The term PRMD was developed by Zaza and colleagues tying many musculoskeletal disorders into a common aetiology (Zaza et al., 1998). Hoppmann and Patrone describe pain as the primary PRMD symptom, but in contrast to Zaza et al., offer a more selective description of aetiologies, in which PRMDs present with little loss of motor control and [are] not attributable to entrapment syndromes (Hoppmann & Patrone, 1989). Brandfonbrener and colleagues also assert that pain is the primary symptom of PRMDs, with instrument-specific complaints varying, describing them as either, “achy, burning, electrical or pulsating in nature” (Brandfonbrener, 2003). Understandably, several authors criticise what is deemed to be a lack of scientific clarity and stipulation of precise aetiologies (Dawson et al., 1998; Lippman, 1991). Rotter et al. (2020) could not identify enough studies that used appropriate study designs when assessing risk factors. In addition, Bragge and colleagues suggest that survey methodologies used to measure PRMD prevalence amongst musicians contrast between studies, and many lack an operational definition of PRMDs to identify cases (Bragge et al., 2006a). Baadjou and colleagues criticise a lack of prospective studies (Baadjou et al., 2016), and both Wu (2007) and Baadjou et al. cite cross-sectional associations within studies as an inhibitor to establishing causality. Winspur goes as far as to state that, “the obstacles of loose and imprecise language, non-scientific observation, and ‘‘junk science’’ interfere” (Winspur, 2003). Rotter and colleagues (2020), suggest that prospective, long-term cohort studies that properly consider the influencing factors, are still needed.

Within the literature, PRMDs are frequently described as overuse syndrome (Amadio, 2003; Fry, 1986; Parry, 2003), repetitive strain injury (RSI) (N. Byl et al., 1996; James & Parry, 1994) and cumulative trauma disorder (Morse et al., 2000). Harrington and colleagues define overuse syndrome as, “specific painful disorders that can be clearly diagnosed, such as carpel tunnel syndrome, lateral and medial epicondylitis, and de

Quervain's tenosynovitis" (Harrington et al., 1998). Lederman and Calabrese expand further, describing five categories of overuse syndromes caused by extrinsic factors including: 1. those involving bones, joints, and bursae; 2. disorders of the musculotendinous unit; 3. primary muscular pains or cramps; 4. nerve entrapments; and 5. occupational palsies (Lederman, 1986). More generalised terms and definitions are also described. Fry defines overuse syndrome as, "a condition of pain and loss of function in muscle groups and ligaments through excessive use" (Fry, 1988) whilst Betzl and colleagues in their 2020 systematic review, describe, "non-specific musculotendinous disorders causing pain with a less clear pathophysiology and definition" (Betzl et al., 2020). Winspur (2003) suggests that overuse syndrome is, in fact, better described as "misuse", attributable to mistreatment of the body through excessive practice and workload, together with the neglect of the fundamentals of sleep, exercise, good diet, and a calm lifestyle. Lippman (1991) also criticises the term "overuse" when applied to musicians, stating that, "overuse is a simplistic descriptive label which ignores various other possible correctable causes of disfunction or malfunction in the playing of a musical instrument".

PRMDs that present as entrapment neuropathies involve the compression and/or irritation of peripheral nerves as they travel through narrow anatomical spaces (Schmid et al., 2020). They may occur at any point along the course of the peripheral nerve (Lederman, 2006) and are generally considered to be focal in nature, being classified as mono-neuropathies (Lederman, 2006). Carpel tunnel syndrome and cubital tunnel syndrome are the most commonly reported disorders (Wilson et al., 2014) although in their 2006 study, Lehmann and colleagues found thoracic outlet syndrome to be more prevalent (Lederman, 2006). Cervical radiculopathy has also been shown to have relatively high prevalence and may be present in musicians complaining of neck and shoulder pain (Wilson et al., 2014). Amongst string players, ulnar neuropathies appear frequently amongst violin and viola players due to constant flexion of the left elbow (Lederman, 2006), alongside radial neuropathies (Lederman, 2003). Wind players report cranial mono-neuropathies including trigeminal neuralgia and lip numbness (Liu & Hayden, 2002), whilst brass players are also susceptible to conditions caused by elevated intra-abdominal and intra-thoracic pressures (Fiz et al., 1993). Less common entrapment syndromes include flautist's digital neuropathy,

affecting the left index finger due to instrument pressure, pronator syndrome in string instrumentalists, ulnar nerve entrapment in flautists, posterior interosseous neuropathy in drummers and violinists and long thoracic neuropathy (Wilson et al., 2014). Outcomes for both non-operative and operative treatment have yielded mostly good to excellent results, similar to the general population (Wilson et al., 2014). Similarly, treatment outcomes for bone, joints, bursae, and musculotendinous PRMDs reported in the literature, are excellent in many studies (Miliam and Basse, 2009; Molsberger and Molsberger, 2012; Wilk et al., 2016; Quarrier and Norris, 2001).

Musicians' focal dystonia is also classified as a PRMD within the literature. Several alternative definitions of MFD exist amongst earlier studies, including occupational palsy (Critchley, 1977; Lederman, 2000; LeVine, 1983), craft palsy (Critchley, 1977; LeVine & Irvine, 1984; Rider, 1987), and occupational cramp (Charness et al., 1996; Wilson et al., 1993). Differences in the medical interpretation of focal dystonias as being either organic or non-organic conditions have existed for more than a century and contribute to these and other differences in terminology. For example, Kinnier Wilson (1940) described writer's cramp as an "occupational neurosis, physiologically akin to hysteria". Marsden (1976) describes the "psychogenic" nature of focal dystonias, going on to describe them as "somatic disorders". Eldridge and Fahn (1976) describe the "frequent misdiagnosis of the symptoms as manifestations of a psychiatric ailment". However, modern imaging technologies, revealing abnormalities in the sensorimotor networks of affected musicians, give weight to organic causes.

Conversely, an incomplete aetiology of MFD has also kept the organic/non-organic debate alive. Psychological triggers and factors are now an accepted part of MFD aetiology and as in other conditions may be associated in the somatisation of physical symptoms (Chan & Ackermann, 2014; Kenny, 2010; Leaver et al., 2011). Anxiety and depression are commonly co-morbid in clinical populations, including in those presenting with musculoskeletal pain (Kenny & Ackermann, 2015; Kenny, 2010). Psychosocial factors including pressures from peers/educational institutions or work organisations, work and non-related stress, social phobia and extreme perfectionism are also involved in the development of a variety of PRMDs (Altenmuller & Jabusch, 2009; Chan & Ackermann, 2014; Ioannou & Altenmuller, 2014; Ioannou et al., 2016a;

Rousseau et al., 2021; Schneider et al., 2021). Music performance anxiety (MPA) is a problem frequently reported amongst musicians, with an estimated prevalence rate to be between 15 and 25% (Spahn et al., 2016). Physical symptoms of MPA include tachycardia, sweating, tremor, dry mouth or shortness of breath (Wesner et al., 1990) accompanied by emotional and cognitive problems, including panic, stress, self-doubt or expectation of failure (Fernholz et al., 2019). An estimated 21% of MPA sufferers experience anticipatory anxiety in the days or weeks prior to a performance (Van Kemenade et al., 1995) and very few sufferers (approximately 15%) seek help for the condition (Wesner et al., 1990).

In conclusion, clearly defining performance-related health issues within the literature is challenging. The nomenclature is often unclear, with a large amount of heterogeneity amongst studies. PRMDs are often described in broad terms with exact definitions often lacking amongst studies.

2.4 THE AETIOLOGY OF MFD

Although the pathophysiology of MFD has become clearer in recent years, the exact aetiology of the condition remains elusive. Dystonia is a clinically and genetically heterogeneous syndrome (Gasser et al., 1996) and as with other forms of adult onset focal dystonias, many possible contributing factors have been identified, both organic and non-organic. Altenmüller and colleagues confirm that, “while there may be a family history, neurophysiological, physical, and environmental factors, trauma and stress contribute to the phenotypic development of MFD” (Altenmuller & Jabusch, 2009).

Genetic predisposition to MFD has been postulated through several studies looking into familial history and gene mutation (Altenmüller, 1998; Jankovic & Ashoori, 2008; Schmidt et al., 2009). An earlier, pre 2000 study looking at multiple types of focal dystonia confirmed that a quarter of participants had a family member with dystonia (Waddy et al., 1991). Results were confirmed in similar research, suggesting the presence of an autosomal gene or genes with reduced penetrance as a common cause of focal dystonias (Stojanović et al., 1995). Although genetic markers, including the DYT1 gene series have been established as being involved in early onset forms

of generalised or focal dystonias, genetic involvement in musicians' focal dystonia, which is generally late onset, remains inconclusive. To date, there has also been no specific genetical study on larger samples of musicians with hand dystonia (Butler & Rosenkranz, 2006a).

In their 1996 primate study, Byl and colleagues confirm that, as in humans, highly repetitive sensory inputs over a large region [of the brain] induced plasticity-based remodelling of the primary somatosensory cortex, with enlarged and overlapping cortical receptive fields (N. N. Byl et al., 1996). Over a period of months, a movement control disorder was triggered and degradation, enlargement, and blurring of digit representations was recorded in the somatosensory cortical field. Similar research involving primate subjects has also shown focal dystonia development as a consequence of digital syndactyly, using skin grafts to join adjacent fingers of adult owl monkeys. This gives weight to the argument that focal dystonia may be an acquired condition (Allard et al., 1991). Contrasting research however suggests that symptoms may manifest themselves when repetitive movements of the hand superimpose on the latent pathological condition in the sensorimotor systems (Tamura et al., 2009). A latent pathology may also explain the observation of bilateral abnormality of the sensory and motor systems, despite unilateral symptoms (Fiorio et al., 2003; Tamura et al., 2008).

As the search for a definitive aetiology remains inconclusive, MFD research has increasingly surrounded the role of extrinsic triggers such as overuse, chronic pain, perfectionism and anxiety disorders (Schneider et al., 2021). MFD sufferers frequently report psychological disturbances that they associate with their condition which validates research showing that areas of the brain associated with dystonia are also involved in the mediation of cognitive and emotional processes (Butler et al., 2007). In 1982, Sheeny and Marsden found no evidence of psychiatric disorder comorbidity in their study of 22 patients with FDs (Sheehy & Marsden, 1982). The question of whether the psychological traits of FDs were in fact secondary psycho-reactive responses to FDs was debated in a further study (Ludolph & Windgassen, 1992). In contrast, Frommer and colleagues have demonstrated primary psychological and psychosocial connections to FDs, reporting high levels of pre-existing obsessive-compulsive

disorders (OCD) and anxiety amongst patients (Frommer, 1992; Windgassen & Ludolph, 1991). Related pathological findings have revealed that over-activity of the direct striatopallidal structures of the basal ganglia, which are associated with dystonia, are also involved in the mediation of cognitive and emotional processes (Butler et al., 2007; Ioannou et al., 2016a). Dysfunctional basal ganglia circuity, identified as playing a fundamental role in physical symptomatology of FDs may also extend to limbic loops involving the amygdala and orbitofrontal cortex that elicit or suppress motor activity in response to emotion (Ron, 2009).

Several studies have demonstrated compelling evidence for the involvement of psychological disorders and MFD onset (Altenmüller & Jabusch, 2010; Aránguiz et al., 2015; Ioannou & Altenmuller, 2014; Ioannou et al., 2016a; Jabusch & Altenmüller, 2006). Co-morbid psychiatric disturbances have been identified as causing significant morbidity and reduction in quality of life, independent of the motor aspects of dystonia (Zurowski et al., 2013). In their 2014 study of psychopathology in MFD, Ioannou and Altenmüller identified two distinct groups of musicians, those with high psychological effects (HPE) and those with low psychological effects (LPE). They confirm that musicians with MFD are 5.9 times more likely belong to the HPE group and suggest that psychological features may not be a psycho-reactive phenomenon; instead, anxiety characteristics are likely to pre-exist in musicians before the onset of dystonia (Ioannou & Altenmuller, 2014).

Although not present in every case, specific personality traits are commonly identifiable amongst MFD sufferers. In their 2009 study, Altenmüller and Jabusch confirm that musicians with dystonia show a pattern of exaggerated perfectionism, social phobia, and specific phobias that are not seen in healthy musicians (Altenmuller & Jabusch, 2009). The pre-existence of psychological disorders including anxiety and depression amongst MFD sufferers have also been revealed in several studies (Butler et al., 2021; Ioannou & Altenmuller, 2014; Schneider et al., 2021). Together with sensorimotor triggering factors such as overuse, technical difficulties, bio-mechanical obstacles, and genetic factors, MFD presents as a multifactorial condition with organic and non-organic causes.

2.5 PATTERNS OF ONSET

Symptoms of MFD usually begin insidiously as a subtle loss of dexterity or motor control (Chiaramonte & Vecchio, 2021), although a sub-set of sufferers report a sudden onset of symptoms, with no identifiable warning signs. In these cases, patients describe acute onset, occurring immediately after a marked increase in practice time, increase in difficulty of repertoire, marked over-practice of a particularly difficult passage, change in instrument mechanics, or sudden psychological or emotional stressors (Conti et al., 2008). Complex repetitive movement patterns associated with intensive training regimens and excessive practice provoke structural and functional changes in the cortical and subcortical regions responsible for sensorimotor functions (Furuya et al., 2015). Research has revealed abnormalities in three main areas: (i) reduced inhibition in the motor system at cortical, subcortical and spinal levels (ii) reduced sensory perception and integration; and (iii) impaired sensorimotor integration (Altenmuller & Jabusch, 2010). A lack of pain associated with MFD distinguishes it from other conditions including repetitive stain injury or occupational fatigue syndrome (Altenmuller & Jabusch, 2010; Frucht, 2009) although aching of the affected area is commonly reported (Chen & Hallett, 1998).

In instruments with different work load, different complexity of movements or different temporospatial precision for both hands, focal dystonia appears more often in the more heavily used hand (Altenmuller & Jabusch, 2010). In their review of studies comparing the distribution of symptoms amongst a total of 1144 musicians, Rozanski et al. found that 68% of bowed stringed instrumentalists had left hand symptoms, whilst right-handed symptoms were reported in 78% of plucked string musicians. Woodwind players presented only a slightly increased manifestation of symptoms in the left hand (39%) compared to the right hand (32%) followed by embouchure dystonia (26%). Altenmüller and colleagues suggest that amongst this group, this might be due to the combination comprising prolonged support of the instrument with the thumb (left in the flute and right in clarinet and oboe) and fine motor control of the other four fingers (Altenmuller et al., 2012). Amongst brass players, 96% presented with embouchure dystonia whilst percussionists were slightly more affected in their right hands (49%) then their left hands (41%) and finally their feet (8%) (Rozanski et al., 2015). Amongst keyboard instrumentalists (piano, organ, harpsichord) the right hand is significantly

more affected (78%) although in 6% of cases the condition progressed to both hands. As found in similar studies (Jabusch & Altenmüller, 2006), FD in both hands was higher amongst keyboard instrumentalists (followed by woodwind players) where similar movement patterns in both hands are required. Embouchure dystonia is far more prevalent amongst brass players compared to woodwind players. Lim and Altenmüller confirm that brass players are required to fine tune the tension of embouchure muscles to obtain a highly precise control of frequency and amplitude of lip vibrations, which accounts for this variation (Lim & Altenmüller, 2003).

2.6 MFD RISK FACTORS

Risk factors associated with a variety of musicians' health problems, including MFD are classified in several ways. They are broadly described as physical and psychosocial (Berque et al., 2016; Chan & Ackermann, 2014; Kaufman-Cohen & Ratzon, 2011; Leaver et al., 2011), or intrinsic and extrinsic (Foxman & Burgel, 2006; JNAL Leijnse et al., 2015). Intrinsic risk factors, are defined as characteristics over which the individual has little or no control: for example, age, sex, size, strength, or flexibility (Chong et al., 1989). They include genetic predispositions (Jankovic & Ashoori, 2008), limb size (Ackermann et al., 2002), number of years playing (Baadjou et al., 2016; Wu, 2007) or hyper/hypo mobility (Rickert et al., 2013). Extrinsic factors are more modifiable or controllable variables such as frequency of repetitive movements (Altenmüller & Ioannou, 2016; Chan & Ackermann, 2014; Furuya et al., 2020), performance-related workload (Baadjou et al., 2016; Martín López & Farías Martínez, 2013), posture (Nyman et al., 2007; Spahn et al., 2014), biomechanics (Liliana S. Araújo et al., 2017; Brandfonbrener, 2009; Silva et al., 2018) physical conditioning (Baadjou et al., 2016; Barton & Feinberg, 2008), lifestyle choices (Liliana S. Araújo et al., 2017; Kenny & Ackermann, 2015; Kenny & Ackermann, 2012), environment (Ackermann & Adams, 2004; Kenny et al., 2016) and psychological aspects such as stress (Chan & Ackermann, 2014; Wood, 2014), MPA (Baadjou et al., 2016; Kenny & Ackermann, 2015), perfectionism (Ioannou & Altenmuller, 2014; Ioannou et al., 2016a; Onwuegbuzie & Collins, 2007) or depression (Kenny & Ackermann, 2015).

In MFD, an additional, gradual decline in precise motor function develops in response to a combination of the above risk factors. Altenmüller and colleagues have introduced a classification for the deterioration of motor controls that consists of; (1) duration and development of the problem, (2) triggering mechanisms, (3) psychological profiles, (4) response to treatment, (5) accompanying symptoms, and (6) genetics (Altenmüller et al., 2014). Genetic risk involvement is speculated due to a 4:1 ratio of male to female patients (Altenmuller & Jabusch, 2010) and a family history of task-specific focal dystonia in up to 36% of cases (Schmidt et al., 2009). A 2014 study has also suggested a risk variant at the arylsulfatase G locus, although no replication of findings has of yet been undertaken (Lohmann & Klein, 2017; Lohmann et al., 2014). Such factors could influence a wide range of processes, from the gating of synaptic plasticity through to the determination of personality traits or musical ability (Sadnicka et al., 2018). The moment in which musical training begins in life, is also significant. Adaptability of the central nervous system is the highest before the age of six (Altenmüller et al., 2014) and musicians that start their musical learning after the age of 10 are at much higher risk of developing MFD (Schmidt, Jabusch, Altenmüller, Kasten & Klein, 2013). Sadnicka et al. confirm that it may be a pre-requisite that training is initiated when the motor system is most adaptable during early childhood (Sadnicka et al., 2016).

In focal dystonias, high-risk groups are characterised by exceptionally high task-accuracy requirements (Sadnicka et al., 2018) with 10,000+ hours of practice suggested as being the approximate threshold of onset amongst musicians (Altenmüller & Jabusch, 2010; Ericsson et al., 1993; Rozanski et al., 2015). Fatigue, overuse, and injury are also important risk factors for task specific dystonias (Altenmuller & Jabusch, 2010; Sadnicka et al., 2018). In her review of 58 musicians with MFD, Brandfonbrener noted that ten participants had abruptly increased their playing workload and that eight had either changed their instrument or an element of their technique (Brandfonbrener, 1995). In their 2015 study, Leijnse and colleagues present a model of peripheral risk factors including overuse injury that may be present prior to MFD onset. Several triggering mechanisms are explored including instrument prevalence, previous injury, and technical overload. Their model identifies processes in which compensatory movements affect physiologically sustainable movements and discriminating physical constraints (including reduced finger independence) become effective (J Leijnse et al., 2015). Spatiotemporal acuity demands are dictated by

instrumental differences and usually predict which area of the body is affected. For example, pianists and guitarists are more commonly affected in the right hand (Altenmuller & Jabusch, 2009; Candia et al., 2002; van Vugt et al., 2014) whilst violinists and cellists are usually affected in the left hand (Altenmüller & Jabusch, 2010; Altenmuller & Jabusch, 2010). MFD incidence amongst string instrumentalists also increases as the size of instrument decreases, suggesting that tools requiring a higher spatial resolution carry greater risk of onset (Altenmuller et al., 2012).

The biomechanics of playing an instrument requires a maximised economy of force at a minimised error rate (Altenmuller et al., 2020). Bio-mechanical restrictions or limitations due to technical deficiencies, or physiological limits are also a significant risk factor (Furuya & Altenmuller, 2013). Overuse syndromes resulting from bio-mechanical problems are frequently reported amongst instrumental musicians. Sakai et al. reveal a suitable example of the problem amongst small-hand-span pianists with increased thumb abduction which increases the risk of de Quervain's tenosynovitis (Sakai et al., 2006). Pre-existing injury may precede or accompany MFD onset, including trauma, ulnar neuropathies, dental work or exposure to neuroleptics (Torres-Russotto & Perlmutter, 2008) although injury may or may not be caused by excessive practice or performance (Sadnicka et al., 2018).

Several studies have demonstrated compelling evidence for the involvement of psychological disorders and MFD onset (Altenmüller & Jabusch, 2010; Aránguiz et al., 2015; Ioannou & Altenmuller, 2014; Ioannou et al., 2016a; Jabusch & Altenmüller, 2006). Historically, research has struggled to define the role of psychological and emotional conditions in MFD. It has been defined as a psychogenic disorder (Cooper et al., 1976; Munts & Koehler, 2010; Newby et al., 2017), a form of hysteria (Sheehy & Marsden, 1982) and even an ‘‘occupational neurosis’’ (Gowers, 1888). Recent investigations of the psychological characteristics of various types of focal dystonias however, confirm that many movement disorders may affect similar neurobiological networks to those implicated in common psychiatric diseases (Ron, 2009). In their cohort study of patients with primary focal dystonias (FDs), Lencer and colleagues suggest that FDs may, in fact, be classified as neuropsychiatric disorders. Co-morbid psychiatric disorders observed amongst FD participants were expressive, including social phobia, panic disorder, agoraphobia, anxiety, depression obsessive compulsive behaviours. Usually diagnosed well before the onset of FD symptoms, 32.6% of

participants reached the threshold for anxious personality disorder, and social phobia, agoraphobia and panic disorder were more than 4.5 times more likely to occur than in the control group (Lencer et al., 2009).

The psychological disorders observed in MFD differ slightly in those commonly observed in others forms of FDs. For example, depression is the prevalent form seen in blepharospasm (Lencer et al., 2009), anxiety and depression are the most common in cervical dystonia (CD) (Fabbrini et al., 2010; Meyer et al., 2009) anxiety in hand dystonia (Altenmuller & Jabusch, 2009; Jabusch & Altenmüller, 2004), and OCD in MFD (Ioannou et al., 2016; Zurowski et al., 2013). OCD has been associated with dysfunctions of cortico-striato-thalamic-cortical loops involved in motor control (Ioannou et al., 2016a, 2016b; Strubing et al., 2012). Butler et al. also suggest that fear-induced processing involves motor control networks (Butler et al., 2007). The impact of an induced stress response upon MFD sufferers is examined by Ioannou and colleagues (2016). They examined the psychological profiles of 20 musicians with MFD and 16 without, and to what extent a simulated stressful condition may affect motor impairment. Results showed no motor changes but did show an increase in muscle co-contraction when under stress, and higher levels of anxiety, stress, and perfectionism in 40% of participants. The group which exhibited these psychological traits had, on average, developed MFD ten years earlier than the rest of the patients (Ioannou et al., 2016b).

Co-morbid psychiatric disturbances have been identified as causing significant morbidity and reduction in quality of life, independent of the motor aspects of dystonia (Zurowski et al., 2013). Studies have shown significantly greater pre-existent anxiety disorders, including specific and social in musicians with MFD, compared to healthy musicians (Jabusch & Altenmüller, 2004; Jabusch et al., 2004). Enders and colleagues suggest that anxiety may in fact be a common pathophysiological mechanism in MFD (Enders et al., 2011) although subsequent studies have identified two distinctive subtypes of MFD, in which increased anxiety, perfectionism and response to stress, may or may not be present (Ioannou & Altenmuller, 2014; Schneider et al., 2021). A 2016 study of MFD 20 patients revealed that 40% of participants higher levels of psychological traits related to elevated anxiety, stress, and perfectionism and that amongst this group, onset of the condition was approximately ten years prior to the other patients (Ioannou et al., 2016a). Studies have also identified other specific

personality traits observed in MFD patients, particularly neuroticism and openness (Enders et al., 2011; Steinlechner et al., 2018). Negative correlations between Neuroticism Extraversion Openness Five-Factor Inventory (NEO-FFI) openness scores and duration of MFD amongst patients suggest that these traits are in fact, a psycho-reactive phenomenon in response to the dystonia (Steinlechner et al., 2018).

Schneider and colleagues discuss the effects of early psychic trauma upon six patients with MFD, theorising that in-depth, early traumatisation most probably led to a dysfunctional stress-coping mechanism (Schneider et al., 2021). Timespan between trauma and MFD onset differed significantly between subjects however, supporting the theory that some musicians may only reach their maximal stressor response progressively over time, rather than directly after the event. Quality of life issues are discussed by Paracka et al. in a study that suggests the impact of negative body concept impairment amongst idiopathic dystonia sufferers. Negative interference upon quality of life both emotionally and physically is surmised and positive correlations between body-image and depression are confirmed (Paracka et al., 2020).

In summary, the risk factors associated with MFD are multifactorial and the combination of triggers may or may not include psychological traits. The pre-existence of anxiety, exaggerated perfectionism, obsessive-compulsive behaviours, or specific phobias may be associated with earlier onset of motor symptoms. Biomechanical problems associated with technical deficiencies or physiological limits, pre-existing over-use injuries, repetitive and highly stereotyped practice schedules, or excessive work schedules may all be associated with higher risk of MFD onset. Genetic pre-disposition in conjunction with a combination of the aforementioned triggers, may further increase the likelihood of developing MFD.

2.7 MUSICIANS ʾFOCAL DYSTONIA - A HEURISTIC MODEL

In their 2010 literature review, Altenmüller and Jabusch (2010) propose a heuristic model that demonstrates the coactions between a predominantly genetically determined predisposition, and intrinsic and extrinsic triggering factors in MFD onset (Figure 1). Genetic susceptibility and male gender are placed as predispositions at the centre of the model with both intrinsic and external triggers feeding into them. At this stage, the model does not offer a timeline of onset, nor does it suggest any degree of

exclusivity concerning risk factors. Intrinsic factors including “need for control” and “deficit in inhibitory actions” are described, the first of which pertains to musical genre (more control required for classical music vs. jazz), and the second suggesting a pre-existing lack of inhibition affecting motor control. Interestingly, “social control”, listed as an extrinsic factor, is also used to describe the role of musical genre and increased risk.

Figure 1. Heuristic Model Altenmüller - Version 1

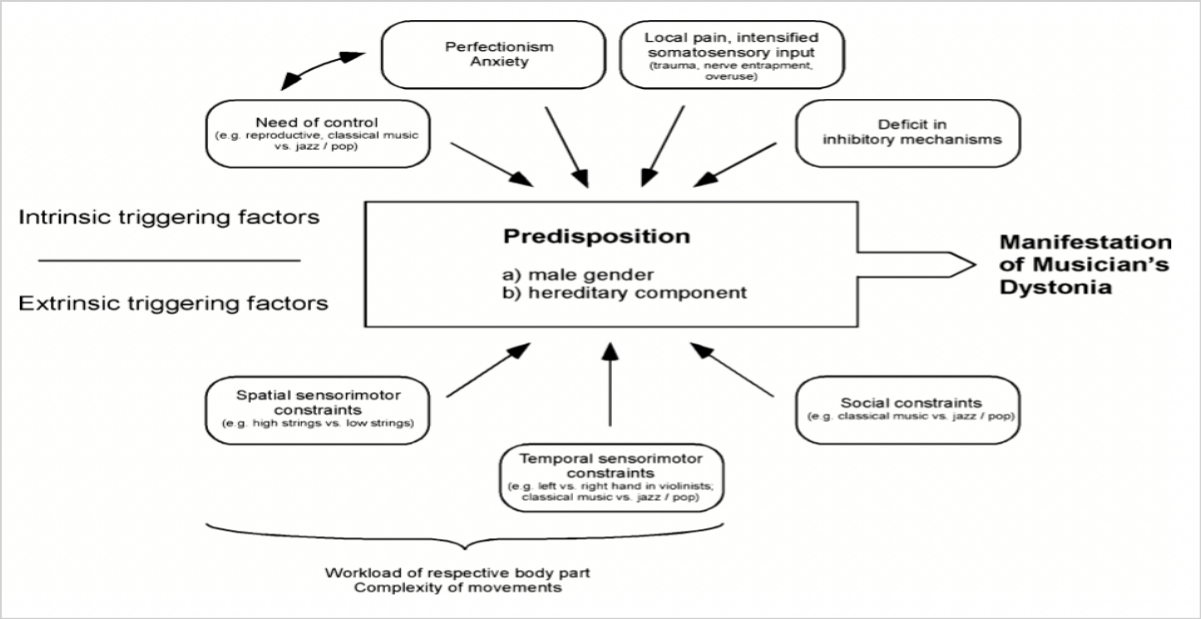


Figure 2.. Heuristic Model Altenmüller - Version 2

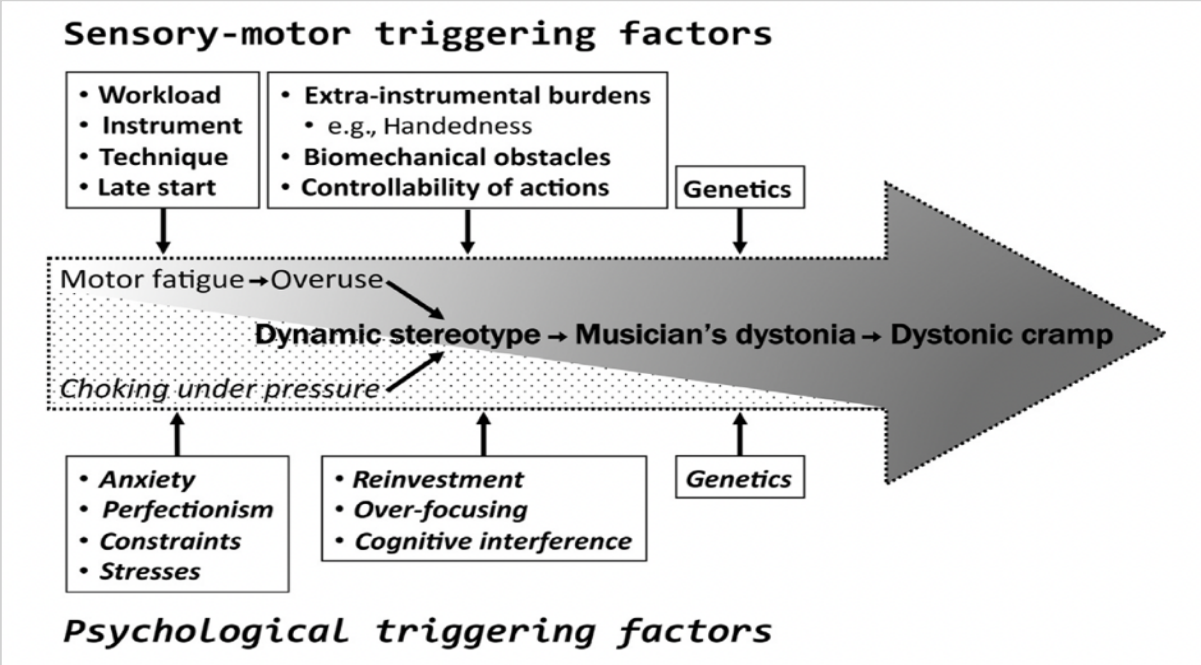
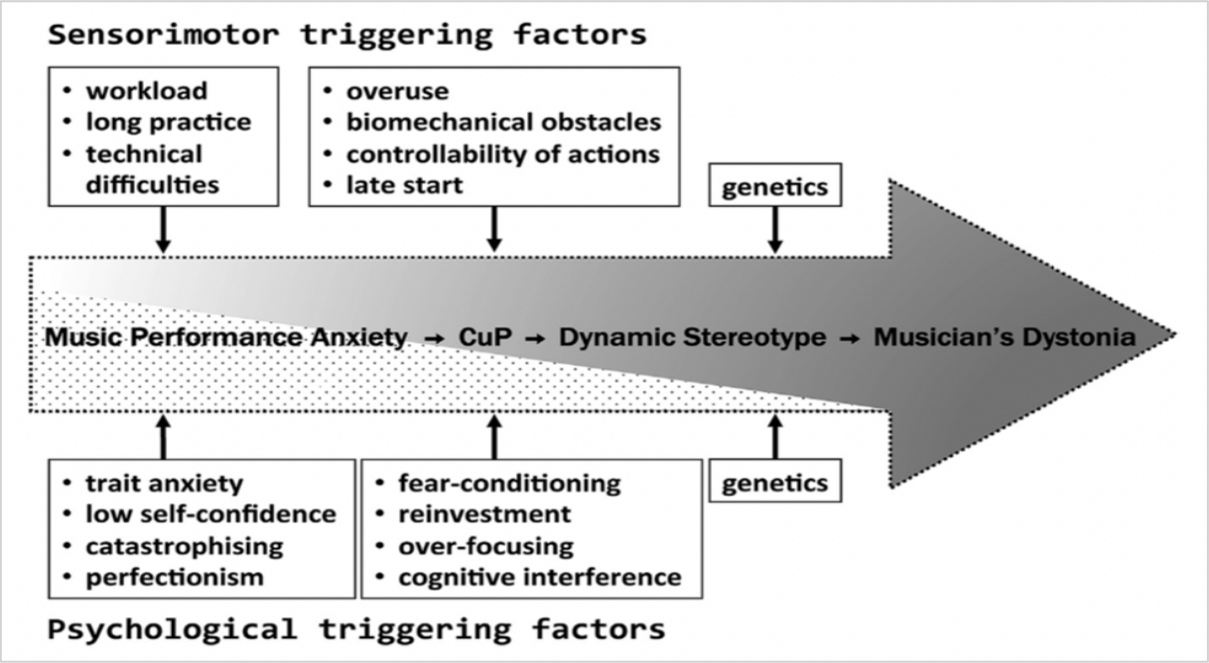


Figure 3. Heuristic Model Altenmüller - Version 3



A further, second version of the heuristic model (Altenmüller et al., 2014) then introduces a graphic representation of MFD progression (Figure.2). In contrast to the 2010 model, psychological and sensorimotor classifications are presented in place of intrinsic and extrinsic triggers. Choking under pressure (CuP) is introduced to the model, representing a combination of the emotional states of anxiety, perfectionism, stress, and social constraints, together with the physical symptoms of motor fatigue and overuse, that when combined may subsequently produce a pre-dystonic state of "dynamic stereotype". Genetic predisposition is then introduced, suggesting its role in transforming the pre-dystonic state of dynamic stereotype into the dystonic state of MFD before a final stage of "dystonic cramp".

The third, most recent model (Figure.3 expands further upon the horizontal progression towards MFD. It represents a significant change from the previous two models. Here, music performance anxiety (MPA) is presented as the first stage in the development of MFD, prior to CuP. This reflects a repositioning of psychological triggers, now expressed as centrals components of MFD progression. Several authors recognise anxiety, perfectionism, and obsessive patterns of thoughts to be common psychological traits in MFD patients (Gowling, 2020; Ioannou & Altenmüller, 2014;

Jabusch & Altenmüller, 2004). Excessive perfectionism is implicated in the development and maintenance of specific anxiety disorders, and perfectionistic thinking contributes to certain types of obsessions (Antony et al., 1998; Limburg et al., 2017; Miegel et al., 2020). Acceleration of symptoms due to perfectionistic traits has also been identified.

In contradiction however, a subset of MFD sufferers that present with no prior history of psychological disorders also exists. Schneider and colleagues describe two distinctive types of motor failures involved in MFD, one linked to stressful experiences, dysfunctional coping behaviours, and increased muscle tone, and one linked to genetic susceptibility of the motor-system without psychological triggering factors. Several studies confirm the presence of anxiety disorders, presenting as either stress (Ioannou et al., 2016a), MPA (Jabusch & Altenmüller, 2004), OCD (Ioannou & Altenmuller, 2014; Strubing et al., 2012), excessive perfectionism (Altenmuller & Jabusch, 2009; Ioannou & Altenmuller, 2014) or a combination of those factors, amongst sufferers. (Schneider et al., 2021). What remains unclear in the literature, however, is to exactly what extent the psychological triggers that accompany MPA, and CuP are present prior to the motor symptoms of MFD or occur because of onset. The 2016 heuristic model (Figure.3) assumes the automatic involvement of psychological factors in the early stages, with genetic involvement being suggested as a later catalyst towards MFD, whereas the two earlier versions do not. It can also be argued that a separate timeline of onset towards MFD exists that does not involve psychological triggers including MPA or CuP, could also be represented through the model, which in turn may encourage a discrimination between varying levels of psychological trigger involvement in onset of the condition.

2.7.1 Choking Under Pressure

CuP is described as a state in which, under pressure, motor actions, such as those required in public speech, surgery, or musical performance, can be compromised, even when these have been well-trained (Furuya, Ishimaru & Nagata, 2021). Musicians often play under circumstances in which pressure may lead to anxiety and performance deterioration (Raôul, Oudejans, Spitse, 2016 et.al) and highly trained movements may become susceptible to cognitive interference, leading to a degradation of motor control and increased anxiety. Paradoxical performance results

from this degradation, a situation in which, “we are able to perform, we intend to perform, we perform—but we do not succeed in what we intended” (Lobinger, Klämpfl & Altenmüller, 2014). CuP has been conceptualised as a motor symptom of musicians ’performance anxiety (MPA), (Hill, Hanton, Fleming, & Matthews, 2009; Altenmüller & Ioannou, 2016). Studies have suggested a prevalence of CuP amongst performing musicians of up to 60% (Altenmüller & Ioannou, 2016; Brugues, 2011a; Steptoe & Fiddler, 1987). Physical manifestations of CuP include elevated muscle activity, muscle co-contraction and rigidity (Yoshie, Kudo, Murakoshi, & Ohtsuki, 2009) and may suggest a pattern of further motor degradation and increasing levels of MPA (Altenmüller & Ioannou, 2016).

Both attentional and drive theory are closely associated with CuP in musicians. Drive theory states that performance depends on the level of arousal and specifically that an optimum level of arousal benefits performance (Baumeister & Showers, 1986). However, high levels of arousal can lead to poorer performance on fine motor tasks by increasing muscular tension (Parfitt et al., 1990). Attentional theory expands upon the notion of heightened physiological arousal responses by elucidating the physical problems associated with higher arousal states. It contemplates this, in two distinctive models of action, distraction, and self-focus, currently used to describe the motor degrading effects of CuP. The distraction model (e.g., Hardy, Mullen, & Martin, 2001; Hill, Hanton, Matthews, & Fleming, 2010a; Mullen, Hardy, & Tattersall, 2005; Oudejans, Kuijpers, Kooijman, & Bakker, 2011) describes CuP occurring because attention shifts from task-relevant to irrelevant cues as a result of heightened anxiety (Gröpel & Mesagno, 2017).

In contrast, the self-focus model identifies the action of conscious interference upon automatic movement and consequential performance degradation. Baumeister (1984, p.610) confirms that, “competition is arousing; arousal heightens self-consciousness [consciously monitoring and controlling one’s movements]; and self-consciousness [consciously monitoring and controlling one’s movements] disrupts performance of some tasks”. Interventions that act upon the distraction model of CuP are concerned with the prevention of internal or external distractions and promote a task-relevant focus of attention during skill execution (Mesagno, Marchant, & Morris, 2008; Mesagno & Mullane-Grant, 2010). For example, Wolf, Tolner & Shea (2007) demonstrate the positive performance gains of an external focus (in this case concentrating on a disc)

upon a task that involves maintaining a stable posture on one leg whilst standing on a flexible support surface. Self-focus model interventions, in contrast, aim to control and reduce reinvestment of explicit knowledge and conscious skill execution. They include studies that regulate or reduce the accumulation of explicit knowledge during skill acquisition (Liao & Masters, 2001; Masters, 2000) or by diverting attention away from focusing on the step-by-step execution using task-irrelevant dual tasks (Beilock, Carr, MacMahon, & Starkes, 2002; Mesagno, Marchant, & Morris, 2009).

2.7.2 "Dynamic Stereotype"

In the context of MFD, the term dynamic stereotype (DS) has been adapted to describe the penultimate stage on the continuum between MPA and MFD, in which more pronounced and sustained motor control symptoms are evident when playing (Altenmüller et al., 2014). Altenmüller and colleagues describe, "a vivid manifestation of the extremely subtle analysis and synthesis activity of the cerebral cortex and is the product of very complex interactions between cortical areas. It can be at least partly conceptualised as a consequence of long-term CuP when these dysfunctional movements are stored in procedural memory traces, maybe as a consequence of conditioned reactions to previous choking experiences and procedural memory formation under stress" (Altenmüller & Ioannou, 2016). There is also a time factor involved in the development of DS and practise predating the development of task-specific dystonia is also often particularly extensive and stereotyped, excessively repetitive, highly rehearsed, and devoid of variation (Sadnicka et al., 2018).

The time sensitive nature of DS is expanded upon by Altenmüller and Ioannou in the following quotation:

"When the lack of motor control persists for longer than four weeks and performance failures occur more regularly, a more serious alteration of the sensorimotor networks may be suspected, leading to a deterioration of motor programmes in the CNS (central nervous system)".

(Altenmüller & Ioannou, 2016)

Movement routines that have been acquired [stereotyped], are performed automatically, and do not necessarily need to be consciously controlled (Lobinger et al., 2014). Altenmüller and colleagues suggest that when treating DS, psychological

techniques, such as the prevention of dysfunctional reinvestment and cognitive interference, will be helpful (Altenmüller & Ioannou, 2016). The constrained action hypothesis (Allingham & Wöllner, 2021; McNevin & Wulf, 2002; Vidal et al., 2018; Wulf et al., 2007) argues that focusing externally, adopting an external focus of attention, allows unconscious or automatic processes to control the movements (Wulf et al., 2007). Cognitive interference is associated with an internal focus, where musicians are more likely to consciously intervene, potentially disrupting automatic control processes (Wulf et al., 2007). Several studies have shown positive performance outcomes connected to external-focus feedback (Allingham & Wöllner, 2021; Kal et al., 2013; Vidal et al., 2018). Studies have also suggested that focus of attention (FOA) task outcomes may also depend on the overall attention demands of the tasks involved (Sherwood et al., 2020). Task 'difficulty' is exemplified by dystonias in performing artists or competitive sports in which the body is pushed to the very extremes of its spatiotemporal capacity (Sadnicka et al., 2016). Motor performance examination has evidenced that the object of a performer's FOA can significantly affect motor skill learning and performance (Wulf, 2013). In DS, psychological triggering factors are more likely to be involved than genetic causes (Altenmüller et al., 2014). Therefore, retraining methods that involve the constrained action hypothesis and external-focus techniques, may benefit motor control failures in pre-dystonic states.

However, although DS offers a tantalising insight into a pre-dystonic state, where interventions may be significantly more effective (Altenmüller & Ioannou, 2016), empirical studies that investigate how DS may be consistently identified, do not yet appear in the literature. It could be argued, therefore, that DS may not be present or distinguishable in cases where onset more sudden and in the absence of psychological triggers. This would align with Schneider et al.'s description of motor failures (Schneider et al., 2021), where one type is linked exclusively to genetic susceptibility. In conclusion, the heuristic model, whilst offering the most complete précis of MFD, both in its evolution and manifestation, may also reveal the need for further investigation into MFD cases that do not include identifiable psychological triggers, in order to complete the model.

2.8 RETRAINING FOR MFD

Treating [FD] patients is difficult and requires, in almost every case, an individual approach (Butler & Rosenkranz, 2006b). Treatment is based on using multiple strategies for the management of the dystonia, with variable results (Chiaramonte & Vecchio, 2021). Several categories of retraining used in MFD rehabilitation are described within the literature, including, neuromodulation, neuromuscular re-education, sensory retraining, and proprioceptive retraining. Systematic reviews of retraining studies for focal dystonias report several methodological shortcomings, in part due to differences in treatment approaches or sample sizes, which complicate assessment. Prudente and colleagues report low to very low GRADE levels, reflecting a lack of randomised or downgraded randomised trials or double upgraded observational studies (Prudente et al., 2018). In their review of MFD neuromuscular retraining studies, Enke et al. conclude that many of the outcome measures used to assess the effectiveness of intervention protocols have not undergone reliability or validity testing (Enke & Poskey, 2018). Chiaramonte and Vecchio also highlight issues with study duration, intensity, quality, and time of application after onset, as well as a need for differentiation between severity of symptoms and outcomes (Chiaramonte & Vecchio, 2021).

However, retraining studies frequently report positive benefits and outcomes. Butler et al. emphasise the importance of a multi-disciplinary approach to treatment incorporating an aggressive sensory re-education element (Butler & Rosenkranz, 2006b). Candia et al. confirm the role of sensory-motor retuning (SMR) in remodelling cortical networks and reducing symptoms (Candia et al., 2005). Constraint-induced retraining and slow-down exercises (SDE) have been shown to significantly improve symptoms and studies have even reported a return to normal playing in some cases (Berque et al., 2010). Neuromodulation studies involving transcranial stimulation may enhance rehabilitation when used in conjunction with SMR (Rosset-Llobet et al., 2015) and proprioceptive approaches have shown improvements in sensorimotor organisation (K. Rosenkranz et al., 2008). The following section defines MFD retraining methods and examines the available evidence for their effectiveness in rehabilitation.

2.8.1 Retraining with Neuromodulation

Transcranial magnetic stimulation (TMS), is a non-invasive technique, using electrodes placed on the scalp directly over targeted areas of the brain. Stimulation induces excitability or doping effects dependent upon the type of current used, positioning and polarity of electrodes. When used in conjunction with retraining, some positive outcomes have been observed in musicians with MFD under certain conditions.

In an early seminal study of non-musicians (Pascual-Leone et al., 1995), the authors revealed for the first time that mental practice is effective in maintaining technical capabilities (Rietveld, 2013). Eighteen participants were separated into three groups, two practice groups and one control. A simple five finger piano exercise was given to learn over five days which was practised mentally by one group, physically on a keyboard by the second, and not at all by a third. Each group received TMS stimulation of the primary motor cortex during their group specific tasks, increasing incrementally over the five days. Results revealed improvements in the performance and accuracy of both practice groups and an increased size of digital cortical representation upon the motor cortex. They also demonstrated that mental practice alone led to the same plastic changes in the motor system as those occurring with the acquisition of a skill by repeated physical practice. Whilst the physical practice group did produce the best performances, after only a two-hour physical practice session, the mental practice group achieved a similar performance level confirming that physical practice with a musical instrument is not a unique means for skill acquisition (Furuya, 2018).

However further TMS studies of non-dystonic professional musicians have shown mixed outcomes. In their 2014 study, Furuya et.al compared the effects of TMS on 13 professional pianists and 13 non-pianists. (Furuya, Klaus, et al., 2014). Three different stimulation protocols were tested using transcranial direct current stimulation (tDCS). Pre, during and post-stimulation measures were taken from each participant over three sessions carried out, two weeks apart. Amongst the non-pianists, enhanced fine motor control was observed when executing a short, predetermined sequence of notes using, whilst the professional pianists displayed no improvement and demonstrated a deterioration in fine motor execution. They concluded that the provocation of cortical

excitability in trained pianists may in fact disrupt patterns of highly trained movement co-ordination. Interestingly, MFD is also characterised by abnormal overactivation (excitability) of the motor cortex (Pujol et al., 2000). This would suggest that uncontrolled use of TMS in MFD retraining could in fact be detrimental to recovery.

Studies directly involving MFD patients with retraining have also produced mixed results. Buttkus and colleagues (Buttkus et al., 2011) examined the effect of a single twenty-minute session of cathodal tDCS, combined with slow, voluntary controlled movements on a group of nine professional pianists with MFD and in a study one year previously, ten guitarists (Buttkus et al., 2010). In each study they concluded no benefit or statistical change in symptoms pre and post-test using the tDCS protocol. The short duration of treatment and a lack of neurophysiological tests to measure cognitive performance were cited as a possible factor for the negative outcome. In contrast, Furuya and colleagues reported improvements in fine motor control and timing in a group of ten pianists with MFD (Furuya, Nitsche, et al., 2014). Over five sessions, comparing a series of stimulation protocols, bi-hemispheric tDCS together with bimanual mirrored finger exercises produced improvement of rhythmic accuracy amongst the experimental group. Two possible causes were cited, firstly, that bi-hemispheric tDCS may directly increase interhemispheric inhibition into the affected motor cortex, reducing excitability in FD patients, or secondly it may augment the fraction of motor commands transmitted from the unaffected to the affected cortex helping stabilise abnormal motor programmes. Llobet and colleagues then compared the effects upon two groups of MFD sufferers utilising sensory motor retraining (SMR) together with, or without the same, bi-hemispheric tDCS protocol used in the Furuya 2014 study (Rosset-Llobet et al., 2015). Both groups reported improvement of symptoms over a two-week period but patients that received the SMR with tDCS showed statistically greater gains.

Retraining techniques together with TMS may be beneficial under specific conditions. A bi-hemispheric tDCS protocol has been shown to be effective when combined with bimanual finger exercises, but possible deterioration in fine motor control has been demonstrated under certain parameters. SMR has been shown to be significantly more effective amongst a small group of pianists when combined with tDCS.

Long term studies and larger sample groups are needed to validate outcomes, and further forms of retraining together with TMS protocols should be examined. To date, the literature includes a handful of studies of pianists and guitarists, but research looking into the effect of TMS and retraining upon embouchure dystonia is not yet available. Furthermore, only one case study was found involving TMS and bowed strings where a viola player reported an eighty percent improvement in symptoms, but the quality of study was poor (Kieslinger et al., 2013). Subjective reports from participants may also help to validate objective measures in future TMS studies with MFD sufferers.

2.8.2 Biofeedback

Biofeedback refers to methods for providing external and augmented information about ongoing internal, physiological activity that is directly and linearly related to fluctuations in the physiological system being monitored (Levee et al., 1976). Studies involving musicians with MFD and biofeedback techniques are scarce, however, available research suggests positive results using electromyography (EMG) as the feedback tool. Levee and Rickles, in their early 1976 case study, examined EMG effects upon, “throat and facial tension and tics” experienced by a 52-year-old flute player. The subject had recently undergone treatment and rehabilitation for alcohol abuse and began biofeedback training 5-months later as an outpatient. The training consisted of four phases of relaxation training over a period of twenty, 45-minute sessions. Phase one involved placing electrodes on the frontalis muscle, the bridge of the nose, and either the right or left orbicularis orris. An EMG feedback unit with seven light-emitting diodes was used that represented different levels of peak-to-peak muscle tension, per light. The subject was instructed to turn off as many of the seven lights as possible by relaxing the appropriate muscles, and tension reduction recorded. The second phase involved the same procedure but with electrodes connected to muscles surrounding the throat instead of the face. The third session repeated the second phase but whilst playing the flute in a single walled acoustically controlled IAC 403 series chamber and phase four involved the same procedures without an acoustic chamber present. The patient reported significant improvements in symptoms and “an increased sense of control and refinement”, confirmed by recording feedback gains at

each phase. Reduction of symptoms remained after a six-month follow-up. (Levee et al., 1976).

In their 1981 study of 9 healthy intermediate and advanced string instrumentalists, Morasky et al. used EMG to measure feedback levels of the extensor muscles of the forearm in a three stage, pre-test, biofeedback, and post-test experiment. A series of 15-second, pre-written left-hand tasks involving trills and vibrato were performed 10 times in each stage. During the biofeedback phase, an analogue-pulsed tone sounded every time an EMG threshold of 90Hz was passed and participants instructed to keep below the threshold as much as possible. EMG reductions were recorded and became generalised to a no-feedback condition (post-test). A further study by the same authors using the same measures was designed to examine EMG biofeedback on a group of 8 intermediate and advanced clarinettists (Morasky et al., 1983). Results mirrored the 1981 study and the author confirmed that, “biofeedback training and not practice was the critical component in reducing unwanted muscle tension during performance”.

A further 1983 study case-study examined the effect of an in vivo temperature biofeedback exercise upon a violist with right-handed “occupational palsy” (MFD) (LeVine, 1983). A feedback thermometer was used to train the patient to raise fingertip temperature by central vasomotor control during a sequence of six, half-day sessions. During the two daily 30-minute exercise periods, the subject was asked to warm-up and when a fingertip temperature of 91º was reached to begin playing. If it fell below the target temperature, she stopped playing and began hand warming again until her fingertips reached the prescribed temperature. Temperature feedback provided a detector that, by registering a decrease in finger temperature, indicated the anxiety that accompanied the obsessive attention to bowing. By the end of her training, she could maintain a fingertip temperature of 93º during a 15–20-minute period. Subjective improvements in physical symptoms and anxiety were reported and maintained over the following four-year period.

The biofeedback studies involving musicians cited above are limited and present several methodological shortcomings. FDs of the hand including writer’s cramp have been explored more extensively within the literature and have shown positive

outcomes (Berger et al., 2007; Deepak & Behari, 1999; Hashimoto et al., 2014; McKenzie et al., 2009). Further, larger scale studies of the effects of biofeedback training for MFD are warranted in response to current findings.

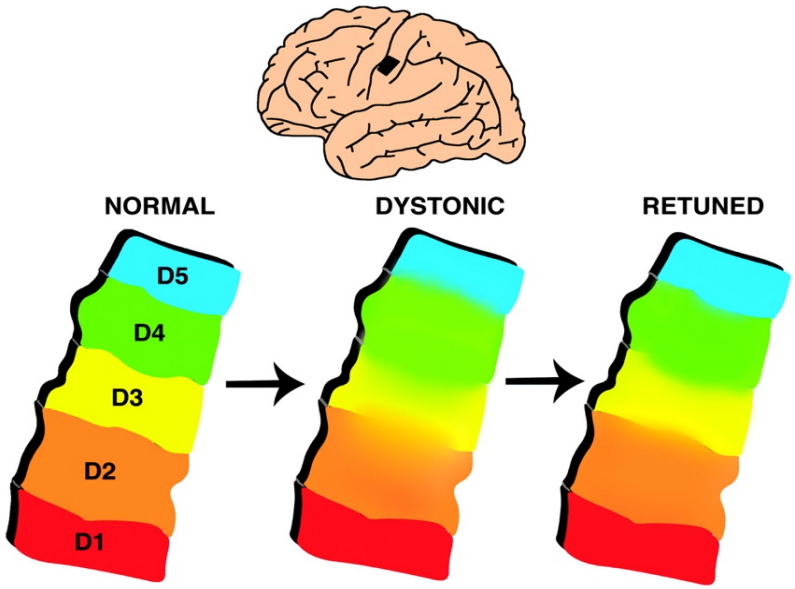
2.9 NEUROMUSCULAR RETRAINING TECHNIQUES

Based on the principles of neuroplasticity, neuromuscular re-education programmes aim to improve motor control, sensory discrimination, and performance through normalizing somatosensory representations of affected digits which become blurred (Byl et al., 2003). The term plasticity was coined by Italian psychiatrist Ernesto Lugaro in the early 20th Century to describe anatomic-functional relations between neurons that alter and adapt to facilitate psychic maturation, learning, and functional recovery after brain damage (Berlucchi, 2002). It is an important organisational feature of the human brain that allows our central nervous system (CNS) to adapt to changing environmental conditions and newly imposed tasks (Altenmüller & Furuya, 2016). It also occurs on many levels including, the creation of individual neuronal connections, neuronal network connections or even the neuronal connection of an entire region of the brain (Stegemöller, 2014).

The 1991 Allard et al. primate study revealed the effect of an unexpected event on cortical representation, whilst the 1996 Byl et al. study demonstrated the learning-induced effects upon the same phenomenon. The same learning-induced mechanisms have also been clearly demonstrated in human studies (Byl & McKenzie, 2000; Byl et al., 2003) in which maladaptive plasticity leads to degradation of finger representation boundaries. Altenmüller and colleagues also describe MFD as representing a syndrome of central-nervous system maladaptive plasticity (Altenmuller et al., 2012). Elbert and colleagues state that the cortical representation of affected digits is blurred or overlapped, leading to a lack of discrimination between digits and the “fusion of the digital receptive fields” (Elbert, Candia, Altenmüller et.al, 1998). Enlargement of cortical digital representations is also observed, as well as irregular patterns of organisation due to unexpected sensorimotor experiences (Nudo, 2003). The following diagram (Figure.4) shows the fusion, enlargement, and encroachment upon the somatosensory cortex representations of the fingers D3 and

D5 by the dystonic digit D4 (centre), compared to the normal representation (left) and the “retuned” version after retraining therapy (right).

Figure 4. Nudo - Finger Representation Blurring



(Nudo, 2003)

(Figure.1) *Finger representations D1-D5 on the surface of the somatosensory cortex showing D4 enlarged and overlapping into D3 and D5 in the dystonic state (centre)*

Multiple studies describe the involvement of dysfunctional, maladaptive neuroplasticity (Altenmüller, 2003; Altenmüller et al., 2012; Berque et al., 2013; Furuya & Altenmuller, 2015). Repetitive motor activity alters neuronal activity contributing to an overlapping of digital representations upon the somatosensory cortex, and subsequent fine motor control problems. Stimulating healthy plasticity in MFD through retraining aims to normalise the somatosensory map and allow musicians to return to a degree of normal playing. The restoration of healthy plasticity to normalise the somatosensory map may therefore produce a reduction in symptoms (Nudo, 2003) which is the principle aim of plasticity centred retraining for MFD.

The mechanisms through which this goal may be reached however, are complex and multifactorial, involving physiological, psychological, and psychosocial processes (Altenmuller & Jabusch, 2010; Ioannou & Altenmuller, 2014; Schneider et al., 2021).

The following passage is taken from the book "*Intertwined, How to Induce Neuroplasticity*" by Joaquin Farias:

> The borders between that which is emotional, mental, and motion blur, making it imperative to consider these three elements as one. In essence, the experience of not being able to stop thinking, feeling, or moving is due to these same processes. We need to explore the interrelationships among emotion, thought, and movement during rehabilitation in order for it to be effective. (Farias, 2012)

The sequence of processes that contribute to maladaptive plasticity in MFD remain unclear. Defazio and colleagues suggest that peripheral injury or repetitive motor activity in a certain part of the body, or by both, might cause sensory receptive changes in the corresponding cortical brain areas (Defazio et al., 2007). The concept of "motor-chunking" is suggested by Sadnicka and colleagues, in which repetitive training of a narrow repertoire results in the formation of progressively larger and highly stereotyped motor "blocks" that become poorly transferable to new tasks, essentially provoking a reduction in motor plasticity (Sadnicka et al., 2018). Studies also suggest the encoding of motor performance in response to emotions (Altenmüller, 2003; Ioannou & Altenmuller, 2014; Ron, 2009) and the involvement of limbic structures associated with emotion in the alteration of basal ganglia circuitry (Berardelli, 2006; Lin & Hallett, 2009).

Early age of musical skill acquisition and enhanced meta-plasticity is discussed within the literature. Schmidt et al. (2013) have shown that MFD patients begin playing their instruments at 10 (+/- 4.7) years old, approximately 3 years later compared to healthy musicians (7.7 +/- 2.2 years). Studies have also confirmed the neuroprotective impact of early extensive sensorimotor training upon sensorimotor networks throughout life (Krampe & Ericsson, 1996; Meinz, 2000). Altenmüller and Furuya propose that prior extensive sensorimotor training improves age-related decline of motor functions, which also implicates a relation of musician's meta- plasticity to aging (Altenmüller & Furuya, 2016).

The following section discusses specific neuromuscular retraining techniques currently utilised in MFD rehabilitation that are centred around neuroplasticity modulation.

2.9.1 Slow-down exercises

Slow-down exercises (SDE) describe a technique in which the execution speed of a particular piece of music is reduced by the musician until it may be reproduced without provoking the dystonic movements. Over a course of a period of weeks or months the speed of execution will be increased incrementally, and any improvements recorded. Sakai and colleagues (2006) recruited 20 dystonic pianists who were requested to reduce the performance speed of a piece of music until the dystonic hand movements had disappeared. The baseline slow speed was then recorded with a metronome, and the musicians proceeded to rehearse the music at the baseline speed for 30 minutes a day for two weeks. If no dystonic symptoms were observed, then the speed was then increased by 10-20% over a further two weeks. If dystonic symptoms resolved then the speed was increased by a further 10-20%, but if symptoms persisted, the speed would be reduced back to the previous level. All subjects reported improvement with 8 reporting only mild impairment and 12 returning to normal playing.

In a further study, Berque and colleagues (2010) used slow-down exercises in conjunction with constraint-induced therapy on six professional musicians and two amateur musicians with MFD, involving the hand. The sensory motor retuning element (using constraints) involved splinting the affected wrist and fingers, dependent upon the individual dystonic pattern. The finger to be trained was not splinted, whilst one or more adjacent fingers were constrained to reduce co-contraction. Specific finger patterns were played daily for a week by participants, aimed at normalising movements of the dystonic digit. They rehearsed for 10-minute periods with 2-minute breaks, during a 2-hour period. A metronome was used to gradually increase the speed of the finger patterns every 2-minutes during each 10-minute sequence until the maximum tolerated speed was reached for each participant. The second phase of SDE retraining was added in the second week, based upon the same methods used by Sakai et al. (2006). Significant improvements were observed using the Frequency of Abnormal Movements scale (FAM) after six months of retraining although they

suggest that a minimum of eight months is more optimal based on Tukey's post-hoc test results. Berque and colleagues long-term follow up study (2013) accompanied the same group of participants during the following four-year period. A within-subject, repeated measures design tested the effects of the first study during 9 sessions across four years. An 80% reduction in abnormal movements was recorded after the first 12 months which was then maintained during the four years.

Significant decreases in abnormal movements and increases in metronome speed without dystonic symptoms were observed in each study and clearly demonstrate the benefit of SDEs, either on their own, or in conjunction with constraint-induced retraining. However, each of the cited studies required a significant time commitment. The average adherence time in the Sakai et al. study was 2 years, and the initial 2010 Berque et al. study, and follow-up 2013 study required participation of one year and 4 years respectively. A great deal of patience and dedication is required by participants utilising SDE retraining. During the Sakai et al. study, several participants reported that they disliked the SDE exercises, citing low motivation and difficulties in regularly completing the task. Berque et al. (2010) also suggest that the inclusion of only one simple piece in the retraining may avoid methodological difficulties caused by the inability of some participants to play more challenging repertoire without stopping.

Further limitations regarding the currently published SDE studies include the lack of control groups, and small sample sizes. Additionally, when studied in conjunction with other retraining methods, SDE improvements cannot be attributed to one intervention alone, but to a combination of both (Berque et al., 2010). However, additional studies of SDE retraining amongst larger populations and across a wider range of instruments are needed although outcomes of existing studies are positive.

2.9.2 Constraint-Induced Retraining

Retraining with constraints, also known as sensorimotor retuning (SMR) was first introduced to musicians with MFD in 1999 (Candia et al., 1999). It involves intensive motor retraining with the affected body part while unaffected joints are constrained to avoid compensatory movements (Prudente et al., 2018). Adapted from its use in the rehabilitation of stroke patients (Taub & Uswatte, 2003), this type of retraining aims to

reverse the cortical fusion or ‘blurring ’also seen in MFD sufferers, by challenging the behavioural mechanisms that are believed to underpin involuntary movement incoordination.

Previous work by Byl and colleagues (Byl et al., 1997; N. N. Byl et al., 1996) has shown that as with MFD sufferers, primates exhibit motor disturbances with degradation of hand movements and unorganised digital representation upon the sensorimotor cortex during repetitive tasks. The Allard et al. study (1988) created digital syndactyly by fusing adjacent fingers in a primate, revealing highly modified finger surface representations after several months of fusion. As observed in primates, aberrant learning and degradation of the cortical hand representation is also present in MFD sufferers. Therefore, it can be surmised that constraining compensatory movements in affected digits will modify sensorimotor representations.

In the first SMR case study for MFD, Candia and colleagues recruited five professional musicians with MFD (3 pianists and 2 guitarists) that had not responded to previous treatments (Candia et al., 1999). Unaffected fingers were constrained, and SMR exercises utilising the dystonic limb were executed over an eight-day period. All subjects showed improvement, confirmed by findings from a dexterity/displacement device and by neurological evaluation. A further 2002 case study using the same measures involving eleven pianists and guitarists with MFD produced similar results (Candia et al., 2002). However, in both studies, small sample sizes and no control groups were used, raising doubt as to their statistical importance. In addition, in the latter study, three wind players with MFD of the hand were recruited and did not respond to SMR. Two possible explanations were offered, firstly that the somatosensory representation of the fingers and the mouth may have encroached upon one another, causing additional ‘blurring ’or interference, or secondly, the biomechanical position of the wind instrument required an extra force to maintain position which altered SMR results. Hirata and colleagues corroborate the first explanation in their study of sensory mapping of lip representation in brass players with ED that showed a decreased distance between lip and hand representations amongst participants (Hirata et al., 2004).

In their 2008 study, Zeuner and colleagues address the question of whether constraint induced therapy could benefit focal hand dystonia sufferers (writer's cramp) when applied in a non-task specific context (Zeuner et al., 2008). A group of ten patients followed a task-specific retraining programme whilst a further group of eleven followed a non-task specific programme. Interestingly they concluded that both programmes were equally beneficial to recovery and that the most seriously affected patients benefited most. The expansion of constraint-induced therapy was then developed further by Berque and colleagues, who combine a constraint-induced therapy intervention (using identical measures to the previously cited studies) with motor control retraining (Berque et al., 2010). The motor control retraining element of the study consisted of a programme of slow-down exercises (Sakai, 2006). Over a 12-month period, significant improvements were observed in the Frequency of Abnormal Movements Scale (FAM) amongst a small group of musicians with MFD >8. Although improvements in playing fluency and accuracy were observed during the study, the small sample size, lack of control group and missing inter-occasion data may all have affected outcomes.

Butler et al., as part of their 2018 feasibility study using mixed, sensory-motor rehabilitative therapy, have developed an intervention combining sensory re-education, SMR, mirror therapy and SDE, alongside five generic hand therapy treatments (soft tissue massage, ultrasound therapy, forearm stretches, shoulder exercises and hand strengthening exercises). 12 participants completed the study (7 musicians with MFD and 5 with writer's dystonia WD) over a 6-month period. Sensory re-education included exercises that focus upon palpation and visualisation of an object including learning to read braille.

The literature confirms the validity of motor control benefits of constraint-induced therapy and supports the theory that somatosensory cortical blurring in MFD sufferers is improvable or reversible through training. However, control groups have not been included, and sample sizes in each study are small, may be due to the length of adherence required to fulfil the requirements of retraining and the availability of suitable candidates. It may also be interesting to investigate how healthy controls respond to this type of retraining. Therefore, constraint-induced therapy integration into a multi-disciplinary retraining programme with larger sample sizes, maybe more

statistically significant than studies that approach it as a standalone therapy for MFD, and programme length should be further evaluated to optimise results.

2.9.3 Sensory Motor Organisation and Proprioceptive Retraining

The sensorimotor organisation (SMO) of the motor hand area is abnormal in focal hand dystonia (K Rosenkranz et al., 2008) and there is converging evidence that proprioceptive training can yield meaningful improvements in somatosensory and sensorimotor function (Aman et al., 2015). In musicians, the SMO lies midway between that in healthy subjects and musicians' focal dystonia (K Rosenkranz et al., 2008).). In musicians with MFD, Rosenkranz et.al (2005) suggest that this reorganisation might have gone too and then interferes with motor control rather than assisting it (Rosenkranz et al., 2005).

Studies confirm that extensive use may modify cortical organisation (Pascual-Leone et al., 1993; Sterr et al., 1998). Sensorimotor tests, including 2-point discrimination, muscle vibration stimulation and point localisation, serve as diagnostic tools for measuring the extent of reorganisation. Single-touch localisation (point localisation) and gap detection tests have shown spatial frequency abnormalities in focal hand dystonia (Bara–Jimenez et al., 2000). Rosenkranz et al. examined how proprioceptive input affected motor cortical excitability in a group of five dystonic musicians compared to five healthy musicians and five non-musicians (Rosenkranz et al., 2000). Muscle vibration stimulation was applied to the relaxed, flexor carpi radialis (FCR) in each participant, and TMS applied 3 and 9-seconds after the stimulation. Motor-evoked potentials (MEPs) were recorded in both the FCR and the extensor carpi radialis (ECR). In both healthy musicians and non-musicians, MEPs were facilitated in the FCRs and decreased in the ECRs. Amongst dystonic musicians, both MEP and FCR MEPs were both reduced, suggesting reduced inhibitory control in response to vibration.

The work of Nancy Byl and colleagues has confirmed the potential of specific learning based sensorimotor and proprioceptive retraining as a protocol for MFD. Their early 1996 study proposed the sensorimotor learning hypothesis as an aetiology for focal hand dystonia (N. N. Byl et al., 1996). Further, evidence-based studies have confirmed the role of sensory discrimination deficits amongst FD patients (Byl & McKenzie, 2000; Byl et al., 2000; Byl et al., 2003; McKenzie et al., 2003). In their 2003 study, significant

gains in the SMO reorganisation of three MFD sufferers using 2-point discrimination, stereognosis (3-d object identification), and graphesthesia (sensing writing patterns on the skin) were observed (Byl et al., 2003). A 2006 study sets out a comprehensive learning-based therapeutic and training regime for FD patients (Byl, 2006a). As part of the process, and in response to possible difficulties in achieving normalised movements through motor control exercises, the author sets out a comprehensive schedule for recovering sensory and proprioceptive deficits of the hand. Preliminary activities for retraining laterality and hand positioning, mental imagery of playing and use of a mirror box to copy a mirror image of the unaffected side are suggested, followed by an extensive repertoire of exercises utilising stereognosis, graphesthesia, proprioceptive and kinaesthetic learning. A further 2006 study objectively reviewed the effects of physical function amongst a group of FD patients and controls. In addition to three descriptive studies investigating neuromusculoskeletal performance, somatosensory evoked responses, and sensory responses to magnetoencephalography (MEG), three intervention studies involving retraining methods described in the previously cited studies were also applied, in a single group design. All subjects improved and SMO improved similar levels as the healthy controls. All but two subjects were able to return to playing (Byl, 2006b).

Aman and colleagues 2015 systematic review of proprioceptive retraining as a tool for improving motor function, reports an average improvement of 52% across all outcome measures and suggests that this type of training can yield meaningful improvements in somatosensory and sensorimotor function (Aman et al., 2015). The evidence for proprioceptive retraining techniques for FD is similarly positive and reenforces the need for a multidisciplinary approach to rehabilitation. When describing an FD rehabilitation framework, Sadnicka et al. confirm that multifaceted interventions tailored to specific individuals' risk profiles to be the best treatment approach for task-specific dystonia (Sadnicka et al., 2018). For MFD patients too, positive outcomes utilising proprioceptive rehabilitation techniques are statistically significant and similar recommendations have been made for a multidisciplinary approach which includes proprioceptive retraining (Butler, 2010; Rosenkranz et al., 2009).

2.9.4 The Sensory Trick Phenomenon

The sensory trick phenomenon, first described in cervical dystonia patients, in which touching the face contralaterally or ipsilaterally to the direction of head rotation may

reduce or abolish involuntary muscle activity (Wissel et al., 1999) has also been found to aid musicians through the use of a latex glove, although the effect has been found to be short-lived (Altenmüller, 2003). Paulig and colleagues' study of 30 dystonic pianists confirmed their hypothesis that a strong response to a sensory trick may indicate that the dystonic movement patterns might be easier to modulate and that, consequently, treatment might be more effective. 39% of participants in the study reported statistically significant improvement of fine motor compared to baseline after a 4.8-year period (Paulig et al., 2014). Van Vugt and colleagues reported objective gains of 42.9% in a similar study (van Vugt et al., 2014) although small sample sizes and patient group overlap were also reported between the two studies.

Contrastingly, in a 2013 study of 12 pianists with MFD and 25 healthy controls, Cheng and colleagues tested the effect of both of both tactile sensory input and altered auditory feedback (AAF) in a sequence of 4 experimental conditions (Cheng et al., 2013). The first experiment involved 3 AAF conditions consisting of normal "in-ear" feedback, no feedback and delayed feedback whilst playing a scale. The second experiment involved repeating the same AAF scale-playing task using a metronome and then maintaining the same tempo without, in addition to a tactile feedback (latex glove wearing) version. Regularity of scale playing did not differ between the MFD and control groups for either the AAF or tactile feedback conditions in any of the experimental conditions. The results of the study contradicted the author's original hypothesis that AAF or altered tactile feedback would provide a successful sensory trick. Additionally, some degradation in fine motor co-ordination was observed during the scale-playing task in some participants, attributed to heavy reliance upon an impaired internal model of functional cortical networks observed in MFD patients, unaffected by auditory feedback (Lee et al., 2013).

2.10 MFD PREVENTION

As successful treatment is still a challenge, preventing MFD is enormously important (Altenmüller & Ioannou, 2016). Courses in PRMD prevention have increased health awareness, knowledge, education, and health outcomes both in educational settings (Barton & Feinberg, 2008; Guptill & Zaza, 2010; Jansen et al., 2006; Martín López & Farías Martínez, 2013; Palac, 2008; Wolff et al., 2021) and professional settings

(Ackermann et al., 2014; Ajidahun et al., 2019; Brandfonbrener, 1997; Chan et al., 2013; Kenny & Ackermann, 2012; Rousseau et al., 2021). The content of these courses is driven by empirical studies that have clearly identified performance-related health conditions, their associated risk factors, and prevalence amongst musical populations. Unlike the majority of PRMDs however, little MFD research currently exists concerning prevention. Recommendations for prevention including “healthy” practice strategies, economic playing technique, mental practice, variating movement patterns, avoiding mechanical repetition, warm-up and cool-down exercises, regular physical exercise, and taking regular breaks have been reinforced (Altenmüller & Jabusch, 2010; Ioannou et al., 2016a; Jabusch & Altenmüller, 2004) however, to date, no controlled study of the effectiveness of these recommendations in the context of MFD, has been undertaken.

Concerning MFD, Altenmüller and colleagues state that, “we now have the theoretical means at hand to intervene at an early stage” (Altenmüller et al., 2014). The heuristic model developed by Altenmüller, and colleagues (2016) has described sequential steps involved in the development and onset of MFD by establishing a clear five-stage progression of motor degradation, beginning with motor fatigue, then overuse injury, choking under pressure (CuP), DS, and MFD, together with associated psychological traits and genetic predisposition. Initial motor fatigue is associated with temporary degradation of motor skills and additional or alternative recruitment of muscles, which in turn may contribute to dysfunctional movements (Altenmüller et al., 2014). If overuse injuries occur and persist, maladaptive plasticity may arise (N. N. Byl et al., 1996) as dysfunctional motor patterns stabilise in procedural memory (Altenmüller et al., 2014). The model of peripheral neuro-musculoskeletal predisposing factors in MFD onset presented by Leijnse and colleagues (2015), suggests that discriminating constraints such as limited finger independence or reduction in joint motion may stimulate the development of compensatory movements that detrimentally affect functional playing movements (J Leijnse et al., 2015). Constraint-induced therapy, which aims to identify compensatory movements and temporarily block them, has been shown to a be a beneficial form of MFD retraining, whether as a stand-alone therapy, or in conjunction with SDE (Berque et al., 2010). The identification of compensatory movements caused by bio-mechanical problems or technical difficulties may disrupt the development of

motor disturbances and stereotyped movements associated with MFD onset. Therefore, early intervention with constraint-induced therapy and/or SDE, may modify MFD onset in some musicians that present with compensatory, stereotyped movements resulting from bio-mechanical technical difficulties.

Psychological traits and emotional risk factors of MFD including MPA, exaggerated perfectionism and obsessive-compulsive traits have been identified, (Altenmuller & Jabusch, 2009; Ioannou et al., 2016a; Steinlechner et al., 2018) and may be modifiable through efficient treatment therapies including cognitive behavioural therapies, mindfulness-training and various breathing and relaxation techniques (Altenmüller et al., 2014). Although a sub-set of MFD patients have been identified that may not demonstrate a psychological profile including perfectionism or clinically significant anxiety prior to onset (Altenmuller & Jabusch, 2010), they may, nevertheless, benefit from interventions that draw attention to behaviours that are associated with their onset. Interventions that address dysfunctional reinvestment and cognitive interference (Altenmüller & Ioannou, 2016) may influence practice habits and alter unhealthy thought processes. In turn, it could be surmised that by developing such interventions, more healthy movement patterns may emerge, together with increased awareness of motor control.

According to the heuristic model (Altenmüller & Ioannou, 2016), CuP is associated with anxiety driven “reinvestment” that in turn may cause cognitive interference whist performing causing dysfunctional movements, similar to the unhealthy compensatory movements that may manifest and become stereotyped in response to injury or pain. MPA arises via sympathetic activation of the autonomic nervous system and includes narrowing of thought, heightened alertness and concentration on fear of failure (Altenmüller & Ioannou, 2016). Fear of making a mistake may lead to anticipating errors and attempts to “prevent” the error from occurring. Ruiz et al. identified anticipation of motor execution errors amongst professional pianists to be 50ms prior to the error (Ruiz et al., 2009). Therefore, attempts to cognitively control errors before they occur may lead to a deterioration of motor control (Altenmüller et al., 2014). Musicians that display signs of CuP during performance may be at increased risk of developing more sustained motor failures or MFD in the future. Extreme levels of MPA

or CuP in musicians are likely to be best prevented by mental training and specific cognitive strategies, which are already being applied in sports psychology (Altenmüller & Ioannou, 2016).

Compared to MFD, DS is described as, “more modifiable and fluctuating, especially during stressful performance” (Ioannou et al., 2016a). Altenmüller and colleagues describe “islands of wellbeing” which may occur for a few hours or days (Altenmüller & Ioannou, 2016). Treatment for MFD itself is mostly symptomatic, depends upon the type of dystonia, and psychological interventions appear to be less effective in MFD compared to DS (Altenmüller et al., 2014). Therefore, it could be speculated that for musicians suffering from persistent motor disturbances, the existence of short periods of symptom free playing may signify a pre-dystonic phase, that may respond more readily to intervention. Altenmüller and colleagues suggest that DS is more likely linked to psychological triggering factors than to underlying genetic causes (Altenmüller et al., 2014) and that prevention of dysfunctional reinvestment and cognitive interference via psychological techniques, may be helpful (Altenmüller & Ioannou, 2016). The authors also suggest that sensorimotor retraining that redefines spatial and temporal processing capacities may be beneficial at this stage.

The bio-psychosocial approach to PRMD prevention also involves the holistic perspective, often reported through the lived experiences of musicians (Bolling, 2021; Bolling et al., 2021; Butler et al., 2021; Rousseau et al., 2021). In the field of sports science, Bolling suggests that, “there is no standard injury prevention measure that acknowledges the diversity of circumstances and contexts of daily sports practice.” (Bolling et al., 2021). The same idea is surely applicable to MFD. For example, risk factor profiles change over time, (Sadnicka et al., 2018). This, in part, may be due to changing situations or circumstances, in which the right conditions, may lead susceptible musicians to develop symptoms associated with the onset of MFD. The ways in which sufferers initially perceive symptoms, particularly in the context that they are experienced, is therefore a key element in developing tools for prevention. Attitudes towards injury amongst musicians are also often similar to those in athletes. In her 2021 study, Bolling noted that, “sports injury was not defined based on the symptoms, but on its consequence on sports performance.” (Bolling et al., 2019).

Musicians often report, “playing through the pain” (Britsch, 2005; Stanhope & Weinstein, 2021) which in the context of MFD equates to playing through the dystonic movements, which in turn, can worsen symptoms.

2.11 AWARENESS OF MFD

Awareness is a fundamental part of PRMD prevention, and recognition of dystonic movements patterns and their possible presentations is important for musicians that may be experiencing or developing MFD. Studies have identified that bodily awareness can be classified in two distinctive forms, via body schema, or through body image (Gallagher & Cole, 1995), and that aberrant proprioception involving somatosensory areas of the brain is involved in bodily awareness. It could therefore be supposed, that as with patients with other movement disorders including Parkinson’s or Huntingdon’s disease (Pietracupa et al., 2013; Snowden et al., 1998), bodily awareness must be distorted in MFD, and that the experience of dystonic posturing or movements is not always perceived by the sufferer. However, studies have shown that this is not necessarily the case. For example, a recent 2020 study by Ferrazzano and colleagues has shown that in a group of 25 patients with cervical dystonia (CD), a majority of participants were able to correctly identify their patterns of dystonic postures when asked to identify similar symptoms in others (72%), or when observing videos of themselves (84%) (Ferrazzano et al., 2020). The preservation of bodily awareness, both involving body schema and image was unexpected, and to date, the literature does not include similar studies involving MFD sufferers. The Ferrazzano study presumes that proprioceptive information is prioritised in patients, and that a reduced awareness of symptoms may in fact, involve neurological processes that are separate from the dystonia. Observational studies of dystonic movements whilst playing from the practitioner’s point of view are common (Altenmüller & Jabusch, 2010; Jabusch & Altenmüller, 2004; Lederman, 2000), yet studies involving the musicians’ perspective, and how they perceive their own movements whilst playing are less so.

Improving education and awareness remains a research priority within the field of adult-onset focal dystonias (Altenmüller & Jabusch, 2010). PRMD education and

awareness programmes are increasing, both in quantity, quality, and in scope, and several studies involving both student and professional musicians have revealed statistically significant health improvement instigated by programmes of PRMD awareness (Baadjou et al., 2019; Chan et al., 2013; Chan et al., 2014; Rickert et al., 2015; Williamon & Thompson, 2006). To date however, within the field of MFD, such programmes remain largely generic, and do not offer detailed information relating to focal dystonia itself. One possibility for this, is the fact that the condition is still regarded as a "rare occurrence", although a 1% prevalence (Altenmüller & Jabusch, 2010) amongst musicians would suggest that this is not exactly the case. A further consideration is that the condition is known to be "incurable", therefore it could be argued that detrimental mental health and wellbeing effects may be disproportionally harmful, when exposing musicians pre-emptively to information about a complex condition.

However, considering my personal experiences of MFD, and the frustration of not knowing precisely what was happening to me physically at the time, I would argue that a prior understanding of MFD, as with other, more prevalent PRMDs, is important. Additionally, as revealed in recent several studies, a culture of "playing through the pain" is still common, both in student and professional musicians (Bragge et al., 2006b; Ling et al., 2016; Panebianco, 2021; Stanhope & Weinstein, 2021). As MFD is considered a painless condition (Enke & Poskey, 2018; Ioannou et al., 2016b; Sadnicka et al., 2018), and excess practice is a recognised factor in the aggravation of musicians 'motor control issues (Quartarone & Hallett, 2013), it may stand to reason that prior awareness of MFD would avoid unnecessary suffering for many musicians, that may not yet have developed full blown MFD.

2.12 CONCLUSIONS

From a standpoint of awareness and prevention, MFD presents a significant challenge, in part due to the incomplete aetiology, the variability of symptoms, and differences in onset between sufferers. A combination of intrinsic/extrinsic physiological and psychological triggers are agreed to be involved in the development of MFD, and a horizontal timeline of progression from performance anxiety to full blown

MFD has been demonstrated (Altenmüller & Ioannou, 2016). For a subset of dystonic musicians however, the aforementioned heuristic model of MFD development may diverge when sudden, acute onset occurs (Conti et al., 2008). Further research that focuses upon, and ultimately explains onset differences amongst subsets of sufferers, will be an important factor in further understanding and developing strategies for prevention.

Existing programmes of PRMD awareness and prevention offer recommendations for healthy practice, disseminate information on identifying signs and symptoms of injury and where to seek help, yet specific guidance for MFD awareness and prevention remains elusive. Several MFD studies have produced positive treatment outcomes, involving distinctive, retraining types. Specific TMS protocols in conjunction with other retraining methods, including SDR exercises, or constraint-induced therapy have been shown to benefit MFD sufferers significantly more than as a stand-alone treatment. Biofeedback studies involving musicians are limited, yet the current literature points to positive outcomes, especially in WD. Further studies that involve biofeedback in combination with other retraining methods for MFD, would be warranted.

Neuromuscular retraining methods for MFD aim to improve somatosensory and sensorimotor function. The SMO of musicians has been shown to lie midway between that in healthy subjects and musicians 'focal dystonia (K Rosenkranz et al., 2008). SDE and other forms of proprioceptive retraining methods have been shown to restore SMO in several studies (Byl & McKenzie, 2000; Byl et al., 2000; Byl et al., 2003; McKenzie et al., 2003). Once again, studies that involve a combination of treatment protocols reveal positive treatment outcomes (Aman et al., 2015; Avanzino & Fiorio, 2014; K Rosenkranz et al., 2008; Rosenkranz & Rothwell, 2012). Studies that combine SMR, SDE and other proprioceptive retraining, together with or without the inclusion of TMS protocols, have yielded the most promising treatment outcomes. Given that the SMO of healthy musicians appears to be on a midline between normal (non-musician) and dystonic, from a standpoint of MFD prevention, an advocation for retraining interventions is justifiable.

CHAPTER 3 - Research Design and Methodology.

3.1 INTRODUCTION

The following chapter presents the procedures for the three studies that comprise the PhD. The research paradigm and theoretical underpinnings of the PhD are explained, followed by a detailed evaluation of the methodological choices and procedures for each study, including sampling decisions, recruitment methods, and validity. Data handling is also discussed before presenting the ethical considerations for the PHD and conclusion.

3.2 RESEARCH PARADIGM

The PhD adopts a broadly pragmatic philosophical worldview which supports the integration of different research methods and approaches. Carlsen and Montere describe pragmatism as, “seeking to ground theorising in what it is that people actually do, social action, rather than beginning with theories abstracted from action” (Pierce et al.). More contemporary worldviews such as these endorse pragmatism as an intermediate approach or “third way” which stands between qualitative and quantitative research methods. The philosophical tradition of pragmatism asserts that a theory or belief is determined by its practical implications and usefulness in the real world.

Critics from more conservative epistemological and ontological perspectives argue against the validity of mixing of qualitative and quantitative methodologies, suggesting that pragmatic researchers have “anti-philosophical” or “anything goes attitude[s]” towards their work (Molina-Azorin, 2016; Biddle & Schafft, 2015; Hall, 2013; Ma, 2012). In response to this, Maarouf explicitly defines the ontological, epistemological, and axiological positions of the pragmatist paradigm whilst addressing necessary principal bias, ontological mobility and observable measurable knowledge (Maarouf, 2019). Feilzer also provides additional clarification by explaining that pragmatism requires researchers to study “singular and multiple realities that are open to empirical inquiry” (Feilzer, 2010) for solving practical problems in the real world.

Maarouf (2019) introduces the concept of “double-faced knowledge” to demonstrate that pragmatists do not select their methods randomly, and it is in fact because knowledge exists in both observable and unobservable forms, depending on the researcher's positionality. Through this adaptable perspective, researchers can obtain objective data whilst also recognising personal realities, enabling them to combine both positivist and constructivist research approaches. Kraemer for example explains that survey research enables quantitative description of particular population aspects (Kraemer, 1991). However, the author also establishes that surveys contain subjective elements that measure individual opinions and thoughts.

Zhang suggests that “in health sciences, researchers need to apply research methods to address complex, multidisciplinary research problems” (Zhang, 2015). The adoption of a pragmatic worldview permits this flexibility when approaching the research questions. It also allows the researcher to incorporate both positivist and interpretivist approaches as is deemed more appropriate to the situation.

For this reason, a mixed-methods research (MMR) approach was adopted for this PhD. Timens and colleagues confirm that in MMR, “two epistemological positions are identified that matter most: a positivist approach that gives rise to quantitative methods and a constructivist approach that is home to qualitative methods” (Timans et al., 2019). It reflects a philosophy that, “considers the research question(s) to be the centre of inquiry”, whilst also, “linking all methodological decisions to the research question(s)” (Johnson & Owuegbuzie, 2004). Doyle and colleagues also confirm that, “MMR is viewed as the third methodological movement and as an approach it has much to offer health and social science research” (Doyle et al., 2009). The approach requires a worldview and approach to research that highly values opinions and perceptions, whilst also maintaining objectivity. Greene describes “multiple ways of seeing and hearing, multiple ways of making sense of the social world, and multiple standpoints on what is important and to be valued” (Greene, 2007). MMR also assumes relatively equal importance to both the quantitative and qualitative phases of the research and is also compatible with the sequential timing and particular research objectives (Leavy, 2017). The pragmatist lens enables researchers to create adaptable methods for developing research questions, which in the case of this PhD, is appropriate to its exploratory nature.

3.3 THEORETICAL UNDERPINNINGS

The theoretical framework of this PhD draws upon neurological, psychological, therapeutic, and educational perspectives, each addressing the multifaceted nature of MFD (Altenmüller & Jabusch, 2010; Grifoni et al., 2024). The neurological foundations of the condition, including the involvement of maladaptive plasticity and sensorimotor disturbance, provide significant understanding of the physical symptoms experienced by musicians. Additionally, psychogenic components of dystonias (Lane et al., 2021; Quartarone & Ghilardi, 2022) remain prominent factors within the research field (Edwards & Bhatia, 2012), highlighting the importance of non-motor symptoms and their physical manifestations, together with the effects of stress, anxiety, and trauma. Together they form a more comprehensive and holistic perspective of the condition (Gowling, 2020; Ioannou et al., 2016b; Jabusch et al., 2004; Schneider et al., 2021).

Theories of music education also contribute to understanding the experiences of musicians during their retraining journeys, framing them through a lens that includes experiential and constructivist learning (Amineh & Asl, 2015; Kolb, 2014), self-determination theory (Ryan & Deci, 2024), and adult learning theory (Knowles, 1984). They guide the interpretation of emerging themes and constructs that are reflected in the recommendations presented in the research, including the centralisation of playing-related health education within conservatoires, the measured dissemination of sensitive health information, and improvements to playing-related health discourse. Each of the three studies is built around stakeholder collaboration and narrative, stressing the importance of musician participation together with educational expertise and medical insight.

The three main components of the PhD (MFD awareness in Higher Education, individual experiences of retraining from MFD, and insights gained from personalised retraining approaches) complement each other rather than offering stand-alone recommendations. The theoretical underpinnings also enable connections that combine empirical evidence with personal experience, drawing attention to the complexities of musicians' health. It also acknowledges the dynamic nature of MFD

and the need for continuous interaction between musicians, educators and healthcare providers, to effectively manage the condition.

The following section presents the methodologies for each of the three studies that comprise the PhD. Ethical considerations are discussed separately later on in the chapter, in section 3.7.

3.4 STUDY 1 (Chapter 4) – METHODOLOGY

An exploratory survey was developed to collect novel data about Musicians' Focal Dystonia (MFD) and Performance-Related Health Issues (PRHI) discourse between two sample groups, active instrumental teachers and students at UK conservatoires. An extensive search of the literature found no existing survey instruments that could satisfactorily answer the research questions; therefore, a bespoke instrument was developed. Likert style questions were chosen over multiple-choice responses to facilitate straight-forward comparison and consistency of responses between the two groups. It was also important to make the questions as straight-forward as possible to understand, respond to, and to minimise any difficulties with question interpretation.

3.4.1 Survey Development

The question format, structure, and semantics of the survey were developed and refined following a piloting phase in which a representative sample of five music conservatoire students and three conservatoire teachers were invited to respond to a preliminary version of the survey. Distribution of the pilot survey was carried out via personal invitation on the SurveyMonkey'© online platform. Feedback from the process resulted in the reduction of the survey size from a parallel set of 15 questions to a final total of 10 (refer to Appendix D). Question wording was adjusted to simplify definitions and maintain equal meaning for both groups, and question order was changed to encourage engagement towards the second half of the survey.

Final Survey Instrument -

The 10 item Likert scale questionnaire (please refer to Appendix A.) addressed four topics of concern. Relevance, clarity, redundancy and scaling were assessed, with

appropriate changes made following the process, including survey size reduction, simplification of wording, and the removal of questions with overlapping constructs.

3.4.2 Validity and Reliability

To assess the validity and reliability of the survey, the following measures were employed. Cronbach's alpha was used to assess internal consistency with a result of .725 (refer to Table 1) which was considered to be acceptable for the exploratory nature of the study.

Table 1. Study 1 - Cronbach's Alpha

Cronbach's Alpha	Cronbach's Alpha Based on Standardized Items	N of Items
.725	.757	20

Construct validity was confirmed using exploratory factor analysis, with 7 components explaining 67.21 of variance (Please refer to Appendix H). Both statistics were produced utilising SPSS software (Version 29.0).

3.4.3 Recruitment and Sampling

Recruitment for the study was undertaken in two ways. For the teacher group, non-probability convenience sampling was used, with individual e-mail invitations being sent to teacher mailing lists across the UK music conservatoires. A total of 206 active, under-graduate instrumental teachers received a study invitation, with a total of 71 acceptance replies, equating to a survey response rate of 34.5%. For the student group, purposive sampling was undertaken, with invitations sent to UK conservatoire research departments and hubs, student union representatives, and student liaison

officers across the UK conservatoires. Invitations were subsequently published in conservatoire e-newsletters, student notice boards, and on conservatoire student group pages and websites. The estimated reach was approximately 2000 students with a total of 96 acceptance replies received, giving an approximate response rate of 4.6%. This was disappointing but not unexpected, as the survey was sent in May, a typically busy period for instrumental students preparing for exams. Additionally, without control of how the survey was distributed, it was also difficult to send follow-up reminders or to increase survey visibility closer to the deadline.

Inclusion criteria for the study were clearly set out both in the e-mailed survey invitation and at the beginning of the online consent form (refer to Appendix A). Participants were required to be over 18 years of age, currently part of the undergraduate teaching faculty or studying instrumental music as an undergraduate at a UK music conservatoire and never been diagnosed with focal dystonia. Meeting these criteria was confirmed through self-validation.

3.4.4 Data Handling

Of the 71 teacher responses received, five were incomplete (at least one of the questions was not answered) and subsequently discarded, giving a total of 66 responses. To match the two groups numerically, random number generation was carried out using SPSS software (Version 29.0), producing 66 completed samples from each of the two groups.

Data normality was confirmed using a Shapiro-Wik test for distribution, and Levene's test of equality of variance was also performed. Descriptive statistics of the means and standard deviations for each of the survey questions were then collected and established to identify response patterns. The mean difference (MD) of the responses between each of the two sample groups was then calculated and independent sample t-tests carried out to look for significance. The significance level was set at. $p<.05$ and all data was processed using SPSS statistical software (Version 29.0).

(Please refer to Appendix I for the raw SPSS data).

3.5 STUDY 2 (Chapter 5) – METHODOLOGY

Study 2 examines current retraining utilisation and experiences of MFD retraining processes amongst dystonic musicians. The methodological decisions taken to conduct the study were made considering the need for a layered approach to data collection that could contextualise quantitative data and be able to accurately reflect the lived experiences of musicians. It was also predicted that due to the sensitive nature of the research topic, a modest survey response rate would justify the inclusion of a qualitative data collection phase. Therefore, a sequential, explanatory mixed methods approach was considered to be the most appropriate choice for producing a broad picture of the phenomenon, as well as thoroughly interrogating the research questions.

3.5.1 Survey Development - Quantitative Phase

It is important to acknowledge the known difficulties of adopting mixed methods designs, including significant time requirements and feasibility of resources to collect and analyse both data types (Bowen et al., 2017). However, as Nayak and Narayan confirm, an online survey (such as the one developed for this study), can be conducted at a low cost, and over a relatively short period of time, which was appropriate to the timescale of this PhD. In this setting, the researcher is able "to start the survey, pause the survey, and restart the survey whenever [they] want" (Nayak & Narayan, 2019). This convenience also allows the researcher to reach the target population with less difficulty as well as facilitating the development of survey questions and piloting within a reasonably short and flexible timeframe.

A review of the literature confirmed an absence of standardised questionnaires for subjective evaluation of dystonic musicians undertaking retraining for MFD. Therefore, a bespoke survey was developed and guided by established questionnaire design methodologies to evaluate retraining from the musicians' perspective.

The survey design was divided into the following four sections:

1. **Demographic Information:** Background information including age of participant, gender, instrument, age when diagnosed with MFD, time since MFD diagnosis, and body area affected by the condition, was collected. This information was essential to identify potential correlations and to understand the heterogeneity of the sample.

2. **Retraining Utilisation:** This section asked participants about their retraining utilisation. Retraining type and duration were recorded to identify the steps taken by participants to address the condition.

3. **Retraining Effectiveness:** Participants were asked to evaluate pre/post retraining outcomes of their retraining and to rate its overall effectiveness.

4. **Quality and Expectations:** The quality and expectation section assessed the retraining experiences of participants. Participants were asked to rate retraining quality, support during and following retraining, and to what extent their retraining had met their overall expectations.

Piloting:

An initial piloting phase for the survey was conducted to refine the question content, question suitability, semantics, and quality. A small group of 4 dystonic musicians with similar characteristics to the target population that had undertaken retraining for their MFD were asked to complete a preliminary version of the survey. Participants were asked to include a short list of their observations/ recommendations together with their survey submission. The feedback received from the participants was used to improve question relevance and clarity, to improve answerability, and to evaluate the overall survey experience.

Several recommendations were made during this stage via qualitative feedback, highlighting perceived survey strengths and areas for improvement. The instrument

itself consists of a repeated set of questions that are applied to a possible total of six specific retraining types. Participants remarked about question repetitiveness, particularly when multiple retraining modalities were being assessed. Therefore, it was important to streamline the variable set to a manageable size that would avoid lack of participant engagement or high incomplete response rates. Conditional questioning was also improved to eliminate question redundancy and improve navigation. Further recommendations included a reduction in survey length and the re-wording of retraining type definitions to avoid confusion (please refer to Appendix E for the final survey version).

Procedures

The SurveyMonkey© platform was utilised to design, publish and distribute the survey, offering a convenient way for participants to share information online via the site's secure sever. The survey was disseminated via on-line posts on two specialised Facebook group pages dedicated to musicians with focal dystonia (refer to Appendix B). Direct links to the survey were included in the posts, allowing potential respondents the option of giving participation consent electronically, without the need to enter into contact with the researcher directly. The post provided a brief overview of the study objectives whilst also guaranteeing response confidentiality and anonymity before asking members to participate voluntarily. The survey link remained active initially for three months, extended for a further month following a follow-up "reminder" post to boost the response rate.

3.5.2 Validity and Reliability

A Principal Component Analysis (PCA) using Varimax rotation was conducted using SPSS software (Version 29.0) to assess the reliability of the survey instrument (refer to Appendix E). A three-factor solution was selected for the analysis as it accounted for 76% of the total variance in the data. In the first factor, 36.156% of the variance was explained, in the second, 24.458%, and in the third, 15.739%, leading to a cumulative explained variance of approximately 76%.

The component matrix showed strongly loaded variables across the three factors being examined which suggests that the variables are well associated with the underlying factors. The first factor mainly comprised variables related to time, symptom levels, and perceived effectiveness of retraining method. The second consisted of variables associated with support and satisfaction with retraining, and the third included variables associated with the duration and consistency of the retraining process. The communalities of the variables ranged from 0.625 to 0.942, indicating that the extracted factors explain a significant proportion of the variance across variables, suggesting that they are adequately represented, and therefore provide useful insights into the questions addressed by the study.

SPSS software (Version 29.0) was also used to perform a power analysis to assess sampling adequacy and statistical power. The result indicated a non-centrality parameter of 4.0879419, a critical t-value of 1.9966521, degrees of freedom of approximately 65.8450761, and a statistical power of 0.980664 (refer to Table 2).

The results showed that the 70-participant sample in the survey phase had sufficient power to identify significant findings within the data. The power value of 0.98 also shows that the study can effectively detect real effects and minimises Type II errors.

Table 2. Study 2 - Power Analysis

Input: Tail(s)	=	Two
Parent distribution	=	Normal
Effect size dz	=	0.5
α err prob	=	0.05
Total sample size	=	70
Output: Non-centrality p δ	=	4.0879419
Critical t	=	1.9966521
Df	=	65.8450761
Power (1-β err prob)	**=**	**0.9806643**

3.5.3 Recruitment and Sampling

Due to the specific nature of MFD, a non-probability, purposive sampling strategy was chosen to select the sample group from a population of musicians diagnosed with focal dystonia and who were undertaking some form of retraining for their MFD. The survey was shared with two online community chat groups for musicians with MFD, the first with 1140 members and the second with 321 giving an estimated total reach of 1461 members. The group's administrators authorised a post and invitation link to the study which was accessible to all group members. The recruitment window for the survey was 12 weeks, and only one response per IP address was accepted to avoid possible response repetition.

Sample recruitment was conducted utilising the following inclusion/exclusion criteria:

Inclusion Criteria:

- **Clinician-diagnosed MFD:** A confirmed medical diagnosis of focal dystonia.
- **Age ≥18 years:** A minimum age of 18 years or older to comply with ethical requirements and to ensure adult consent.
- **Retraining engagement:** Currently or previously engaged in at least one retraining approach for MFD.
- **Professional musician:** Self-identificationas a professional musician.
- **Capacity and language:** Able to complete an online survey in English and provide informed consent.
- **Willingness to participate:** Willingness to participate in the research and a clear understanding of the importance of participant engagement in obtaining reliable results.

Exclusion Criteria:

Participants were excluded from the study based on the following criteria:

- **No confirmed diagnosis:** Self-report of no official diagnosis of MFD.

- **Age <18 years.**
- **Non-professional status:** Musicians that did not classify themselves as professionals.
- **Not engaged in retraining:** No history of MFD specific retraining.
- **Incomplete responses:** Incomplete responses were rejected to preserve data quality and accuracy of information.
- **Withdrawal:** Participants who withdrew consent at any point.

The eligibility criteria were chosen to match the study objectives and maximise internal validity. A total of 91 survey replies were received accounting for 6.2% of the total population of both groups. There are several possibilities for the low response rate. Firstly, each of the Facebook groups chosen in which to advertise the survey had open membership policies. Therefore, it is difficult to accurately calculate the true number of eligible members that could have participated in the study. Furthermore, the sensitive nature of the topic may have contributed to participant hesitation, as may reluctance to discuss rehabilitation that may not have been successful. On-line survey distribution methods also have known limitations including digital exclusion and a lack of personal interaction. The impact of recruitment on generalisability is acknowledged in the limitations section (please refer to section 7.7 (Study 2).

The final sample (n=70) consisted of a heterogeneous group of professional musicians from a range of age groups and instrumental/musical backgrounds. Participants included musicians from all the main instrumental families (bowed strings, plucked strings, keyboard, woodwind, brass, percussion, voice) with variation in body region affected, time affected by MFD, and stages of retraining.

3.5.4 Data Handling (Quantitative)

Quantitative data were analysed in SPSS (v29.0) using a combination of descriptive and inferential techniques. In addition to descriptive statistics used to collect

frequencies and means, cross tabulation and Pearson's Chi-square tests were used to check for associations. Pearson correlations were also carried out, and retraining outcomes were measured using paired-sample t-tests. Analyses used two-tailed tests with $\alpha=.05$ with Likert questions were summarised with means and standard deviations (SD) and treated as such for analysis. List-wise deletion was applied for the relevant analyses where necessary, to account for missing data. (Please refer to Appendix J for the raw SPSS data).

3.5.5 Interview Development - Qualitative Phase

The interview phase of the study was developed to expand upon observations made during the quantitative phase. The high utilisation of self-developed retraining and considerable variability in perceptions of effectiveness and quality across modalities, together with differences in support during and following retraining were central to development of the interview schedule. Onset of MFD and diagnosis, decision-making around retraining choices, the evolution of retraining approaches, perceived mechanisms of change, markers of progress, support experiences, and impacts on playing and identity were included in questioning to give breadth and depth to the findings. The design of the interview questions was deliberately open-ended, and neutral prompts were prioritised to stimulate response and minimise the effects of leading questioning (refer to Appendix G for the full interview schedule).

The interview schedule was refined during a brief piloting process consisting of two interviews with dystonic musicians known to the researcher. To remain focused upon the qualitative process, none of the participants had completed the survey. The questioning was refined in response to criticism of a lack of clear definition, particularly surrounding questioning of retraining quality and support. In response, any repeated concepts were removed to minimise question redundancy. Question ordering was also changed to bring together questioning of the two concepts.

Recruitment for the interview phase was made via personal invitations sent to survey respondents that had indicated that they would be available and willing to participate in the interview phase of the study (refer to Appendix B). A total of 16 emails were sent

with 12 replies received. Three invitations were refused leaving a final sample of n=9. Consent to participate was confirmed initially by invitation acceptance, and then again, verbally online, immediately prior to interview. Participants were requested to take part in a single online interview via the Zoom© platform at a time of their choosing. Interviews followed a semi-structured format of between 45 to 60 minutes in duration. The sessions were recorded with consent to ensure the integrity of the participants' accounts, and a copy of the recording was transferred to the researcher's personal computer for transcription. (Please refer to Appendix K for full redacted interview transcripts).

3.5.6 Data Handling - Qualitative

Braun & Clarke's iterative six phases of coded thematic analysis were followed for analysis. Interviews were transcribed verbatim, and the data initially coded line-by-line. Axial codes were then developed and transformed into potential themes (refer to Appendix M for the axial code book). Themes were developed and marked according to the relevant survey item number and research question (please refer to Table 37). Four overarching themes were generated and refined, each with clearly defined sub-themes. Themes were linked to their appropriate quantitative strand, which each being mapped to the relevant survey items (1–12) and research questions (RQs). Participant quotations provided evidence for the themes, together with occasional quantitative patterns for enhanced transparency.

3.5.7 Data Integration

Methodological triangulation was achieved by the integration of quantitative results and qualitative findings. In Theme 1, the results concerning the timeline between symptom onset and diagnosis, and diagnosis to retraining initiation were substantiated by the qualitative data. The survey patterns observed in Theme 2 concerning retraining duration, retraining combinations, and retraining modality utilisation were contextualised and expanded during the interview phase. Perceptions of pre-post retraining outcomes were more clearly defined by qualitative accounts in Theme 3, and quality and support ratings were also framed and substantiated in Theme 4. The

explanation and expanded meaning of patterns observed in the survey significantly enhanced the validity of the study outcomes and permitted the development of a meaningful narrative.

3.6 STUDY 3 – (Chapter 6) METHODOLOGY

Study three was developed in response to findings in Study 2 which confirmed that over half of study participants (51.4%) had used self-developed retraining methods. A non-hypothesis driven approach was chosen to study the phenomenon due to the exploratory nature of the subject. The experiences of musicians undertaking retraining using their personalised approaches was central to addressing the research questions, therefore a qualitative methodology was considered a best fit.

The main concern when conducting qualitative research is achieving quality and rigour. The fundamental importance of transparency is emphasised by Dodgson, *"The reader must be able to trust that the way the researcher has conducted their study, minimised bias, and that they have transparently described the research process"* (Dodgson, 2017). Braun and Clarke also comment on how qualitative work is analysed suggesting that, *"researchers select analytic approaches for all sorts of reasons, sometimes conceptual, sometimes pragmatic and sometimes because an approach is familiar and comfortable"* (Braun & Clarke, 2006). The methodological choices for this study confirm this premiss, with decisions made considering positionality, the nature of the inquiry, and the experience of the researcher. Willig describes these decisions as important so that, *"the method used fits the project's purpose, that theoretical assumptions, research questions and methods are in alignment, and that the overall research design is coherent"* (Willig, 2013).

A "one size fits all" approach to analytic approaches in qualitative research is difficult to justify. Braun and Clarke confirm that, *"unless the analysis can only be tackled in one way (which is not the case for those interested in exploring patterned/across-case meaning) there is nearly always a range of options"* (Braun & Clarke, 2021).

This study follows these principles in its analysis, with two commonly utilised approaches to qualitative data collection being initially considered, grounded theory (GT) and thematic analysis (TA). Acknowledging that as with most qualitative methodologies there is some overlap between the two approaches, achieving a "best fit" requires careful consideration of the options. As the design phase of the study developed, it became clear that the objective was not to develop new theory, but rather to identify and analyse emerging themes that were of interest to the research questions. In taking this decision, data interpretation was prioritised over process identification, a position more congruent with TA than GT. Data analysis however, maintained a more systematic analytic process including initial, axial and selective coding, more rigorously followed in GT.

3.6.1 Study Development

A semi-structured interview guide was developed to ensure adherence to the research aims and objectives. The interview script was elaborated considering the iterative nature of the analysis process, focusing on drawing out the individual experiences of musicians. The following table (refer to Table 3) shows how the finalised interview questions were grouped:

Table 3. Interview Schedule for Study 3

Subject	**Question**
Background and Onset	1. Could you start by telling me a bit about your background as a musician and the instruments you play?
	2. When did you first notice something was off, and how did you identify it as a possible problem like dystonia?
	3. How did you finally achieve a diagnosis? Was it around this time?
Initial Reactions and Coping	4. How were your experiences with the process of being diagnosed ?

	5. How were you coping emotionally at the time? *Feel free not to respond to this question if you would rather not.*
Development of Retraining Methods	6. At what point did you start developing your own approach to retraining?
	7. Could you share some details about your approach ? What made you decide to develop your own retraining approach?
	8. Can you describe the process through which you began developing your own approach to retraining? What steps did you take?
	9. How did you identify retraining techniques that might be effective for you?
Retraining in Practice	10. Can you walk me through a typical retraining session when you're following your approach?
	11. How did your approach evolve over time? Can you provide specific examples?
Motivation and Decision-Making	12. What motivated you to develop your own retraining approach? `what were your influences?
	13. What did you consider when developing your retraining approach (e.g., ease of implementation, cost, time, previous experiences, guidance from others)?
Challenges and Obstacles	14. Can you share any challenges or obstacles you faced while establishing and maintaining your retraining approach?
Measurement of Progress	15. How did you decide to follow your own approach? What were the signs of its effectiveness for you?
	16. How do you measure success or progress in your rehabilitation?

	17. How long do you think it took before you saw any notable progress?
	18. What impact has your retraining had on your playing at the moment, and on your identity as a musician?
	19. What are your overall thoughts on your retraining approach and the outcomes you've achieved?
Reflection and Advice	20. How has this journey changed your approach to your playing /teaching/performing?
	21. What could other musicians gain from your own approach to retraining?
	22. What would be your message to young musicians and those facing similar challenges?
	23. Do you think there's anything you would have done differently in your training if you had known about dystonia beforehand?

A review of previous qualitative studies informed the initial content of the script including psychological coping (Détári et al., 2022; A. Lee, C. Eich, et al., 2015; Zosso & Schoeb, 2012), onset and diagnosis (Beghi et al., 2015), and experiences with methods of retraining (Butler et al., 2021), also helping to shape the dimensions of the interview questions. Questions were developed and refined in consultation with two dystonic musicians that had themselves experienced the retraining process and were previously known to the researcher. Participants were invited to complete a pilot interview and provide feedback on their interview experience directly following their interview.

The following issues were identified and addressed (refer to Table 4):

Table 4. Study 3 - Interview schedule Changes

1. **Question Removal:** Two redundant questions concerning retraining approach decisions were removed.
2. **Terminology Alteration:** “Retraining Method” and “Retraining Strategy” were replaced with “Approach” to avoid confusion.
3. **Sensitive Questioning:** Question 5 was considered to be a particularly sensitive topic requiring a disclaimer informing the participant of their non-obligation to answer which was subsequently added.
4. **Broader Questioning:** Question 7 was modified to ask about participants’ external influences on their retraining decisions.
5. **Extra Question:** Question 21 was added to allow space for participants to share thoughts on the practical application of their retraining approach for others.
6. **Language Simplification:** All questions were revised for unclear or over-complicated language use.

Question order was designed to facilitate a flow of the narrative that followed a logical transition from pre-diagnosis to post-retraining reflections. It also emphasised open-ended questions that allowed interviewees to provide in-depth accounts of aspects of their retraining process that were of particular importance to them. Language was carefully selected to maximise sensitivity during questioning that required recalling personal challenges or difficulties and to avoid imposing assumptions or pressure, rather focusing on conveying compassion and respect.

3.6.2 Validity and Reliability

Qualitative research, as with all research, requires rigour to be considered valid. In the absence of statistical data confirmation, validity and reliability is achieved through

“trustworthiness”, which consists of credibility, transferability, dependability, and confirmability (Guba & Lincoln, 1994). If this process of verification is not carried out during the study, the investigator runs the risk of missing serious threats to the reliability and validity until it is too late to correct them (Morse et al., 2002). Within the context of qualitative research within this PhD, it was important to consider the practicalities of achieving validity and reliability. Triangulation with other researchers was discounted, both for ethical and logistical reasons, as was more prolonged engagement with study participants due to the time constraints of the research. Therefore, member checking was carried out during the initial “pilot” phase, a validation technique arguably considered to be the “gold standard” of qualitative reliability (Madill & Sullivan, 2018).

After completing their initial interviews via the on-line platform Zoom, the dystonic musicians were invited to participate in the piloting phase (n=2). They were also requested to remain online to discuss and comment upon any issues, problems, or shortcomings they had experienced, and to discuss possible improvements to the process, including the refinement, and development of questioning (refer to Table 4). Following the initial interview and review, each of the participants was sent a copy of their verbatim interview transcripts and requested to verify the accuracy of their responses. A second online conversation via Zoom was then organised individually at their convenience to discuss the changes made to the interview schedule and to consider the impact of said changes to their initial responses.

3.6.3 Sampling and Recruitment

Non-probability convenience sampling was used to recruit participants to the study. A call for study volunteers was made by posting electronic invitations on two, online MFD community group pages. A total of 19 e-mails expressing interest in inclusion were received which were subsequently followed up with an official invitation letter (please refer to Appendix C), together with the inclusion/exclusion criteria, ethical guidelines for the study, and a declaration that the study had been approved by the ethics committee of Trinity Laban Conservatoire of Music and Dance.

In total, 17 completed replies were received. Two failed to meet the inclusion criteria, and a further participant requested to drop out before interview. None of the selected participants had been interviewed in the previous study, although 6 confirmed having participated in the survey phase. A participant group of 14 was considered sufficient to conduct thematic analysis (Fugard & Potts, 2015), although not sufficient to adequately execute a grounded-theory approach (Boddy, 2016), further excluding this approach from consideration.

The inclusion/exclusion criteria for the study are described below:

- **Inclusion Criteria:**
  - Professional musicians over the age of 18 years.
  - An official diagnosis of focal dystonia.
  - Actively utilising self-developed retraining strategies for managing MFD.
- **Exclusion Criteria:**
  - Musicians under 18 years of age.
  - Musicians not officially diagnosed with focal dystonia.
  - Musicians not actively utilising self-developed retraining strategies for managing their MFD.
  - Musicians for whom music is not their primary occupation.
  - Individuals unable to provide informed consent.

3.6.4 Data Handling

Thematic analysis was carried out following Braun and Clarke's procedures and protocols for preserving data quality (Braun & Clarke, 2021), utilising a reflective approach adhering to the following procedures:

1. The initial audio transcripts received preliminary coding to detect relevant concepts and patterns and categories of interest.
2. Axial coding was then applied to organise the first codes into groups whilst developing general themes.

3. Selective coding was used to develop the theoretical framework and to extract concepts from the themes.
4. Continuous comparison of the data with existing codes and categories was carried out to ensure the emergent themes had sufficient depth and validity.
5. Personal thoughts, biases and decision-making processes were reflected upon at each stage of the research to maintain transparency and rigour throughout the process.

Each of the raw interview transcripts was initially transcribed using the transcription feature of NVivo 14 qualitative data processing software. (Please refer to Appendix L for full redacted interview transcripts). Each transcription was then checked manually against the recording to ensure the correct interviewer/participant speaker assignment and vocabulary was selected. In sequence, initial coding was conducted, again using NVivo software, immediately following each interview. Axial coding was then conducted after completion of the interview process by compiling each initial codebook into one document and developing groupings for the initial codes (please refer to Appendix N). Further axial coding and initial code verification was then carried out to confirm that sufficient quantities of emerging ideas and concepts had been captured across the data set before identifying and separating possible themes. The themes were then derived from the iterative process developed during selective coding together with sub-themes that were identified and linked to the central themes. A visual framework of themes, sub-themes, and their connections to each other was then elaborated to complete the process (refer to section 6.4 Table 37).

3.7 ETHICAL CONSIDERATIONS

The sensitivity of playing-related health data together with the small identifiable professional subgroups and use of online tools, required a broad approach to ethical considerations during the research for this PhD.

Ethical approval and governance

Ethical clearance was obtained from the Trinity Laban Conservatoire of Music and Dance Research Ethics Committee before data collection in each of the three study phases. A link to Trinity Laban GDPR information was also included https://www.trinitylaban.ac.uk/about-us/governance/policies-and-freedom-of-information/data-policies-and-subject-rights/. Survey modifications, interview schedule changes, design alterations and recruitment duration changes were reported, prior to execution.

All participants took part in the research voluntarily, being made fully aware and understanding of the research requirements.

Survey participants received study information sheets alongside consent statements before starting SurveyMonkey and Zoom interviews. The information presented included: research aims and objectives, survey length, question descriptions, and a statement concerning the possible risks and benefits. Data usage and storage information was clearly explained for each study. Privacy measures, information retention protocols, participant rights to withdraw and contact information for the researcher and supervisor were also included.

Survey participants submitted electronic consent for their inclusion in the research studies in addition to verbal consent being recorded prior to interviews. Participants from the survey phase in Study 2 were also requested to leave their contact information if they consented to being re-contacted following the survey.

All study participants maintained their right to withdraw from the research at any moment without facing any adverse consequences. Participants could withdraw from surveys before submitting their responses. Participants had the ability to withdraw from the study following the transcript member-checking period and before data redaction was carried out.

The research topic confronts sensitive issues of musicians' heath, identity, and professional employment. Therefore, particular care was taken to protect and respect the integrity of participants. The documentation maintained a neutral tone through carefully approached, non-stigmatising wording. The research design included

questions that did not force participants to reveal more information than needed for the study goals. The research included a distress protocol which enabled participants to pause questions or stop recordings or end interviews at any time. It also provided clear signposting to professional and peer support resources through the debrief materials.

Recruitment and sampling ethics

Study 1 invitations were distributed through UK music conservatoire departments and student-facing channels following gatekeeper approvals from said institutions. The communication materials explicitly stated that participation was voluntary, and participants remained anonymous whilst avoiding any suggestions of institutional backing or performance-related repercussions. Studies 2 and 3 recruitment was achieved via posts in MFD-focused online groups following approval from administrators. The posts distinguished clinical advice from research content and carefully avoided any health-related assertions. Study 2 imposed one survey response limit per IP address to prevent duplicate submissions, informing participants about this policy the survey outset.

Privacy, confidentiality, and data minimisation

The research collected only essential data points that addressed the research questions. Surveys did not collect any personal identification information, contact details or direct identifiers. The optional email addresses for interview follow-ups were kept apart from survey responses and were erased following the procedure.

Recorded interview consent was requested to under-take the transcription process. All identifying information from transcripts was redacted during both the transcription and reporting processes. The small size of particular instrument groups required the researcher to perform category consolidation and aggregation during reporting to protect against deductive disclosure risks. The researcher paraphrased quotations only when essential to protect identity whilst maintaining the original meaning or sentiment.

Data security, storage, and transfer

SurveyMonkey and Zoom were utilised with password-protected accounts and two-factor authentication and a link to the site's data privacy policy https://www.surveymonkey.com/mp/legal/privacy/, was also provided. IP recognition was deactivated on the site to protect participant anonymity. The participants received information about how the third-party platforms maintained secure connections and followed privacy guidelines. Raw data sources were saved utilising encrypted storage which protected institutional servers. NVivo and SPSS project files were located in the same protected system environment. The data management plan established rules for access, backup protocols and incident reporting procedures. The researcher kept redacted datasets and codebooks for the necessary research reproducibility period whilst maintaining identifiable data (audio files and consent logs) separately and destroying them according to predefined time frames (audio files after verified transcription and contact lists after the study ended).

Risk–benefit assessment

The expected risks were minimal, although possible emotional discomfort or distress was a concern. Signposting to U.K Performing Arts Medicine (PAM) organisations (The British Association of Performing Arts Medicine (BAPAM), and www.helpmusicians.org.uk), was provided, both of which offer help and advice for musicians suffering forms of emotional distress. Specific attention was given to answering any questions that participants had, prior to, during, and following their participation. The potential benefits of the research were also explained to participants particularly the opportunity to advance educational knowledge and develop teaching practices related to improving neurological playing health. No clinical guidance or therapeutic recommendations were discussed with participants. The study avoided offers of payment for participation in the research to avoid incentive bias. The research followed reasonable accommodations including flexible interview scheduling and repeated reminders of the participant's right to pause or stop participation at any time.

Dissemination and data sharing

Redacted datasets may be shared according to institutional regulations; however raw audio files or identifiable transcripts are to be destroyed following the PhD process. The research protects participant autonomy and welfare through consent procedures to confidentiality measures, health and data protection, and online platform security across all three studies.

3.8 CONCLUSION

This chapter has set out the research paradigm, theoretical framing, and methodological procedures for the three studies comprising the PhD. The overall design combines both quantitative and qualitative approaches to address the various practice-oriented questions guided by a pragmatic worldview. Neurological, psychological, therapeutic, and educational theoretical underpinnings informed development of the survey instruments together with sampling strategies and interpretation of the findings.

The following chapters (4,5 and 6) present the three studies that comprise the research of the PhD.

CHAPTER 4 - Study 1.

Exploring Musicians' Focal Dystonia Awareness and Performance-related Health Discourse Within the One-to-one Conservatoire Teaching Environment – A Comparative Survey Analysis

(Manuscript Accepted for Publication in the Peer Reviewed Journal "Music and Medicine" on 17th June 2025. Please refer to Appendix O for this version of the study).

4.1 ABSTRACT

This study investigates awareness of Musicians' Focal Dystonia (MFD), a neurological condition that affects approximately 1-3% of professional musicians, negatively impacting fine motor skills, coordination and performance abilities. Given that current treatments offer only palliative relief, and the aetiology of MFD is not yet fully understood, proactive prevention strategies become crucial, including the careful dissemination of information related to the condition. However, current attitudes towards MFD and performance-related health issues (PRHIs) amongst key stakeholders, including music conservatoires, remain inadequately explored. This study analyses a parallel survey administered to active instrumental teachers and students in UK conservatoires, revealing diverging views on PRHI information transmission, variations in MFD awareness, and differences in perceived student autonomy in solving health issues related to their playing. Considering the severe impact of MFD on affected musicians and the importance of the one-to-one teacher/student environment in discussing PRHIs, the study calls for expanded programmes of PRHI awareness that sufficiently address the modifiable risk factors of MFD and performance-related neurological health. It also examines current discrepancies within the one-to-one student-teacher dynamic regarding health information delivery and discourse, confirming the need for more integrated PRHI support systems and channels of communication for both instrumental teachers and students.

4.2 INTRODUCTION

Musicians' focal dystonia (MFD) is a neurological condition affecting approximately 1-3% of professional musicians worldwide (Ioannou et al., 2016b; Rozanski et al., 2015; Schneider et al., 2021). It can significantly affect an instrumentalists' ability to perform, provoking involuntary muscle contractions, tremors, and abnormal postures. The condition impairs musicians' fine motor skills and coordination and can lead to substantial professional and personal challenges (Girach et al., 2019; S. Lee et al., 2020). The exact aetiology of MFD remains incomplete (Furuya et al., 2020; Wolff et al., 2021), with existing interventions and treatments providing palliative, temporary relief from symptoms (Berque et al., 2010; Butler & Rosenkranz, 2006b). Whilst several retraining methods have demonstrated promise in successfully reducing symptoms for some (Chiaramonte & Vecchio, 2021), it is important to acknowledge that no one-size-fits-all solution has emerged, and the long-term efficacy of most retraining approaches remains unclear. The inherent complexity associated with MFD, together with often limited access to effective care, medical attention, and expert guidance, further emphasises the necessity for strategies of prevention. Although the establishment of health awareness programmes within conservatoires has led to the development of effective practice guidelines for mitigating modifiable risk factors linked to PRHIs, the current body of literature concerning prevention remains limited.

Within the context of music conservatoires, the holistic wellbeing of musicians faces distinctive challenges, in part, due to the predominant focus on technical mastery and intensive practice (Ackermann & Altenmüller, 2021; Baadjou et al., 2016; Ioannou et al., 2016a). Central to this is the student-teacher dynamic that can inadvertently expose individuals to conditions and risk factors linked to the emergence of MFD (Détári et al., 2022). Therefore, the delineation of the responsibilities of instrumental teachers in addressing PRHIs remains a pivotal point for consideration.

How issues surrounding MFD and PRHIs are discussed and understood within the one-to-one teacher/student setting and knowing to what extent both stakeholders are aware of MFD and its risk factors, is an important step towards developing

interventions focused on MFD prevention and improved neurological PRHI information. This research reveals inconsistencies within the one-to-one teacher-student interactions within UK conservatories concerning the dissemination of health information and awareness of MFD. Variations and issues in the delivery of PRHI discourse between both stakeholders are highlighted, together with significant differences in perceptions of learner autonomy concerning PRHIs, and knowledge and understanding of MFD. The results emphasise the need for more comprehensive PRHI education and channels of communication to begin to address the neurological movement health of students more effectively.

(Please refer to Chapter 3, section 3.4, for the methodology of the study.)

4.3 DATA ANALYSIS

Cronbach's Alpha for the questionnaire was recorded at .742, and mean difference (MD) between the group responses at .895 (Table.5). Tests for normality showed no outliers.

Table 5. Average Survey scores /Teacher/Student- Study 1

	Teacher or student			Statistic	Std. Error
Average Score	**Teacher**	Mean		3.8712	.06182
		95% Confidence Interval for Mean	Lower Bound	3.7477	
			Upper Bound	3.9947	
		Std. Deviation		.50223	
		Minimum		2.80	
		Maximum		4.90	
		Range		2.10	

	Interquartile Range		.80	
	Skewness		-.033	.295
	Kurtosis		-.551	.582
Student	Mean		2.9758	.05240
	95% Confidence Interval for Mean	Lower Bound	2.8711	
		Upper Bound	3.0804	
	Std. Deviation		.42573	
	Minimum		1.90	
	Maximum		4.10	
	Range		2.20	
	Interquartile Range		.62	
	Skewness		-.102	.295
	Kurtosis		-.058	.582

Positively rated Likert scales were utilised to address the survey questions and results were analysed using descriptive statistics for mean and standard deviation values. Independent sample t-tests were then performed to compare the quality of the means and determine statistical significance.

Q1. Discussing PRHI's in the one-to-one student teacher setting.

Both stakeholders were asked to consider to what extent they engaged with PRHI discourse within the one-to-one teacher student setting (Figure 5). Descriptive statistics (Table 6) and independent sample t-tests (Table 7) were then carried out to determine mean, mean difference and significance levels.

Figure 5. Distribution of PRHI information within the one-on-one instructional setting between stakeholders (Q1)

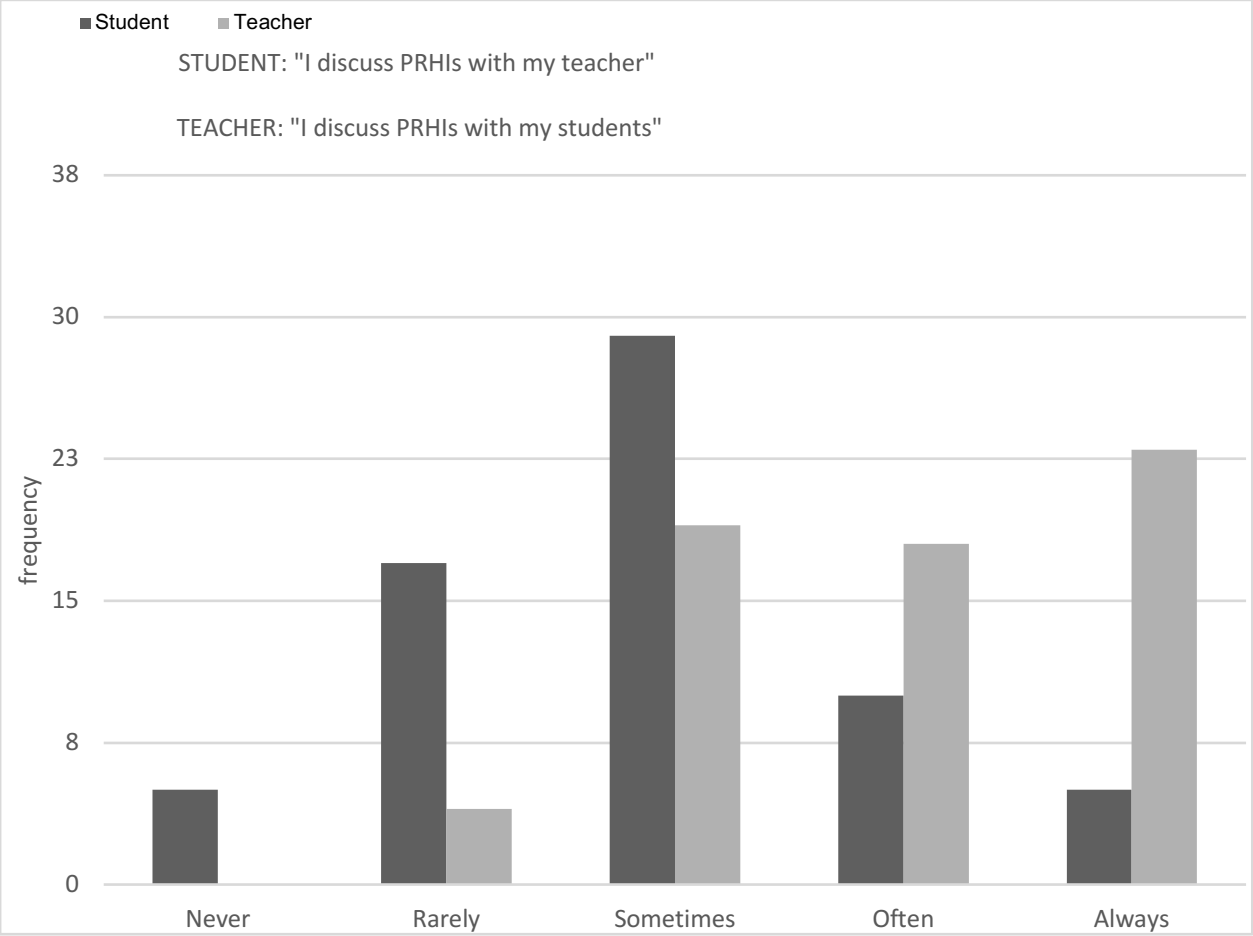


Table 6. Discussing PRHIs with teacher/students- Q1 mean responses.

		N	Mean	Std. Deviation
Q1 "I discuss PRHIs with my students/teacher".	STUDENT	66	2.89	1.010
	TEACHER	66	3.97	.960

Table 7. Study 1 - Independent samples T-test – Q1

Levene's Test of Equal Variance		t-test for quality of means					
F	Sig.	t	df	Sig (2-tailed)	Mean Difference	Std.Error Difference	*95% Confidence Interval of Diff.*

							Lower	*Upper*
.223	.638	6.272	130	**<.001****	1.076	.172	.736	1.415

Significant at the 0.05 Level *

Q2-5 Perceptions of student autonomy in relation to PRHIs.

Participants responded to four statements (Figures 6,7,8 and 9) to evaluate their levels of engagement with issues of learner autonomy and future PRHI resolution. Descriptive statistics (Table 8) and independent sample t tests for Q2-5 (Table 9) are displayed following the question statements.

Figure 6. PRHIs- Discussing strategies for autonomous resolution.

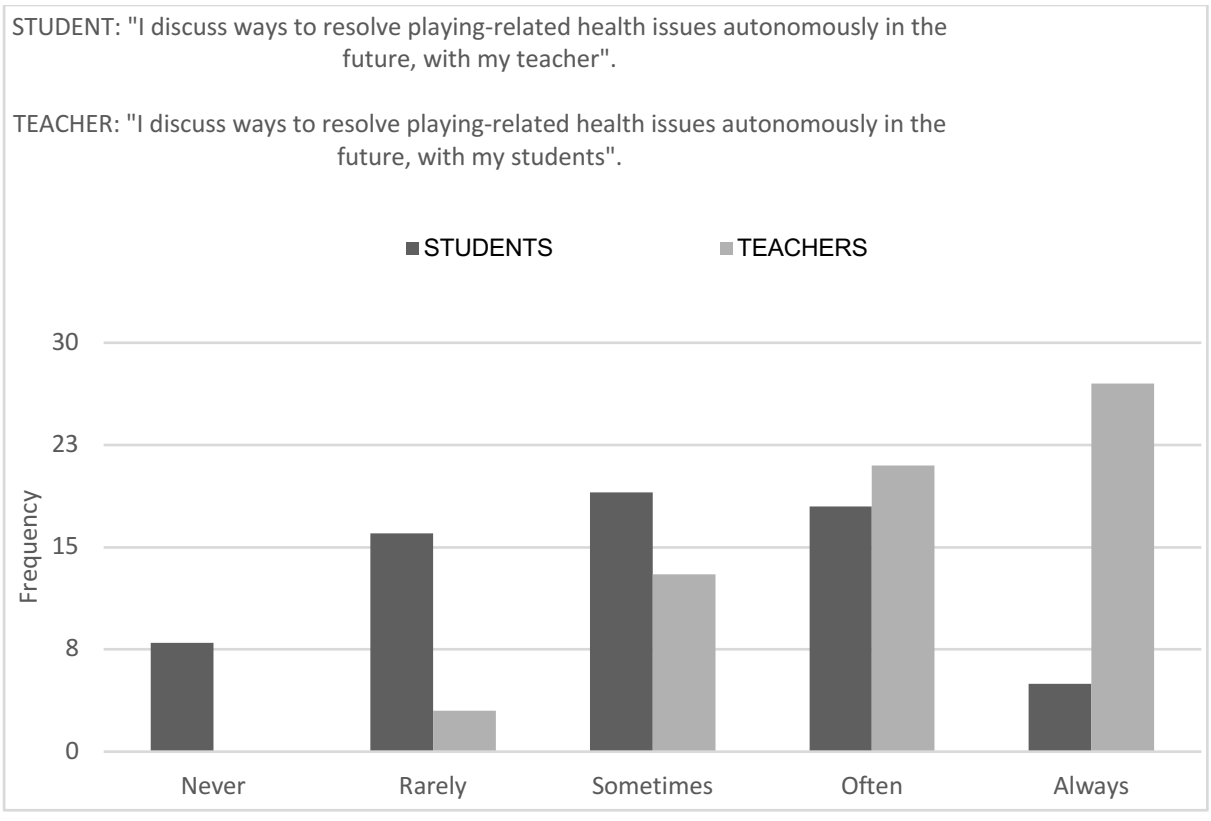


Figure 7. PRHIs- Discussing strategies for maintaining playing health, autonomously.

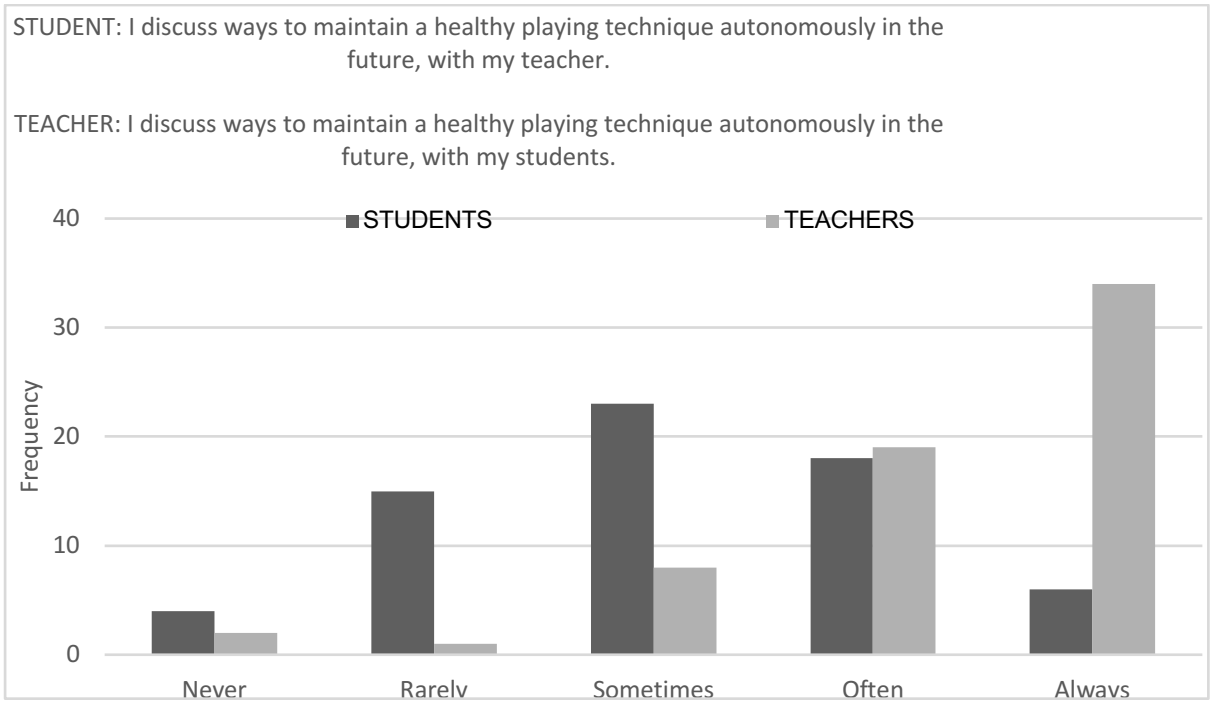


Figure 8. Confidence in student ability to resolve PRHIs, autonomously.

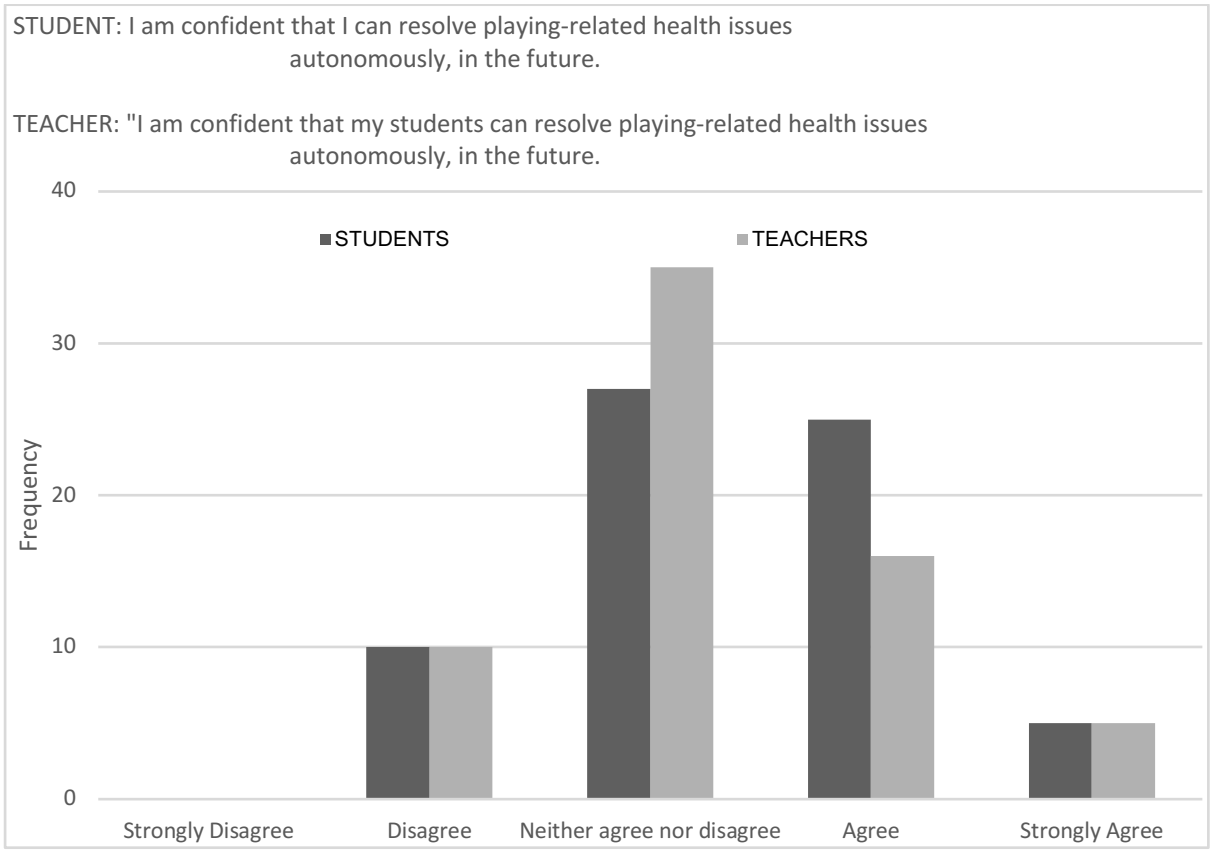


Figure 9. Confidence in student ability to maintain healthy playing techniques, autonomously.

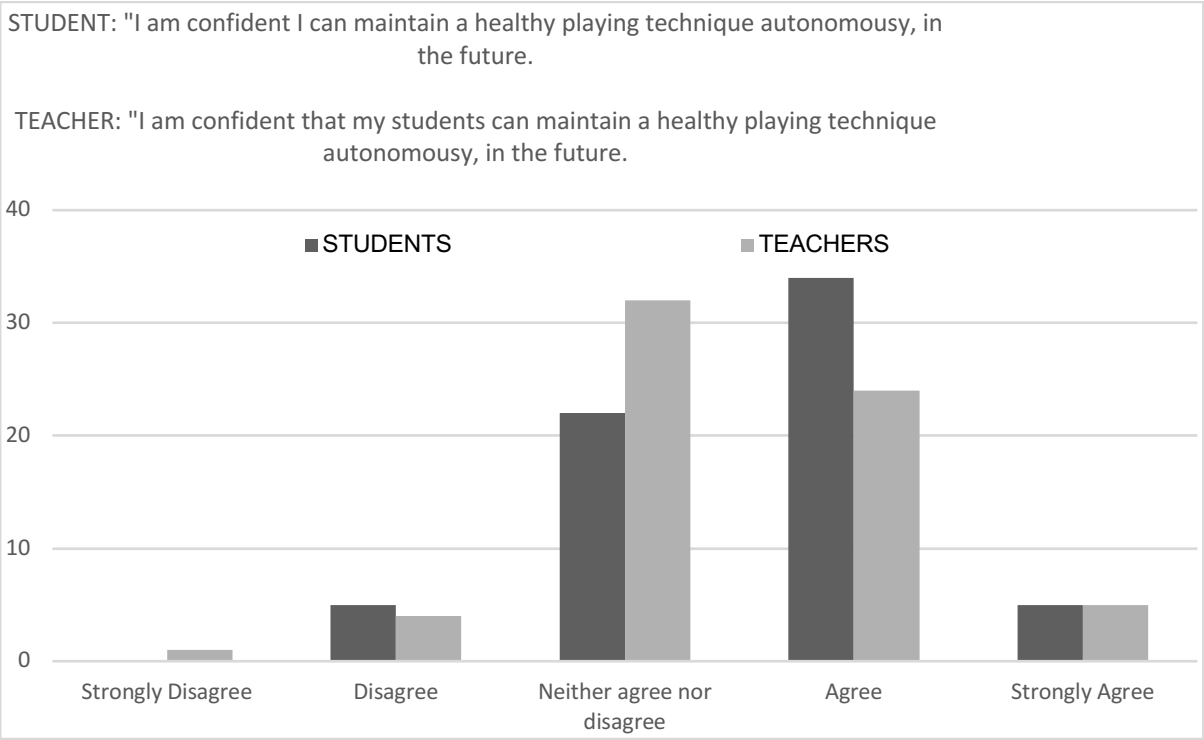


Table 8. PRHI autonomy – Q2-Q5 Mean Responses

		N	Mean	Std. Deviation
Q2 "I discuss ways to resolve playing-related health issues autonomously in the future, with my students/teacher".	Teacher	66	4.29	.957
	Student	66	3.11	1.054
Q3 “I discuss ways to maintain a healthy playing technique autonomously in the future with my students/teacher”.	Teacher	66	4.14	.892
	Student	66	2.94	1.149
Q4 “I am confident that I/my students can resolve playing-related health issues on my/their own in the future.	Teacher	66	3.24	.805
	Student	66	3.35	.813
	Teacher	66	3,42	.786

Q5 “I am confident that I/my students can maintain a healthy playing technique on my/their own in the future.	Student	66	3.59	.744

Table 9. Independent samples T-tests – Q2-Q5

	Levene's test for equal variance		***t-test for Equality of Means***						
	F	Sig.	t	df	Sig (2-tailed)	Mean Difference	Std.Error Difference	**95% Confidence Interval of Diff.**	
								Lower	Upper
Q2	3.503	.064	6.685	130	**<.001****	1.197	.175	.843	1.551
Q3	.521	.472	6.743	130	**<.001****	1.182	.175	.835	1.529
Q4	.104	.748	-1.252	130	.213	-.167	.133	-.430	.097
Q5	.578	.448	-.753	130	.453	-.106	.141	-.385	.173

Significant at the 0.05 Level *

Q6- Identifying students' movements that negatively affect playing, observed by both stakeholders.

Both groups were asked to estimate to what extent they were able to identify sub-optimal movements that negatively affected students' playing (Figure 10). Descriptive statistics and independent sample t tests for Q6 are then displayed in tables 10 and 11.

Figure 10. Identifying students' sub-optimal playing movements.

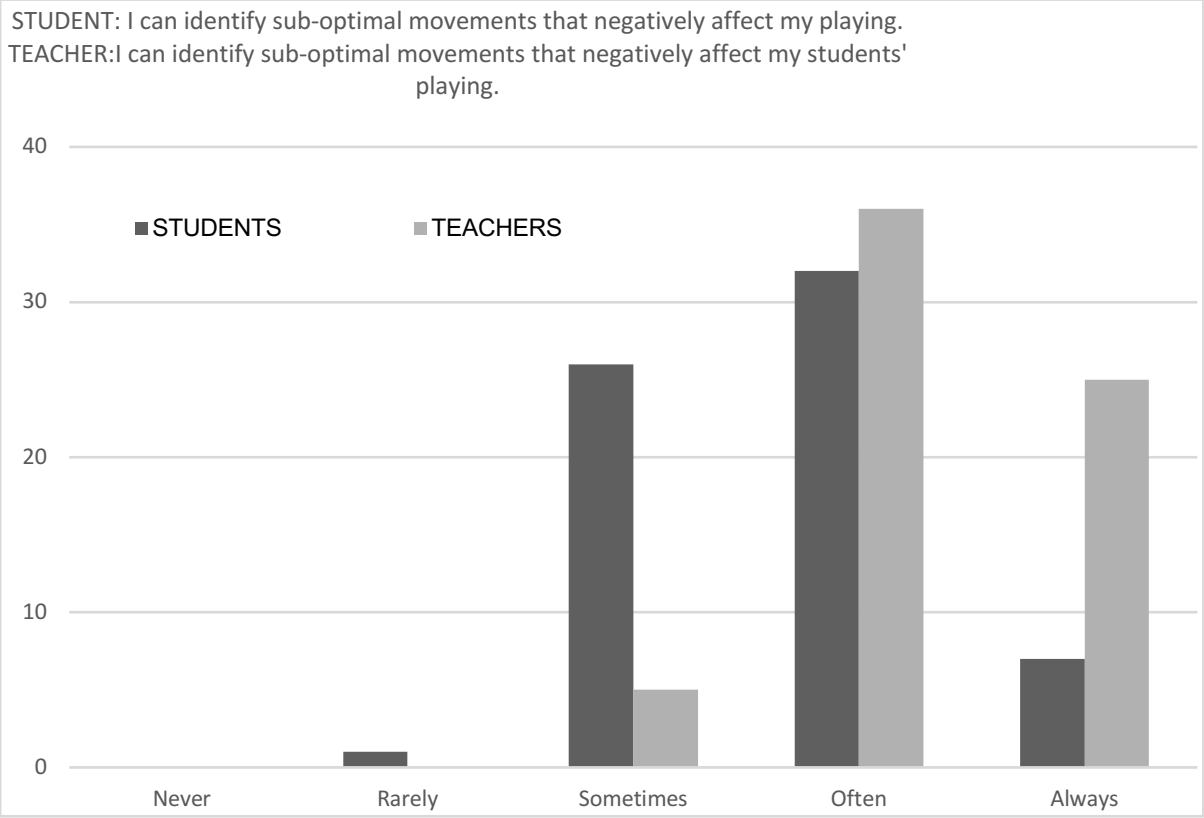


Table 10. Sub-optimal movement awareness in students– Q6 Mean Responses

		N	Mean	Std. Deviation
Q6 "I can identify movements that negatively affect my own/my students playing	Teacher	66	4.30	.607
	Student	66	3.68	.683

Table 11. Independent samples t-test – Q6

Levene's Test of Equal Variance		t-test for quality of means					
F	Sig.	t	df	Sig (2-tailed)	Mean Difference	Std.Error Difference	*95% Confidence Interval of Diff.*

							Lower	*Upper*
1.191	.2277	5.524	130	**<.001****	.621	.112	.399	.844

Q7-10 Awareness and attitudes towards MFD amongst both stakeholders.

The final four questions ascertained current awareness of, and attitudes towards MFD amongst both groups (Figures 11-14). Descriptive statistics (Table 12) and independent sample t tests (Table 13) for Q7-10, are then displayed.

Figure 11. Student/Teacher MFD Awareness Levels

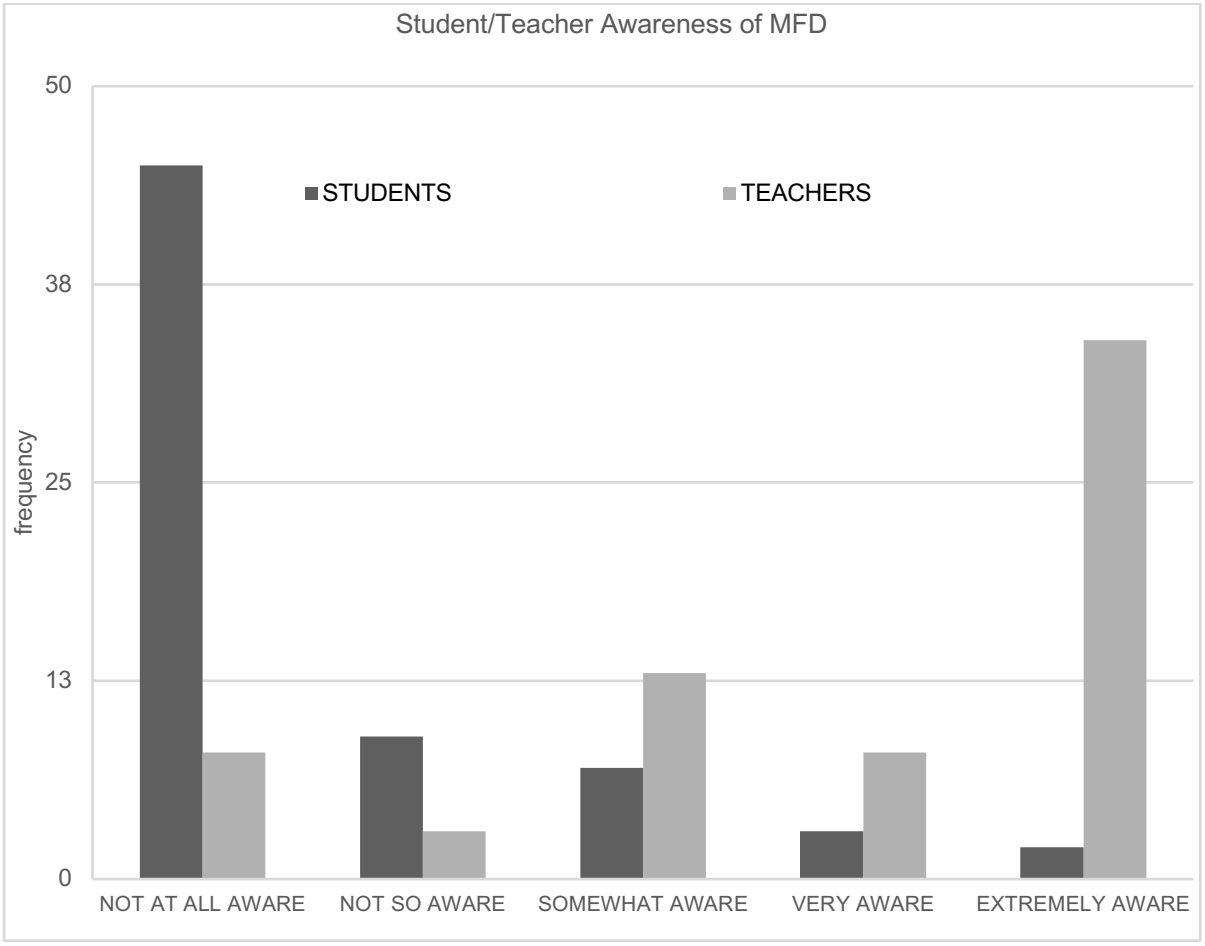


Figure 12. Student/Teacher MFD Risk Factor Awareness

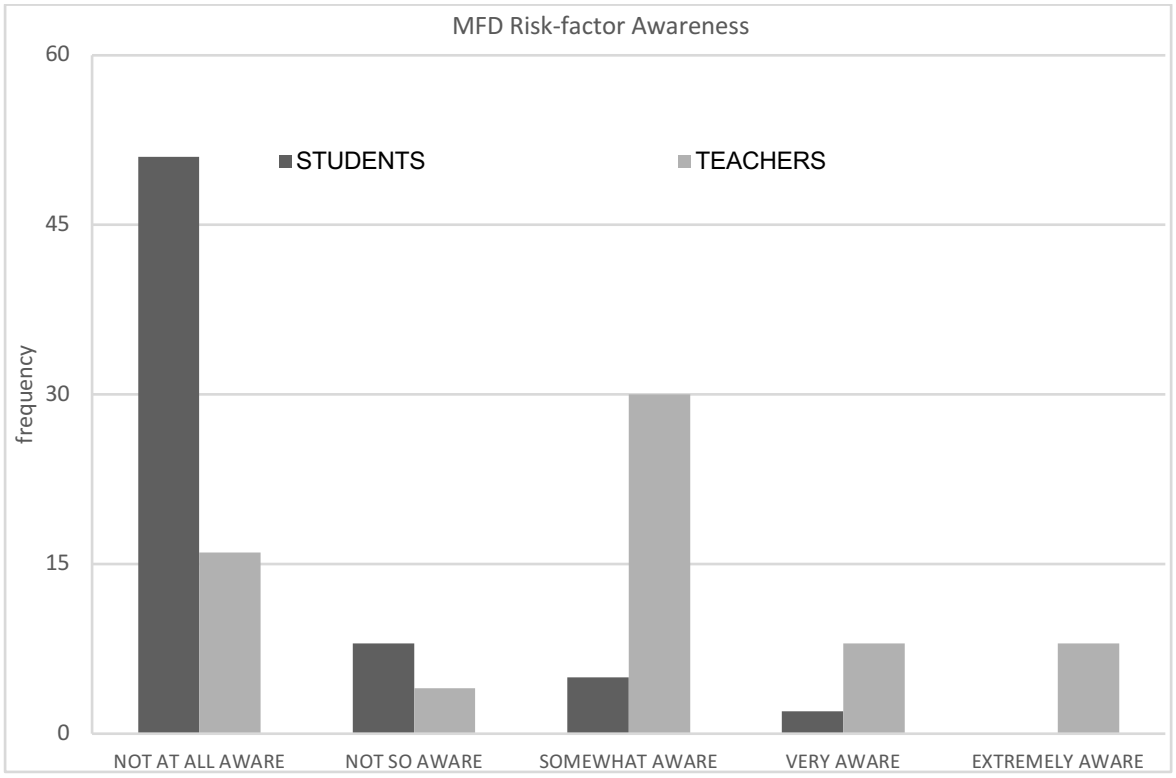


Figure 13. Student/Teacher Concern about MFD

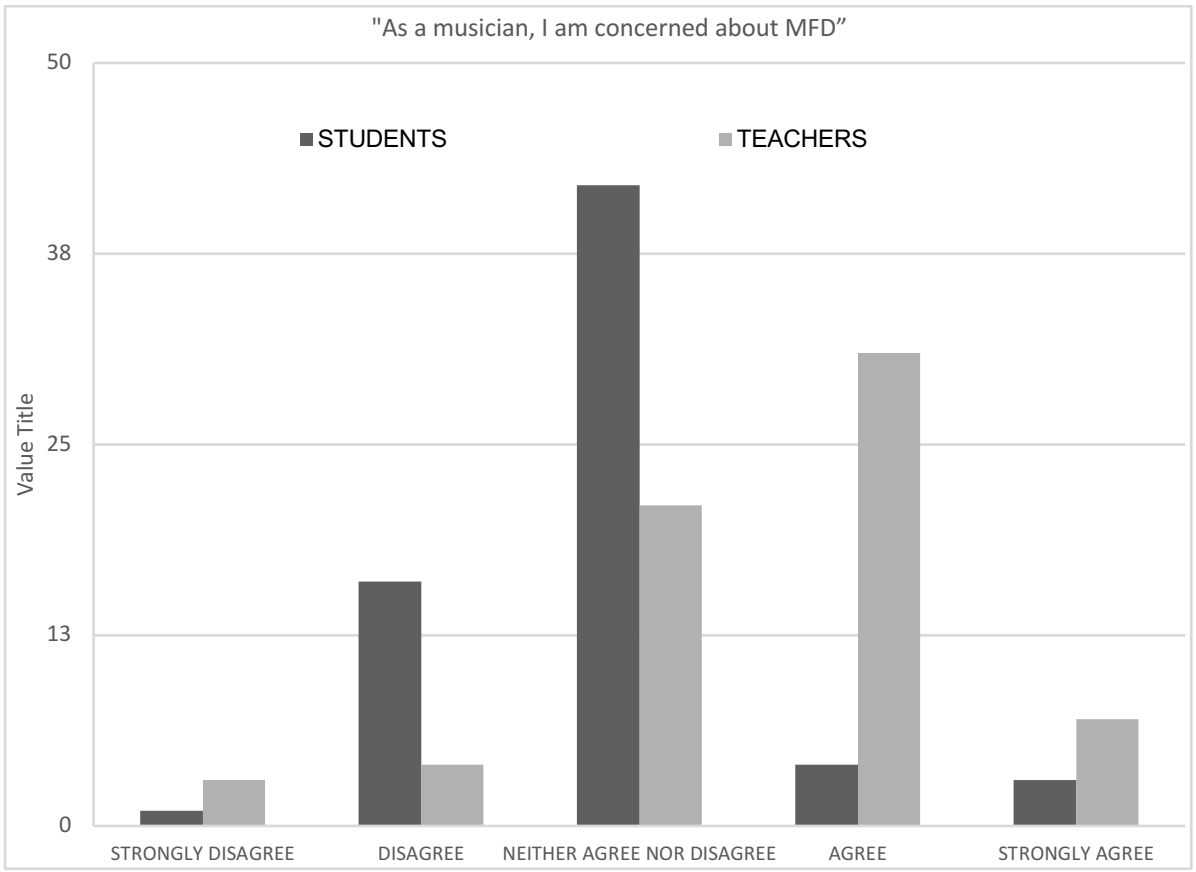


Figure 14. Informing students about MFD- Implications

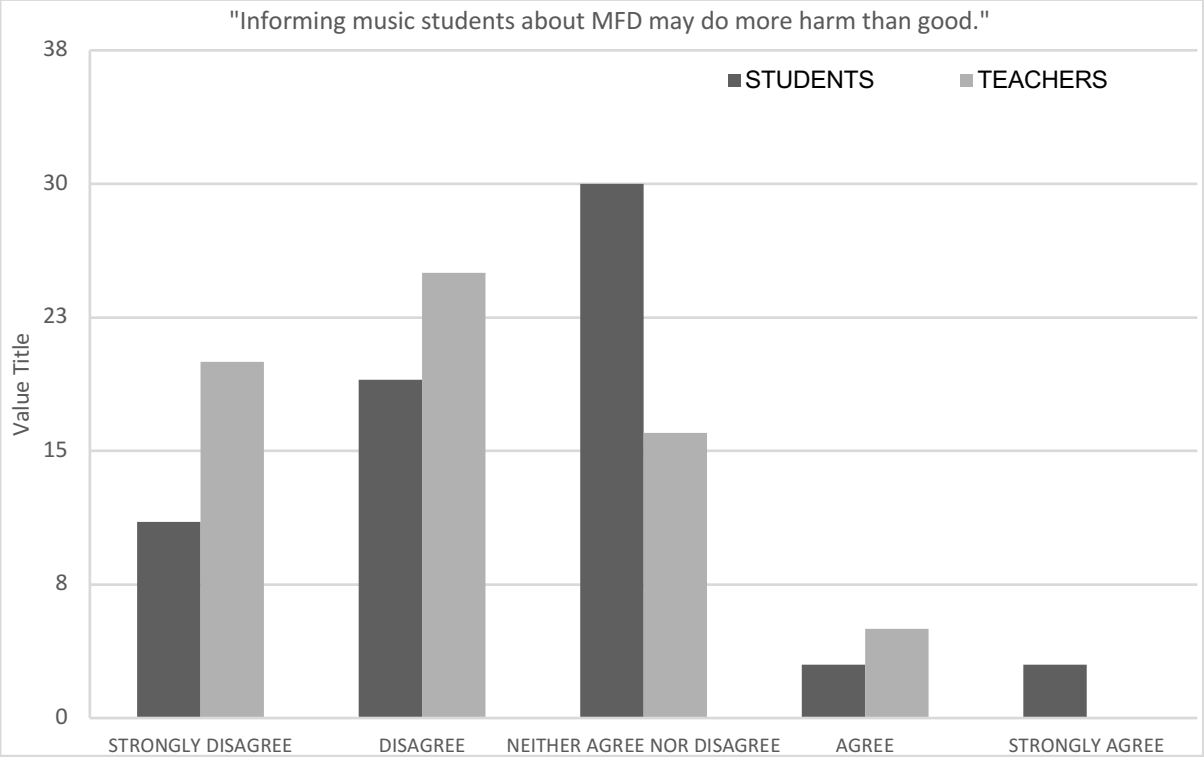


Table 12. MFD awareness and attitudes – Q7-10

		N	Mean	Std. Deviation
Q7 How aware are you of MFD?	Teacher	66	3.88	1.409
	Student	66	1.61	1.051
Q8 How aware are you of risk factors associated with the possible onset of MFD.	Teacher	66	2.82	1.276
	Student	66	1.36	.757
Q9 “As a musician I am concerned about MFD”.	Teacher	66	3.56	.914
	Student	66	3.09	.739
Q10 “Informing music students about MFD may do more harm than good”.	Teacher	66	2.09	.924
	Student	66	3.48	.980

Table 13. Independent samples t-test – Q7-10

Independent samples t-test – Q7-10

	Levene's test for equal variance		***t-test for Equality of Means***						
	F	Sig.	t	df	Sig (2-tailed)	Mean Difference	Std.Error Difference	**95% Confidence Interval of Diff.**	
								Lower	Upper
Q7	8.982	.003	10.505	130	**<.001****	2.273	.216	1.845	2.701
Q8	12.800	<.001	7.964	130	**<.001****	1.455	.183	1.093	1.816
Q9	8.090	.005	-2.802	130	**.005***	-.409	.146	-.698	-.120
Q10	.545	.462	8.407	130	**<.001****	-.166	.166	1.066	1.772

Significant at the 0.05 Level *

4.4 DISCUSSION

Barriers and enablers to PRHI education have been identified (Perkins et al., 2017a) and confirm that the music conservatoire environment continues to expose students to significant amounts of pressure, stress, adverse performance feedback, and frequently excessive work demands. Students are therefore challenged by time constraints and outside influences which negatively affects the priority placed on health issues (Wolff et al., 2021). This, in turn, unintentionally increases the responsibility placed upon their instrumental teachers for PRHI resolution and guidance (Liliana S Araújo et al., 2017). Research has also shown that students typically approach their instrumental teachers with PRHIs before seeking advice from external medical sources (Norton, 2016; Williamon & Thompson, 2006).

The current role of the instrumental teacher as a performance-health sign poster/facilitator and PHRI educator within the one-to-one teaching environment, remains complex. Although institutional access to PRHI information and training programmes for conservatoire students and teachers within the UK have increased

substantially in recent years, it is of importance that we understand how, and to what extent we currently disseminate PRHI information within the intimate relationship between instrumental teacher and student.

The subsequent section offers a comprehensive synthesis of the results obtained from each of the research areas investigated, and presents evaluation and recommendations based upon the findings.

Q1. PRHI discourse within the one-to-one teacher/student setting

The data revealed significant differences in PRHI discourse frequency between student and teachers during their one-to-one lessons (refer to Table 9), with a mean difference of 1.076 (refer to Table 10). Only 6.01% of teachers (n=4) stated that they initiated PRHI discussions with their students rarely, or not at all. This is in stark contrast to 34.8% (n=23) of the student group, that reported having rare or inexistent PRHI discussions with their instrumental teachers. The majority of teachers (62.1%, n=41) reported that they had PRHI discussions with their students on a regular basis, although in contrast, only 22.7% (n=15) reported engaging in frequent discussions with their teacher.

There are two main factors that may account for the results:

I. **Differences in perception:** Teachers and students may have different perceptions of the frequency and depth of PRHI discussions. Teachers may consider brief mentions or less structured discussions as significant, whereas students might not recognise these as substantial conversations on PRHIs.
II. **Communication Gap:** Teachers may believe that they are adequately discussing PRHIs, but students find these discussions insufficient or unclear. This could be a result of a combination of factors, including different communication styles, teaching methods, cultural differences, lack of familiarity with the subject, or discomfort in addressing the topic within the one-to one teacher/student setting.

To improve PRHI discourse within the one-to-one student/teacher environment, clearly defined explanations as to what constitutes a meaningful PRHI discussion are

needed. Factors including depth, relevance, impact, and frequency should be well-understood by both students and teachers to minimise any misunderstandings. Additional training could be provided to teachers, arming them with the necessary tools and aptitude to effectively steer PRHI discussions, enhancing students' perception of these discussions as meaningful and important. Student feedback is also essential to understand whether the discussions are perceived as substantial from their perspective.

Q2-5. Perceptions regarding learner autonomy in relation to PRHIs amongst both stakeholders.

Q2. The results of Q2-5 revealed significant differences in discourse frequency concerning questions of autonomy. Q2 confirmed that teachers reported discussing ways to resolve PRHIs autonomously with students considerably more often than students perceived, with a mean difference of 1.197 (refer to Table 12). A total of 40.9% (n=27) of teachers confirmed always discussing PRHI resolution autonomy with students during one-to-one lessons compared to only 9.0% (n=6) of students reporting the same discussion levels with their teachers (refer to Figure 2). Additionally, only 4.5% of teachers reported “never” or “rarely” discussing autonomous PRHI resolution with their students, whereas 37.8% (n=23) of students reported the same of their teachers.

Q3. The following question (Q3) also followed similar trends in responses between groups concerning the frequency of discourse in maintaining playing health, autonomously (refer to Figure 3) with a mean difference of 1.182. A total of 78.7% (n=52) of teachers stated that they either “often” or “always” discussed the subject with their students during lessons, whereas only 36.3% (n=24) of students reported the same discourse levels with their teachers. Also, 27.2% (n=18) of students compared to only 3.0% (n=2) of students reported either rarely or never discussing the subject.

In both the responses to Q2 and Q3, significant differences in discourse perceptions were confirmed. It is possible that teachers over-estimate their engagement with health-related topics, or they are consistently re-framed to be incorporated into technical or musical issues. It is also possible, as discussed in the previous section

(Q1), that gaps in perception, and communication differences may account for these effects. It is also important to consider the role of discourse context, for example, students might only consider specific conversations, or formal contexts as reportable instances. This may also be due to differences in role expectations, with teachers expected to be responsible for initiating PRHI discussions, whilst students maintain a less proactive role, not necessarily acknowledging health relevant conversations within their lessons.

Q4. This question asked both groups to comment upon to what extent they consider that music students will be able to resolve PRHIs autonomously. Although neither Q4 nor Q5 produced statistically significant results, they both showed similar trends. Amongst the teachers, 53.03% (n=35) neither agreed nor disagreed with the statement compared to 42.42% (n=28) of the student group. Of those that agreed with the statement, 24.2% (n=16) were teachers, and 37.8. (n=25) were students. The results suggest that teachers may not consider the question of autonomous PRHI resolution to be important, or they have not given thought to it in the context of their student's development. From the student standpoint, similar neutral results confirm the same. However, a considerably higher "agree" response to the statement suggests that students are more assured of their ability to resolve PRHI issues than considered by instrumental teachers. Given the professional experience of teachers, it may be that students over-estimate their abilities, somewhat. Therefore, as more than half of teachers remained neutral in their responses to this question, and students demonstrate potentially higher levels of self-assuredness, it further emphasises the importance of increasing channels of PRHI discourse and knowledge dissemination amongst stakeholders. In doing so, it can better equip students to integrate health knowledge into their instrumental education and also encourage more engagement with the subject amongst teachers.

Q5. The final autonomy statement asked both groups to comment as to what extent they consider that music students will be able to maintain a healthy playing technique on their own, autonomously. The results revealed similar average responses of 3.42 for teachers and 3.59 for students.

(Mean results extracted from Table 9)

Q5 “I am confident that I/my students can maintain a healthy playing technique on my/their own in the future.	Teacher	66	3.42	.786
	Student	66	3.59	.744

A total of 48.48% (n=32) of teachers, and 33.3% (n=22) of students “neither agreed or disagreed” with the statement, whilst 34.8% (n=23) of teachers and 50.0% (n=33) of students “agreed" with the statement (refer to Figure 4). The outcome suggests that students have more confidence in maintaining their playing techniques autonomously, but the largely neutral response from teachers also suggests that teachers may not have previously considered how their students manage their techniques outside of the lesson space. It is also possible that expectations of teachers and students is different, with teachers considering technique maintenance as a structured approach requiring guidance, whereas students may consider independent management an existing part of their practice routines.

Q6- Identifying students' movements that negatively affect playing, observed by both stakeholders.

The extent to which teachers can identify movements that negatively affect their students’ playing and that students can identify in themselves, is important in understanding how the one-to-one lesson environment is prepared to guide students through potential movement problems, including the signs of MFD. Mean differences in responses were considerable with the teacher group reporting substantially more ability to recognise sub-optimal movements in their students’ playing compared to the students themselves.

(Mean results extracted from Table 10)

		N	Mean	Std. Deviation
Q6 “I can identify movements that negatively affect my own/my students playing	Teacher	66	4.30	.607
	Student	66	3.68	.683

Survey results revealed significant differences between groups, with 37.8% (n=25) teachers reporting being “always” able to recognise suboptimal movements compared to only 12.1% (n=8) of students. This difference is not surprising considering the experience of teachers, however, a further 54.5% (n=36) of teachers reported being able to recognise suboptimal movements “often” with 48.4% (n=32) of students reporting the same.

These results confirm considerable confidence amongst both groups in their ability to identify movements that negatively affect their playing. Although this question does not consider the identification of potentially dystonic movements, it does confirm that significant attention is given to the quality of playing movements by both groups. This suggests that with appropriate training and guidance, it is likely that musicians could pre-emptively recognise “stereotyped” movements (Altenmüller & Ioannou, 2016), potentially decreasing the risk of MFD onset if corrected promptly. Therefore, it is arguable that increasing awareness of MFD and its risk factors could be particularly effective in reducing the incidence of MFD, particularly amongst younger musicians.

Q7. MFD Awareness amongst both stakeholder groups.

Significant MFD mean awareness differences were observed between the two groups.

(Extracted from Table 12.)

		N	*Mean*	*Std. Deviation*
Q7. How aware are you of MFD?	Teacher	66	3.88	1.409
	Student	66	1.61	1.051

The elevated teacher awareness of MFD confirms that professional experience facilitates greater understanding of the condition and supports the position that continuing exposure to PRHIs within the workplace enhances understanding of occupational health (Ackermann et al., 2025). The considerable differences in MFD awareness between groups may occur partially due to the way in which PRHI information is disseminated over generations. The transmission of musicians’ health

information may filter down to students through several layers, which in turn signifies that younger generations may receive less accurate information about musicians' health and focal dystonia then the wider musical community understands.

An alternative viewpoint to consider is that the ongoing development of musicians' health education programmes within conservatories, although constantly being improved, require more focused improvement on delivering MFD information between students and their teachers. Better health communication can provide students with comprehensive information that is comparable to the depth of knowledge provided to educators and accrued by professional musicians over time. The integration of health discussions into student-teacher dialogue removes a substantial barrier to preventing open discussions about playing-related health issues, including MFD.

Q8. MFD Risk-factor Awareness

The large difference in MFD awareness between groups is not surprising but it is concerning that the teacher group demonstrated a limited understanding of associated risk factors compared to their general awareness of the condition (refer to Table 15).

(Extract from Table 12.)		*N*	*Mean*	*Std. Deviation*
Q8 How aware are you of risk factors associated with the possible onset of MFD.	Teacher	66	2.82	1.276
	Student	66	1.36	0.757

The rationale for this may be attributed to a combination of factors:

1. Gaining the ability to identify and address MFD symptoms in their students may encourage conservatoire teachers to believe they possess a thorough understanding of the condition. They may correctly identify possible physical signs of MFD including involuntary muscle contractions or coordination problems, yet they lack a more comprehensive understanding the condition

including risk factors and underlying causes, highlighting a significant knowledge gap.

2. The complex nature of MFD may create a gap between teachers perceived understanding, and their actual comprehension of risk factors. The disorder's multifactorial neurological, physiological, and psychological elements make it extremely difficult to determine exact causal factors without substantial knowledge about the condition. Conservatoire teachers may encounter the external symptoms of MFD in their students, but then lack experience and understanding of the complex build-up of factors that can lead to onset of MFD.

3. Insufficient training may also be a factor. The visual symptoms of MFD that directly affect musical performance may be familiar to conservatoire teachers, yet they may lack sufficient awareness training to correctly signpost students with potential issues and to address modifiable risk factors including overuse, improper technique and psychological stress.

4. The infrequency of MFD could also be a factor behind this observed difference. Teachers at conservatories encounter MFD cases rarely during their teaching careers, therefore they may not have encountered sufficient cases to appreciate the full complexity of the disorder and its risk factors.

Limited knowledge about MFD risk factors hinders teachers' capacity to share information and to teach effective learning strategies to address the modifiable risk factors of MFD. This situation results in failing to identify early symptoms, delayed signposting and medical treatment, and potentially serious occupational health consequences. The importance of early detection is therefore crucial when considering the significant career disruption or cessation that MFD can trigger.

The known modifiable risk-factors of MFD, including avoiding excessive repetition, excessive practice, taking regular breaks, monitoring stress, monitoring excessive tension, etc., are not specific to the condition. Therefore, from a standpoint of MFD, promotion of these practices as strategies for maintaining or improving neurological

health is a practical strategy to both raise awareness of the condition and its risk factors, and to promote the neurological benefits of existing good practices. It can also stimulate musicians to incorporate them more regularly into their practice regimes, further emphasising the need for more training and education for teachers about MFD and neurological playing health within music conservatoires.

Q9. "As a musician I am concerned about focal dystonia"

Gauging current levels of MFD concern amongst healthy musicians is an important factor in the development of educative strategies and guidelines for increasing awareness and prevention. Results confirmed a greater level of concern amongst teachers which reflects their existing levels of awareness. A total of 57.5% (n=38) of teachers agreed or strongly agreed with the statement, compared to 10.6% (n=8) of students (refer to figure 9). Possible explanations for findings amongst teachers include:

1. Depth of Understanding: Teachers generally have a greater understanding of the impact of MFD. Students may not fully comprehend the severity of this effect, underestimating the impact on their musical futures.

2. Performance Standards: Conservatoire teachers are committed to helping their students reach professional performance levels. However, MFD can drastically affect a student's ability to achieve these standards. Therefore, instructors may worry more about the long-term implications on career potential.

3. Emotional Connection: Teachers often invest a lot of time and emotion into their students. During the course of their career, it is possible that they have had personal connection with a colleague or student with MFD. The fear of students being exposed to information about the condition may heighten levels of concern.

4. Knowledge Sharing: Conversely, teachers may feel a sense of responsibility to educate their students about the risks associated with MFD onset. This concern

might be driven by the desire to improve awareness and mitigate onset in their students.

In contrast to the teacher group, students reported significantly lower levels and understanding of MFD. There are three main reasons that may account for this:

1. Students' reduced concern may stem from their belief that their youth and apparent health status makes them immune to health problems. The younger age and higher resilience of these students make the prospect of developing playing health complications from musical activities appear unlikely to occur in the near future.

2. Students dedicate their time to developing their artistic skills and handling performance-related stressors including exams, competitions and recitals. They remain preoccupied with current difficulties instead of potential health problems that may arise in the future.

3. Lack of awareness of the condition. If MFD is not discussed within student groups, or musicians' health issues are not adequately discussed within educational contexts, then they will naturally remain uninformed about the condition.

Teachers are expected to uphold two essential responsibilities: teaching musical skills and maintaining their students' wellbeing. Those that have spent multiple years in their profession may have observed MFD affect colleagues or former students, which has increased their understanding and concern about the condition. Therefore, equipping teachers with comprehensive information and knowledge about MFD allows them to guide and advise their students, caring for their wellbeing and safeguarding them from potentially serious consequences.

What is also evident is that musicians become more concerned about MFD as they progress through their careers. Mitigation of this concern can arguably be achieved through silence, or by "not rocking the boat". However, from a standpoint of awareness

and prevention, it is important to inform and educate and to recognise that those who are exposed to, or personally affected by the condition, require effective support and guidance.

Q10. “Informing music students about MFD may do more harm than good”

“Mitigating alarm” is a valid concern against increasing MFD awareness, especially amongst students. The saying, "ignorance is bliss" holds weight when dealing with medical conditions that are classified as “rare.”

However, the study results show that teachers strongly disagree with this statement (refer to Table 15). A total of 68.1% (n=44) of the teacher group disagreed or strongly disagreed, compared to 7.5% (n=5) that agreed (refer to Figure 10). Student responses were slightly less conclusive, with 45.4% (n=30) having no opinion, 45.4% (n=30) disagreeing or strongly disagreeing and 9.2% (n=6) agreeing or strongly agreeing with the statement.

The teacher group demonstrated significant opposition to the belief that discussing MFD with their students could potentially cause harm. As discussed earlier in this section, teachers revealed good awareness of MFD, but their understanding of associated risk factors was more limited. It can be assumed from the data that teachers consider educating students about MFD to be beneficial. Teachers demonstrate a basic comprehension of the condition, yet their understanding remains limited to specific aspects of the topic. Therefore, access to more comprehensive information about MFD is desirable to increase the ability to identifying potential problems and raise student awareness of the condition. It also stimulates the establishment of methods for monitoring and enhancing the neurological wellbeing of instrumental students.

The considerable amount of neutral student responses (45.4%, n=30) confirms significant unfamiliarity with the topic. This reinforces the call for expanded educational programmes that bridge the knowledge gaps between teachers and students. It also draws attention to the importance of delivering comprehensive, accurate, and nuanced

MFD information that addresses misconceptions, and encourages open dialogue without inducing unnecessary concern.

Further Considerations

This study offers insight into MFD awareness and performance-related health issues (PRHIs) within the one-to-one conservatoire teaching environment. PRHI education within UK conservatoires has expanded significantly over the past few decades, particularly with the introduction of The Healthy Conservatoires Network. Research has closely examined the health status and behaviours of music students (Araújo et al., 2017; Perkins et al., 2017) and the impact of PRHI programmes within higher music education (Evans et al., 2024), yet the dissemination of PRHIs, including MFD information within the one-to-one teaching environment, remains challenging.

The research advocates for the expansion of PRHI education programmes and for the incorporation of more comprehensive information about MFD for both instrumental students and teachers. This would involve increasing awareness of the condition amongst stakeholders through both training and professional development, better explanations of the neurological processes involved in the condition, and the dissemination of practice techniques that can both mitigate risk and improve neurological playing health. From a standpoint of MFD awareness and the dissemination of MFD information, little attention has been devoted to the individual student-teacher relationship. Current PRHI initiatives within UK conservatoires maintain a somewhat discreet stance on MFD, with a predominant focus on offering general recommendations for developing better practice routines. Although vital, these recommendations fall short of providing clear explanations as to what MFD is, how to identify any early signs of the condition, and what techniques and exercises may be used to maintain or improve the neurological processes involved.

MFD remains a complex issue for musicians. Early detection and minimal delay in achieving diagnosis is fundamental in reducing its potential impact on musicians' careers and increasing chances of recovery. Therefore, the improvement of channels of health discourse within conservatoires and the inclusion of MFD and neurological health education and training for teachers and students is crucial. Equipping

stakeholders with the tools to pre-emptively identify potential problems, to effectively signpost, and adopt preventative strategies to mitigate risk, are important for both the welfare of young musicians and raising awareness and understanding of MFD amongst the profession.

4.5 CONCLUSIONS

The research demonstrates significant differences in how conservatoire students and instrumental teachers discuss playing-related health issues (PRHIs). It demonstrates significant differences in perceptions of PRHI discourse between instrumental teachers and students, with teachers often believing they engage in adequate discussions, whilst students report otherwise. The results suggest that enhanced PRHI training for teachers including MFD is needed to bridge the gap in perceptions and deliver better PRHI support for their students. Data also reveals that students and teachers have differing perspectives concerning student autonomy and PRHIs, indicating that both groups require better guidelines for health-related conversations.

The findings concerning MFD and their associated risk factors are concerning, and although health education resources are constantly improving, it confirms the need for better targeted communication strategies to increase dialogue and enhance health literacy within the student-teacher dynamic. The expansion of health discussions in conservatoire curricula enables teachers and students to identify and approach potential PRHIs effectively which leads to a healthier educational environment and better awareness of potential problems.

CHAPTER 5 - Study 2.

Perspectives of Dystonic Musicians Undertaking Retraining for Focal Dystonia: Utilisation and Insights

5.1 ABSTRACT

This mixed-methods study examines the utilisation and experiences of retraining by musicians in their rehabilitation from focal dystonia. Findings reveal that delays in diagnosis and subsequent retraining commencement correlate with extended retraining periods, highlighting the importance of early intervention in the management of the condition. Amongst the six categories of retraining identified for the study, techniques that address maladaptive neuroplasticity through specific exercise routines and sequences were associated with the most positively perceived retraining outcomes. However, significant variability in outcomes was experienced across all retraining modalities. A little over half of study participants (51.4%) indicated that they had developed custom methods, reflecting the challenges and frustrations faced during organised retraining programmes including geographical and financial restrictions, clarity concerning retraining goals, slow rates of progress, and inadequate professional follow-up and support. The findings confirm the need for improved resource availability, better signposting towards retraining options from health professionals, and clearer retraining goals in order to improve outcomes. Overall, the study highlights the complexities of the retraining process and reinforces the need for the development of effective preventive measures.

5.2 INTRODUCTION

The neurological movement disorder focal dystonia affects approximately 1% of professional musicians worldwide (Altenmuller & Jabusch, 2009), causing problems with fine motor control and involuntary muscle contractions. Studies have shown that

musicians' focal dystonia (MFD) involves physiological, psychological, and psychosocial triggers (Détári et al., 2022; J Leijnse et al., 2015). Standard treatments for the condition include botulinum toxin injections and anticholinergic drugs that provide palliative, symptomatic relief. However, unwanted side-effects, including sustained muscle weakness and tremor, together with the need for ongoing treatment and poor symptom resolution, may lead musicians to avoid or discontinue treatment (Schuele et al., 2005).

Non-pharmacological alternatives have emerged that reflect a broader, therapeutic approach to treatment (Butler & Rosenkranz, 2006b; Prudente et al., 2018). Studies have revealed statistically significant reductions in symptoms for some musicians utilising programmes of proprioceptive and somatosensory exercise protocols (Enke & Poskey, 2018), including object palpation, (Butler et al., 2018; Jabusch et al., 2005), slow-down tasks (Sadnicka et al., 2016; Sakai, 2006), and the use of orthotics to inhibit compensatory movements (Candia et al., 2002; Chiaramonte & Vecchio, 2021; Rosset-Llobet & Fàbregas-Molas, 2018). Neuromodulation has also been shown to improve symptoms in some cases when used in conjunction with controlled exercise protocols (Furuya & Altenmüller, 2015; Furuya, Klaus, et al., 2014; Kieslinger et al., 2013). However, research focusing on the musicians' experiences of retraining is more limited. Surveys of musicians following treatment, and their subjective rating responses to instrument-specific exercises, pedagogical retraining and pharmaceutical interventions (Jabusch et al., 2005; Schuele & Lederman, 2004), relaxation techniques and teacher changes, (van Vugt et al., 2014), and their experiences of a feasibility combination of sensory and motor (Butler et al., 2021) have all been discussed. A further recent follow-up study also confirms the sustainability of long-term gains made through sensory-motor rehabilitation (Butler et al., 2025).

However, experiences of the processes of retraining, particularly for musicians from outside of clinical settings are un-explored. To investigate this phenomenon, this study investigates the utilisation and retraining experiences of musicians with MFD. It considers a range of current retraining approaches, and the ways in which a diverse sample of professional musicians with MFD, from varying musical and instrumental backgrounds, transition through their diagnosis and into retraining. It also examines

the barriers and enablers that currently exist, shedding light upon how the dystonic process is navigated. In doing so, the study provides valuable insight into the lived experiences of musicians that engage in retraining, highlighting the importance of the musicians' perspective in developing and improving the retraining experience.

The research addresses three main questions:

1. (RQ1) How do musicians with MFD approach and navigate the retraining process in their journey to rehabilitation from focal dystonia?

2. (RQ2) How do they evaluate and perceive the outcomes of their retraining?

3. (RQ3) What are their perceptions of their retraining experiences, and to what extent were their expectations met?

(Please refer to Chapter 3, section 3.4 for the study methodology.)

5.3 DATA ANALYSIS

Demographic Data

Demographic data relevant to the study was collected including gender, instrument played, age, and diagnostic age of the study participants (refer to Table 14).

Table 14. Demographic Data - Study 2

Measure	Item	Count	Percentage (%)
Gender	Male	36	51.4
	Female	33	47.1
	Gender Variant	1	1.5

Instrument Group	Woodwinds	17	24.3
	Plucked Strings	16	22.9
	Brass	14	20.0
	Keyboards	13	18.5
	Bowed Strings	10	14.3
Age (years old)	18-24	1	1.4
	25-34	7	10.0
	35-44	22	31.4
	45-54	13	18.6
	55-64	20	28.6
	65+	7	10.0
Age when diagnosed with MFD (years old)	18-24	3	4.3
	25-34	26	37.1
	35-44	21	30.0
	45-54	11	15.7
	55-64	8	11.4
	65+	1	1.4
Total		**N=70**	**100%**

1. Gender Distribution:

The sample group (n=70) consisted of 47.1% females (n=33), 51.4% male (n=36) and 1.5% gender variant (n=1) with an average age of 48.5 yrs. The gender distribution was relatively balanced, with a slightly higher proportion of males compared to females and gender variant individuals. It indicates a relatively diverse sample, however, considering the significantly higher ratio of male to female MFD cases cited within the literature (4:1), it is important to acknowledge potential reasons for this.

a) Sampling Bias: The online recruitment for the study may have inadvertently favoured the participation of females over males and gender variant individuals. (Smith, 2008).

b) Awareness and Seeking Behaviour Differences: Females may have been more likely to participate in the study compared to males and gender variant individuals (Wu et al., 2022). Gender differences in health-seeking behaviour, perception of symptoms, or access to healthcare services could contribute to the observed gender distribution in the sample.

c) Socio-cultural Factors: Socio-cultural norms and stigma associated with MFD may influence the willingness of individuals to participate in specialised research studies. Gender-specific factors related to MFD, such as, coping mechanisms, or social support, may also play a role in the differential representation of genders in the sample.

2. Instrument Group:

Amongst the instrumentalists represented in the sample (refer to Table 14), the most common groups were woodwinds (24.3%), followed by plucked strings (22.9%) and brass (20.0%). Keyboards, and bowed strings were also represented in the sample, although with slightly lower percentages (18.5% and 14.3% respectively), creating a diverse representation of instrument groups in the sample.

3. Age Distribution:

The largest demographic represented amongst the group were musicians between 35-44 years of age (31.4%), followed by those between 55-64 years old (28.6%).

4. Age at Diagnosis with MFD:

Amongst the study group, the highest number of MFD diagnoses occurred between the ages of 25 and 34 (37.1%). A total of 30% received a diagnosis between 35-44, 15.7% were in the 45-54 age group, whilst the 55-64 age group and 65+ age group each constitute 11.4%. The 18-24 age range contained the smallest group at 4.3%. This is confirmed within the literature and indicates a sufficiently

representative sample of the population. The significant decrease in diagnosed cases after age 55 could be related to reporting biases amongst older people.

Further demographic data concerning body part affected by MFD was also collected (refer to Table 15). Pearson Chi-Square tests were carried out to look for association between affected body part and instrument, which confirmed instrumental differences. Significant prevalence of MFD in the Right Hand (*p* value < .001) was confirmed amongst plucked string participants, the left hand of bowed string participants, (*p* < .001), and the embouchure of the brass players (*p* < .001). The keyboard group demonstrated right-handed MFD prevalence (p.011), and the woodwind group presented non-significant hand and embouchure MFD occurrence (p.169), which indicated even distribution. No analysis of Fisher's Exact Test was necessary as cell counts remained above 5 throughout all groups. The results for this population match previously established research which shows that MFD primarily affects the limbs used to perform the most complex instrument tasks.

Table 15. Body part affected by MFD amongst instrumental groups.

	Left Hand	**Right Hand**	**Emb.**	**Pearson Chi-Square**	**df**	**Asymptotic (Sig. 2-sided)**
Plucked St.	2	14	0	17.466	2	**<.001****
Bowed St.	8	2	0	15.556	2	**<.001****
Woodwinds	7	4	6	3.716	2	.17
Brass	0	0	14	42.750	2	**<.001****
Keyboards	3	10	0	9.053	2	.011

< .001* *indicates a high level of statistical significance*

The age distribution of participants who received diagnoses between 25-34 years and 35-44 years matches previous research concerning the average diagnostic age of musicians. The observed patterns of MFD affecting different body parts according to instrument groups is also confirmed by literature in the field, helping to increase validity of the study, matching the documented patterns within the literature.

5.3.1 Survey Items

The following section introduces the survey and how the questions correspond to each of the three research questions (RQ1, 2 and 3). A total of 12 survey items comprises the final research instrument (refer to Table 16).

Table 16. Survey Study 2 - Composition

Item no.	Research Question (RQ)	Survey Items
1	RQ1	How long did it take to get a diagnosis of focal dystonia after symptoms first appeared?
2		How long did it take to begin retraining after your diagnosis?
3		How long have you been using retraining for managing your dystonia in total?
4		Which of the following retraining methods have you used?
5		How long have you utilised this retraining method for in total?

6	RQ2	How able were you to play before the retraining?
7		How able are you to play after the retraining?
8		How would you evaluate the effectiveness of the retraining?
9	RQ3	How would you rate the quality of the retraining?
10		How would you rate the level of support provided during the retraining?
11		How would you rate the level of support received after your retraining?
12		To what extent did the retraining live up to your expectations?

5.4 QUANTITATIVE FINDINGS

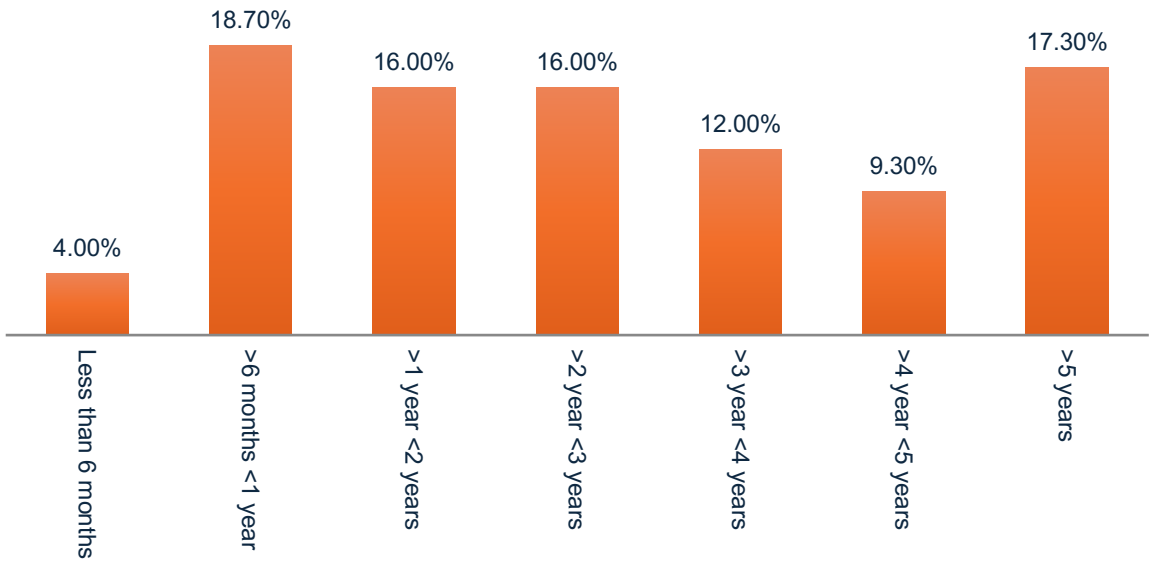
The following section presents the quantitative data and analysis for each of the research questions. The results for each item are presented together to facilitate data source comparison and to highlight the multidimensional aspects of the findings.

RQ1. How do musicians with MFD approach and navigate the retraining process in their journey to rehabilitation from focal dystonia?

Survey items 1-3.

Participants were asked to comment on the elapsed time between their MFD symptom onset and medical diagnosis (Figure 15). The survey results showed that 4% of participants had experienced symptoms for less than 6 months but 17.3% of participants reported having symptoms for 5 years or more. The recorded mean score of 4.19 (refer to Table 17) corresponds to 2 to 3 years duration on the relevant Likert scale.

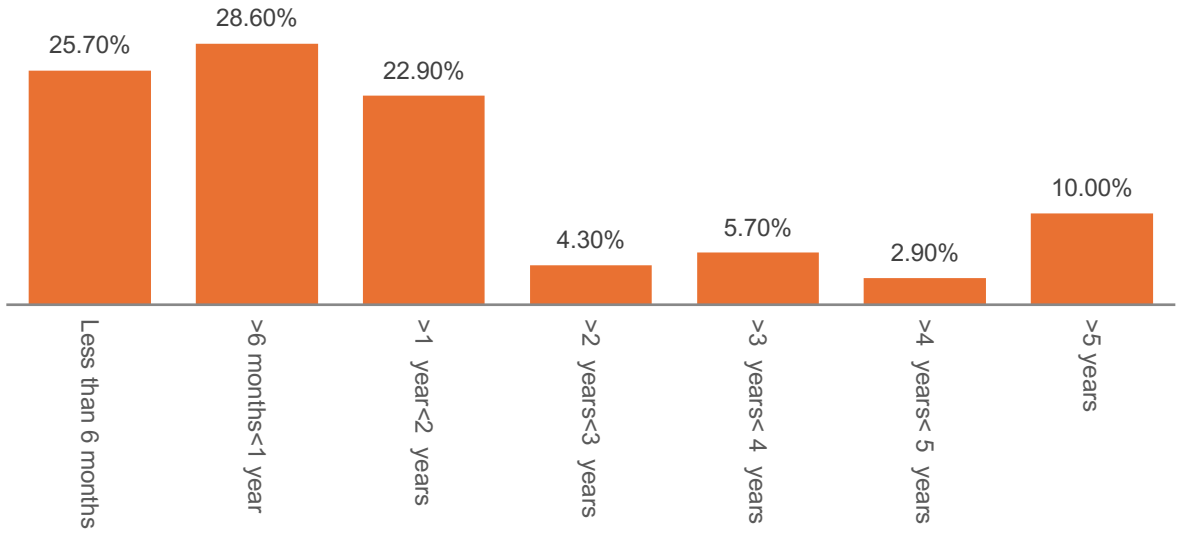
Figure 15. Time After First Symptoms to Diagnosis



Participants were then asked about the elapsed time between their diagnosis and commencing retraining (Figure 16). A majority of 54.3% reported beginning retraining

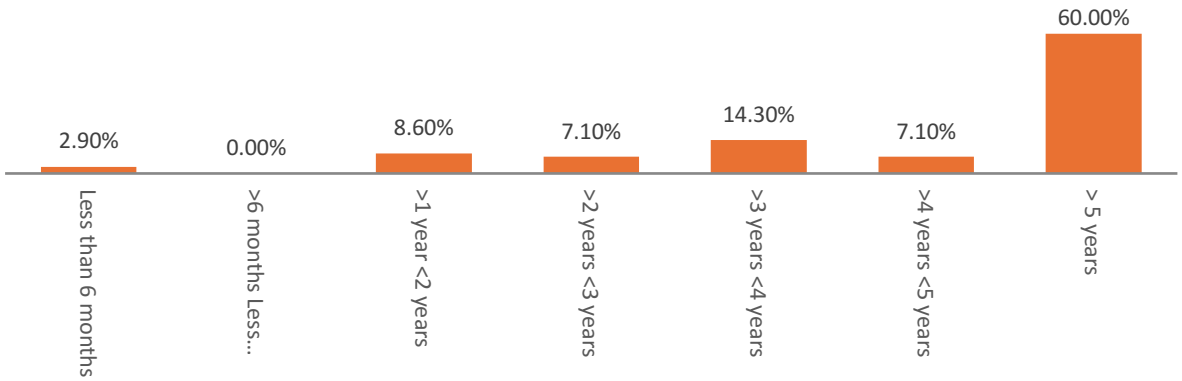
within a year of their diagnosis. The mean score of 2.84 (refer to Table 19) confirmed an average timeframe of 6 months to 1 year.

Figure 16. Time After Diagnosis to Retraining Start



Finally, participants were asked to report the total length of time they had spent retraining following their diagnosis (Figure 17). Sixty percent of participants reported that they were retraining more than 5 years after their initial diagnosis with an average total time of 5.91 (refer to Table 19) corresponding to between 3 to 4 years.

Figure 17. Total Time Spent Retraining



The mean values for the three items (1-3) are presented in Table 17. Item 1 had a relatively symmetrical central tendency with a moderately high SD, whilst items 2 and 3 had a moderately skewed distribution with moderate SD values.

Table 17. Mean Values – Time Between

		1.Time After Symptoms Appeared Before Diagnosis	2.Time After Diagnosis to Retraining Start	3.Total Time Spent Retraining
N	Valid	70	70	70
	Missing	0	0	0
Mean		**4.19**	**2.84**	**5.91**
Std Deviation		1.89	1.86	1.59
Skewness		.16	1.12	-1.38
Sd Error of Skewness		.29	.29	.29

Key:

1. Less than 6 months **2.** < 6 months and >1 year **3.** <1 year and >2 years **4.** = <2 years and >3 years **5**. = <3 years and >4 years **6.** = <4 years and >5 years **7.** = <5 years

A Pearson's correlation test was performed to determine the significance between variables (refer to Table 18). The results demonstrate correlation (.282 at the .018 significance level) between participant age and time elapsed to receive an MFD diagnosis following symptom onset. This implies that older musicians may take longer to receive a diagnosis. Furthermore, a higher correlation (.535 at the .001 significance level) was observed between the time between symptom onset and diagnosis, and diagnosis to the initiation of retraining. This signifies that musicians that receive diagnosis after longer time periods, also take longer to initiate retraining. A further

important correlation (.525 at the .001 significance level) shows that the time between symptom onset and diagnosis also affects the duration of retraining, signifying that longer diagnostic processes equate to longer retraining duration. Finally, a correlation (.357 at the .002 level) was observed between the time between diagnosis and retraining initiation, and retraining duration, signifying that the longer the period between diagnosis and the start of the retraining, the longer the retraining itself.

Table 18. Pearson's Correlation Test - Study 2

		Age of Participant	1.Time from Symptom Onset to Diagnosis	2.Time after diagnosis to retraining start	3.Total Time spent retraining
Age of Participant	Pearson Correlation	1	**.28***	.23	.18
	Sig. (2-tailed)		**.02***	.06	.15
	N	70	70	70	70
1.Time from Symptom Onset to Diagnosis	Pearson Correlation	**.28***	1	**.54**	**.53**
	Sig. (2-tailed)	**.02***		**<.001****	**<.001****
	N	70	70	70	70
2.Time after diagnosis to retraining start	Pearson Correlation	.23	**.54**	1	**.36**
	Sig. (2-tailed)	.06	**<.001****		**.002***
	N	70	70	70	70
3. Total Time spent retraining	Pearson Correlation	.18	**.53**	**.36**	1
	Sig. (2-tailed)	.15	**<.001****	**.002****	
	N	70	70	70	70

*. Correlation is significant at the .05 level (p <.05).

* * Correlation is significant at the .001 level (p <.001).

Survey Items 4 and 5.

The literature review of this PhD draws attention to the lack of clarity in the nomenclature of the exact definitions of retraining methods. To address this issue in the current study, a deliberate effort was made to select six, distinctive categories that encapsulate the range of current retraining strategies (Table 19). Each category was

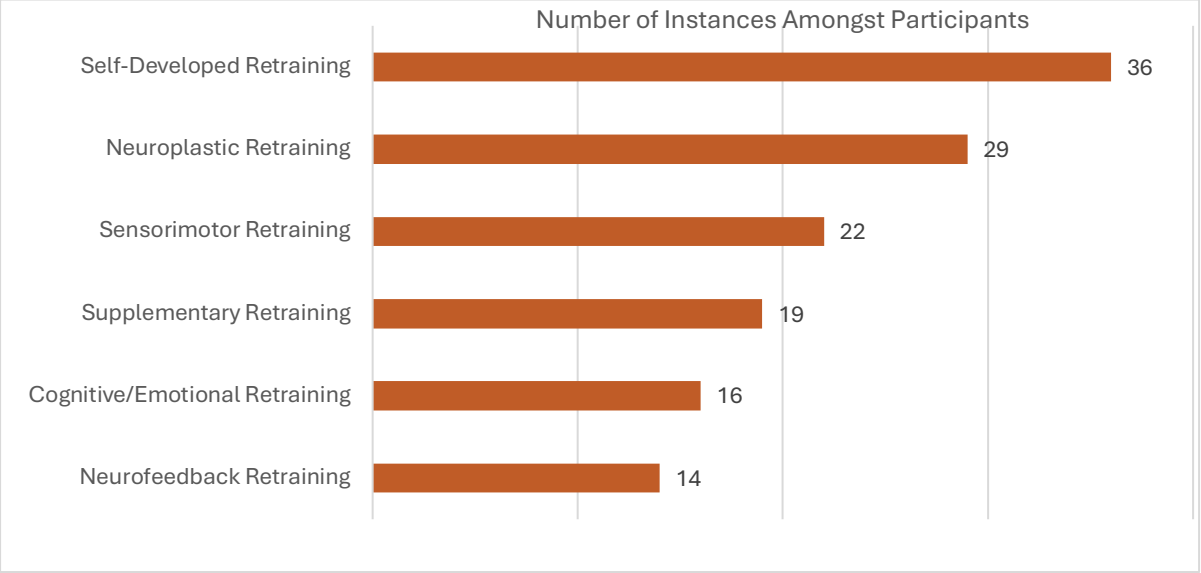
explicitly delineated and clearly identified within the survey. The six categories are classified as follows:

Table 19. Retraining Classifications

1. **Neurofeedback**: Approaches that utilise real-time brain activity feedback for self-regulation, including biofeedback and transcranial magnetic stimulation.
2. **Neuroplastic**: Exercise protocols that target maladaptive plasticity to reorganise neural responses to specific movements.
3. **Sensorimotor**: Sensory feedback and motor control techniques for improving movement coordination, including orthotic splinting.
4. **Psychological**: Cognitive and emotional regulation strategies to address psychological factors, such as brain-spotting.
5. **Self-Developed**: Personalised retraining techniques that are developed either in addition to an established retraining method, or as an individual investigation.
6. **Complementary**: Complementary methods that are utilised in addition to other retraining approaches.

The following Figure 18 shows the frequencies of retraining utilisation amongst the sample group within the six categories.

Figure 18. Frequencies of Retraining Utilisation



Self-Developed Retraining Approaches

More than half of the participants (51.4%) reported using self-developed retraining in their rehabilitation. The following approaches were recorded via open-ended responses during the survey and categorised (Table 20).

Table 20. Self-Developed Retraining Strategies Utilised by Study Participants

	Total (N)
Technical Approaches	
Adapted existing movement exercises to suit	8
Slow practicing	6
Developed individualised finger/arm exercises	6
Repertoire/genre change	4
Developed individualised facial exercises	4
Technique change	3
Movement Compensations	2
N	**33**

Physical Adaptation	
Instrument changes	6
Homemade orthotic devices	5
N	**11**
Other Approaches	
Mirror box	1
N	**1**
TOTAL	**45**

A total of 45 instances were recorded which were categorised into three distinct groups. "Technical" approaches were the most frequently utilised strategies with a total of 33 instances. Within this group, adaptation of existing movement exercises was the most prevalent (n=8). A focus on slow practicing was also reported frequently (n=6), together with the development of personalised finger/arm exercises (n=6). Repertoire and genre changes were undertaken four times, as was the development of individualised facial exercises. Technical changes and compensatory movements were reported three and two times respectively.

"Physical Adaptation" approaches consisted of 11 iterations, changing instrument (n=6)، and the use of orthotic devices (n=5). One instance of the mirror-box technique completed the table.

Complementary Retaining Approaches

The survey also registered complementary approaches to retraining, documented through open-ended questions within the survey (refer to Table 21).

Table 21. Complementary Retraining Approaches Utilised by Study Participants

	Total (N)
Mind-body	
Meditation	4
Tai chi	4
Brain-spotting	3
Yoga	2
Pilates	1
N	**14**
Physical Approaches	
Physiotherapy	6
Rolfing	4
N	**10**
Movement-Based	
Alexander Technique	**3**
Feldenkrais	**2**
Aston Patterning	1
Isometrics	1
N	**7**
Body Awareness	

Body Mapping	4
Dipsokinesis	1
N	**5**
TOTAL	**36**

A total of 36 instances were reported across four categories, “Mind-body”, “Physical Approaches”, "Movement-Based", and “Body Awareness”. Mind-body approaches were the most commonly used (n=14), with meditation (n=4) and tai chi (n=4) being the most frequently reported. Brain-spotting techniques were also adopted (n=3) together with yoga (n=2) together with a single instance of Pilates. Alexander technique (n=3) and the Feldenkrais method (n=2) were the most cited movement-based complementary approaches, with Body Mapping (n=4) and a single utilisation of Dipsokinesis completing the list.

The diversity of both self-developed and complementary approaches to retraining reflects a multifaceted view of MFD management, suggesting that dystonic musicians pursue retraining methods that are a “best fit” with their personal circumstances. More conventional approaches including physiotherapy and Rolfing remain prominent but individualised strategies also represent a key theme, through the development of exercises and technique modifications to fit personal requirements. The implementation of holistic and mind-body strategies including meditation and yoga demonstrates understanding that rehabilitation requires both a body and mind approach.

Retraining duration and utilisation

The average retraining duration for each type of retraining (refer to Table 22) shows that self-developed methods were used for longer periods compared to other approaches, with a mean of 4.89, corresponding to between 3 and 3 years. In contrast, average neurofeedback retraining duration was 2.14, corresponding to between 6 months and 1 year.

Table 22. Average Retraining Durations

Retraining Method	N	Minimum	Maximum	Mean	Std. Deviation
Self-Developed	36	1	7	4.89	2.18
Neuroplastic	29	1	7	3.66	2.21
Sensorimotor	22	1	7	3.18	2.09
Complementary	19	1	7	3.74	2.08
Psychological	16	1	7	3.57	2.10
Neurofeedback	14	1	7	2.14	2.11

Key

1. *Less than 6 months* ***2.*** *< 6 months and >1 year* ***3.*** *<1 year and >2 years*
4. *= <2 years and >3 years* ***5****. = <3 years and >4 years* ***6.*** *= <4 years and >5 years*
7. *= <5 years*

As reported in Figure 13, 60% of participants reported having retrained for a total of five years or more. Therefore, to understand retraining utilisation amongst the sample in more detail, an analysis of retraining combinations undertaken by participants was also exam.

Retraining Combinations

The total number of retraining types utilised by participants is recorded below (Table 23).

Table 23. Number of Retraining Types Utilised by Participants

Number of Retraining Methods Utilised	Participants (N)	%
1	28	40.0%
2	28	40.0%
3	8	11.4%
4	2	2.9%
5	4	5.7%
Total	**70**	**100%**

Participants on average reported using 1.94 different approaches to their retraining. The patterns from the use of single retraining methods or two retraining methods together are illustrated in Table 24. The supplementary table (Table 25) shows retraining combinations that include three or more methods.

Table 24. Retraining combination matrix for single and dual utilisation.

	Neurofeedback	Neuroplasticity	Sensorimotor	Psychological	Self-Developed	Complementary
Neurofeedback	0	2	3	0	1	1
Neuroplasticity	2	8	0	2	5	3
Sensorimotor	3	0	4	1	3	2
Psychological	0	2	1	4	5	0
Self-Developed	1	5	3	5	8	1
Complementary	1	3	2	0	1	4

Table 25. Retraining combination usage for three or more retraining types.

Retraining Combination	**Total No. of Occurrences**
Neurofeedback + Neuroplasticity + Sensorimotor	1
Neurofeedback + Neuroplasticity + Complementary	1
Neurofeedback + Sensorimotor + Self-Developed	1
Neuroplasticity + Sensorimotor + Self-Developed	1
Neuroplasticity + Self-Developed + Complementary	2

Sensorimotor + Self-developed+ Complementary	1
Psychological + Self-Developed + Complementary	1

Neurofeedback + Neuroplasticity + Sensorimotor + Psychological	1
Neuroplasticity + Psychological + Self-Developed + Complementary	1

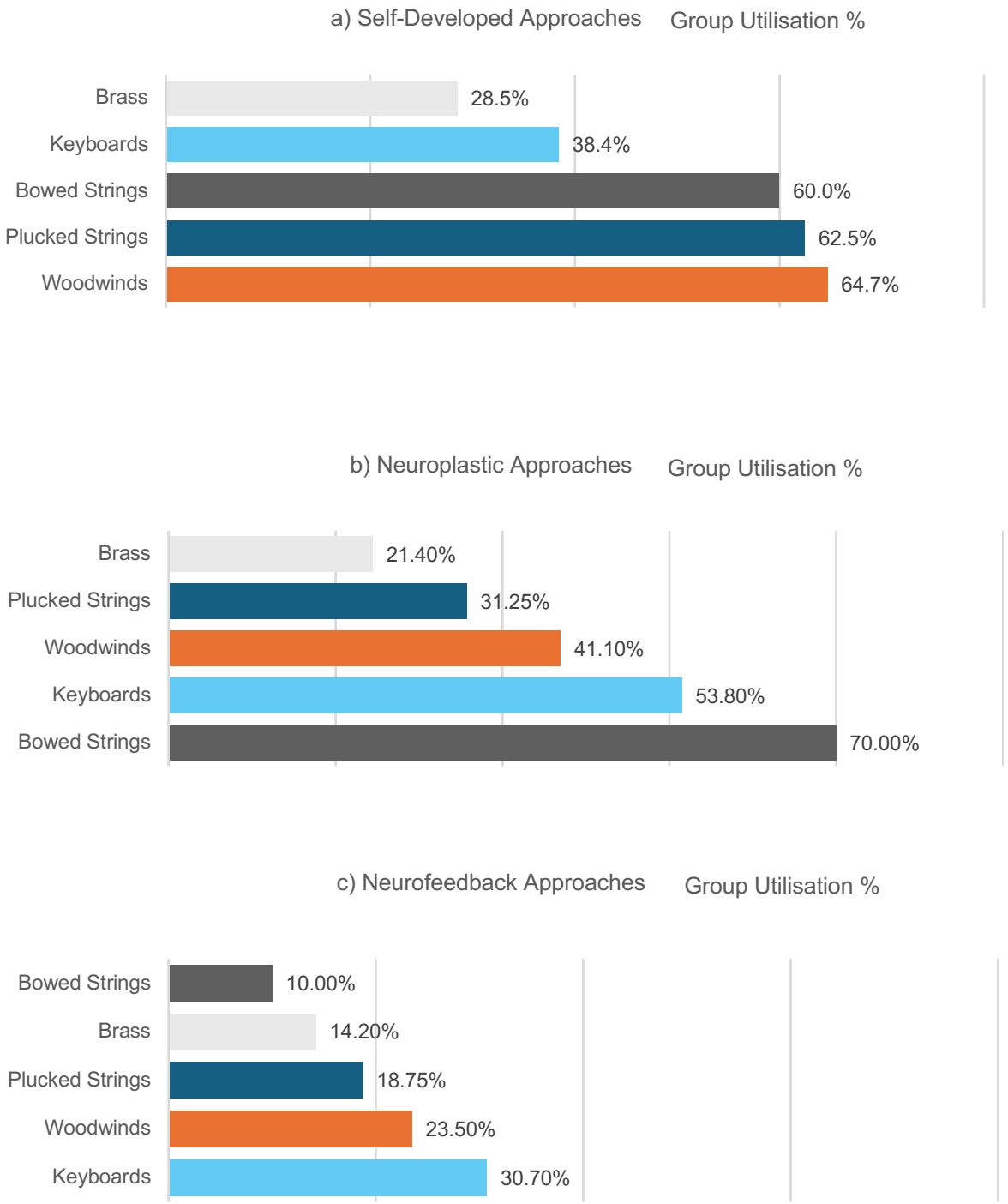
Neurofeedback + Neuroplasticity + Sensorimotor + Self-Developed + Complementary	2
Neurofeedback + Sensorimotor + Psychological + Self-Developed + Complementary	2

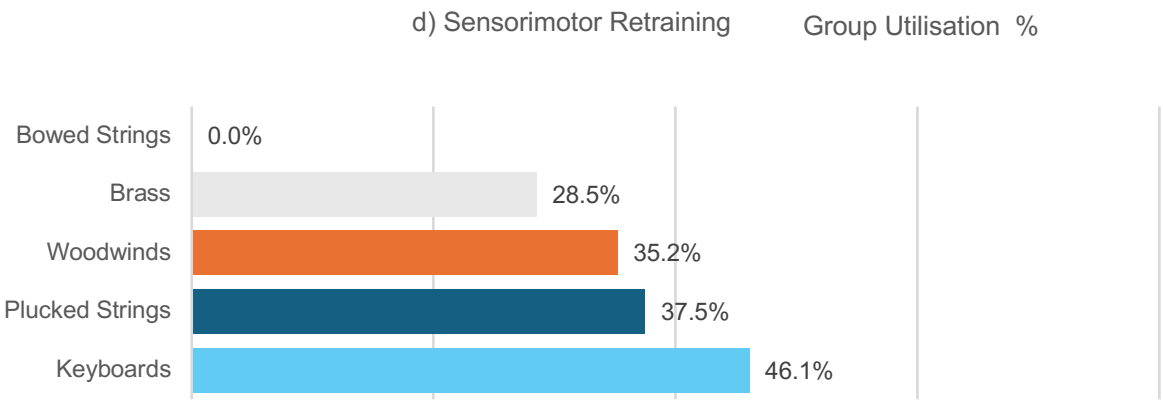
The single and dual utilisation matrix (refer to Table 25) is symmetric about the diagonal and accounts for each pair of methods. Chi-square tests were carried out to look for patterns in combination pairs and their selection by study participants, although none were evident. The results suggest that the sample population has homogeneous and consistent retraining combination choices. Conversely, musicians might be using retraining in a highly personalised manner that does not follow any dominant trend. The absence of patterns may also demonstrate limited retraining selection guidance which may indicate a lack of consensus between stakeholders.

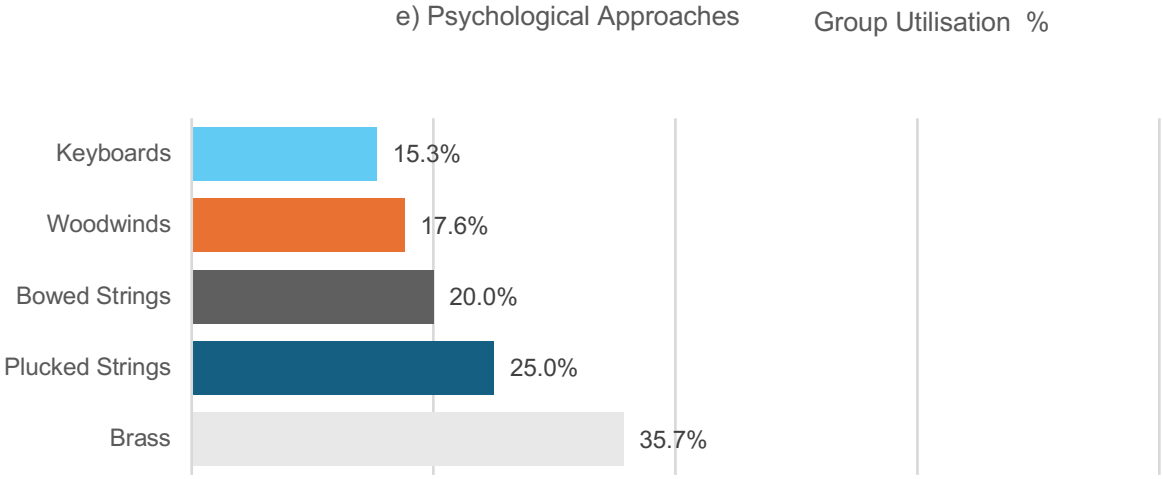
Retraining Amongst Instrumental Groups

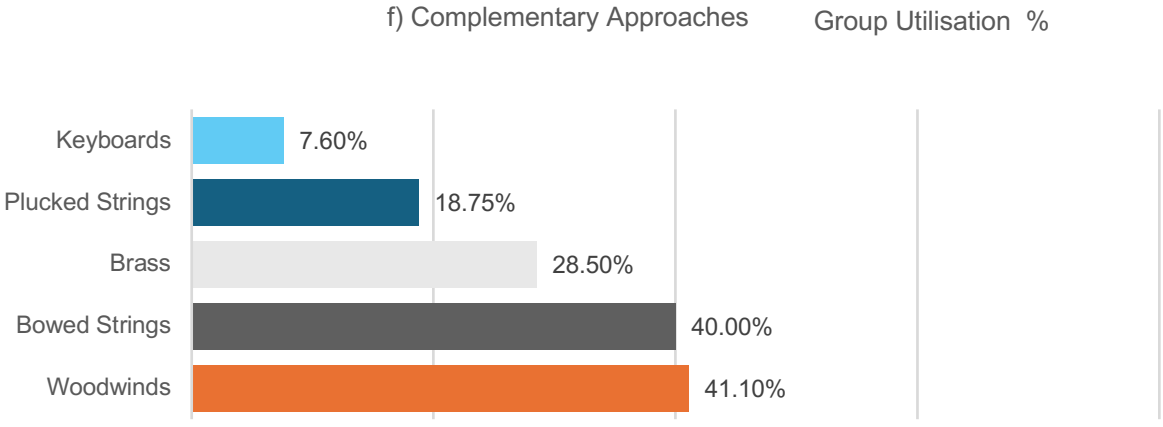
Retraining utilisation amongst instrumental groups was also analysed to investigate possible selection trends and preferences (Figure 19 a-f).

Figure 19. Retraining Utilisation by Instrument Group









The results show the percentage of participants in each instrumental category that have utilised at least one of the six retraining methods. Neurofeedback utilisation was

the lowest amongst the instrumental groups (figure 19c) although 30.7% of the keyboard group reported using this method, which may be due to the fact that there are more studies and interventions involving this group. In contrast, self-developed retraining (figure 19a) and neuroplastic retraining (figure 19b) were the most utilised methods across groups. The highest rate of self-retraining usage was observed amongst the woodwind group (64.7%), whilst the keyboard and brass players had the lowest rates (38.4% and 28.5% respectively). Neuroplastic retraining was utilised by 70% of the bowed string group (figure 19b) whilst the plucked stringed and brass groups accounted for considerably less (31.25% and 21.4%. respectively). The keyboard group had the highest rate of sensorimotor retraining use at 46.1%, (see figure 19d) compared to the brass, woodwind and plucked groups with an average of 33.7%. This observation reflects the existing research on splinting techniques amongst keyboard instrumentalists and to some extent, plucked string players. During the interview phase, amongst the brass cohort (exclusively affected by embouchure dystonia) and woodwind cohort, instrument-specific methods such as oral devices and exercises were also mentioned. Interestingly, the bowed string group indicated 0% utilisation of this technique, which may be due to the difficulties and constraints of using sensorimotor retraining for the left hand, which requires more non-linear, lateral movements, including vibrato.

Psychological retraining approaches amongst brass musicians were reported significantly more frequently than in the other groups (see figure 19e). A total of 35.7% indicated that they utilised these methods, which may indicate a move towards more holistic views of MFD, including psychological factors. On the other hand, the keyboard group, which is most closely associated with utilisation of more objective neurofeedback and sensorimotor techniques, had the lowest level of psychological approaches at 15.3%. Complementary approaches (figure 19f) were significantly varied amongst groups with only 7.6% of the keyboard group and just over 41% of the woodwind group reported adopting such methods. Bowed strings utilised complementary retraining 40.0% of the time, whilst the plucked string group reported less than half of this figure (18.75%). This presents a rather complex picture of complementary retraining usage, which might imply that such approaches are

considered more appropriate or useful for musicians from different instrumental groups.

Concluding this section, self-developed and neuroplastic approaches to retraining emerged as the predominant retraining strategies across the sample group, with notable variations reflecting instrument-specific preference. The higher incidence of psychological retraining amongst the brass group indicates a shift towards more holistic management of MFD, contrasting with the keyboard group's limited engagement in such methods.

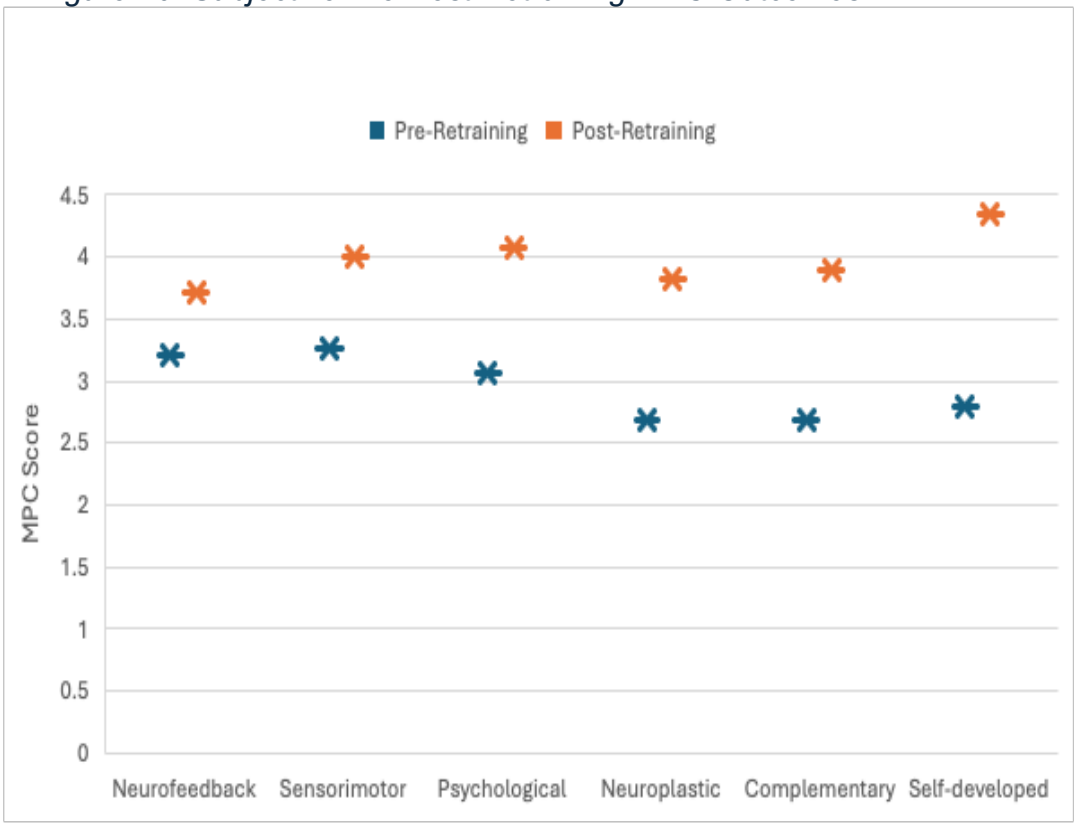
(RQ2) How do dystonic musicians evaluate and perceive the outcomes of their retraining?

Survey items 6 and 7

To address the second research question, study participants were questioned about their music performance capacity (MPC) before and after their retraining periods (survey items 6 and 7). This evaluation was conducted using an adapted version of the Tubiana and Chamagne, MPC rating scale (Ramella et al., 2022) to produce pre-post-test subjective assessment of participants' retraining outcomes (refer to Figure 20).

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Figure 20. Subjective Pre-Post Retraining MPC Outcomes



Key	Music performance capability (MPC)
0	Unable to play.
1	Only able to play a few notes before stopping.
2	Able to play short sequences, slowly and unsteadily.
3	Able to play easy pieces, but unable to play more difficult pieces.
4	Able to play almost normally, but with symptoms when playing certain pieces or passages.
5	Playing normally.

The results confirm perceived pre/post MPC gains across each retraining modality, with self-developed approaches being considered to have the greatest benefits to musicians.

Paired T-tests of the results reveal significant pre/post retraining differences at the 0.05 level (Table 26). Additionally, three of the T-tests had p-values of <.001**, indicating a strong level of significance.

Table 26. Subjective Pre-Post Retraining MPC Paired T-Tests

*MPC = musical performance capacity		MEAN	N	STD. DEVIATION	STD. ERROR MEAN
Pair 1	MPC before Neurofeedback retraining	**3.21**	14	1.37	.37
	MPC after Neurofeedback retraining	**3.71**	14	1.07	.29
Pair 2	MPC before Sensorimotor retraining	**3.27**	22	1.28	.27
	MPC after Sensorimotor retraining	**4.00**	22	1.45	.31
Pair 3	MPC before Psychological retraining	**3.00**	15	1.19	.31
	MPC after Psychological retraining	**4.00**	15	1.13	.29
Pair 4	MPC before Neuroplastic retraining	**2.69**	29	1.31	.25
	MPC after Neuroplastic retraining.	**3.79**	29	1.57	.300
Pair 5	MPC before Self-developed retraining	**2.80**	36	1.41	.24
	MPC after Self-developed retraining	**4.34**	36	1.41	.24
Pair 6	MPC before Complementary retraining	**2.68**	19	1.16	.26
	MPC after Complementary retraining	**3.89**	19	1.2	.27

Study participants demonstrated differing levels of perceived MPC improvement across the various retraining approaches (refer to Table 26). Significance levels for the results are displayed in Table 27. Neurofeedback analysis showed moderate results with participants achieving an average MPC score increase from 3.21 before retraining, to 3.71. For those that had undertaken neuroplastic retraining substantial performance enhancement was reported, with mean scores increasing from 2.69 to 3.79 (p <.001**). Sensorimotor retraining also produced significant results with mean MPC values increasing from 3.27 to 4.00 (p <.002*). The results of psychological retraining showed more marginal effects with the average score increasing from 3.07 to 4.07 at the 0.05 significance level. Self-developed retraining approaches were considered the most effective amongst participants, with mean scores increasing from 2.80 to 4.34 (p <.001). The complementary retraining methods also revealed significant mean MPC score increases from 2.68 to 3.89 (p<.001).

Table 27. Subjective Pre/post Retraining T-test Significance Levels

MPC = musical performance capacity		DF	ONE - SIDED P-VALUES	TWO-SIDED P-VALUES
Pair 1	MPC before Neurofeedback retraining	13	.014	.029
	MPC after Neurofeedback retraining	13		
Pair 2	MPC before Sensorimotor retraining	21	**<.001****	**.002***
	PC after Sensorimotor retraining	21		
Pair 3	MPC before Psychological retraining	14	.008	.016
	PC after Psychological retraining	14		
Pair 4	MPC before Neuroplastic retraining	28	**<.001****	**<.001****

	MPC after Neuroplastic retraining.	28		
Pair 5	MPC before Self-developed retraining	35		
	MPC after Self-developed retraining	35	**<.001****	**<.001****
Pair 6	MPC before Complementary retraining	18		
	MPC after Complementary retraining	18	**<.001****	**<.001****

*. Correlation is significant at the .05 level (p <.05).

* * Correlation is significant at the .001 level (p <.001).

Effect sizes were also calculated (refer to Table 28).

Table 28. Subjective Pre-Post Retraining Levels – Effect Sizes

PAIRED SAMPLE EFFECT SIZES					**95% CONFIDENCE INTERVAL**	
			Standardised	**Point estimate**	**LOWER**	**UPPER**
Pair 1	MPC before Neurofeedback retraining	Cohen's d	.76	-.66	-1.23	-.70
	MPC after Neurofeedback retraining	Hedges Correction	.81	-.62	-1.16	-.60
Pair 2	MPC before Sensorimotor retraining	Cohen's d	.93	-.78	-1.25	-.29
	MPC after Sensorimotor retraining	Hedges Correction	.97	-.75	-1.20	-.28

Pair 3	MPC before Psychological retraining	Cohen's d	1.41	-.71	-1.27	-.13
	MPC after Psychological retraining	Hedges Correction	1.50	-.67	-.12	-.12
Pair 4	MPC before Neuroplastic retraining	Cohen's d	1.37	-.80	-1.22	-.38
	MPC after Neuroplastic retraining.	Hedges Correction	1.41	-.78	-1.19	-.37
Pair 5	MPC before Self-developed retraining	Cohen's d	1.52	-1.00	-1.40	-.60
	MPC after Self-developed retraining	Hedges Correction	1.56	-.98	-1.37	-.59
Pair 6	MPC before Complementary retraining	Cohen's d	.97	1.24	-1.83	-.63
	MPC after Complementary retraining	Hedges Correction	1.02	-1.19	-1.76	-.60

Each of the retraining modalities are associated with increased effect size. Both pair 3 (psychological approaches) and pair 6 (self-developed approaches) registered particularly strong changes, with confidence intervals not containing zero.

Overall, each retraining modality elicited a significant positive response in the performance capacity of participants, reflecting the perceived benefits of each of the six retraining modalities.

Survey item 8 - Perceptions of Retraining Effectiveness

Study participants were also asked to comment on their perceptions of the effectiveness of their retraining. The perceived mean values for each retraining approach are displayed in Table 29.

Table 29. Musician Related Retraining Effectiveness

	N	Min.	Max.	Mean	Std. Deviation
How would you rate the effectiveness of your neurofeedback retraining.	14	2	4	2.71	.66
How would you rate the effectiveness of your sensorimotor retraining?	22	1	5	3.09	1.19
How would you rate the effectiveness of your neuroplastic retraining?	29	1	5	3.24	1.38
How would you rate the effectiveness of your self-developed retraining?	36	1	5	3.25	1.66
How would you rate the effectiveness of your psychological retraining?	15	1	4	3.27	.97
How would you rate the effectiveness of your complementary retraining?	19	1	4	3.47	.84
Valid N (listwise)					

Key:

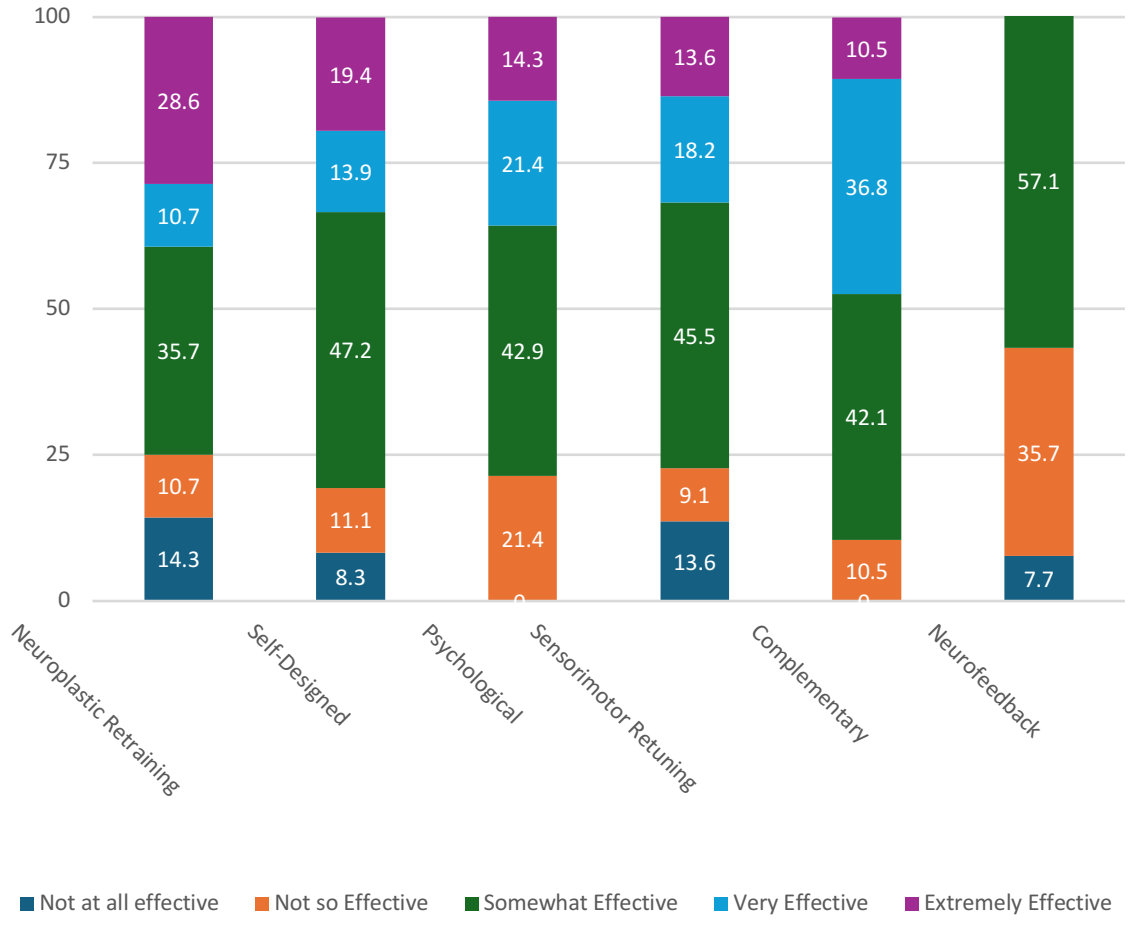
5= Extremely Effective, 4= Very Effective, 3= Somewhat Effective, 2= Not so Effective
1= Not at all Effective

Analysis provides additional context to the findings from the previous section demonstrating how participants perceived similarities and differences between

retraining outcomes and effectiveness. Although self-developed approaches were considered by participants to have the greatest effect on MPC (refer to figure 21), complimentary approaches were associated with perceptions of greatest effectiveness (refer to Table 30). Neurofeedback approaches were considered to be the least effective (refer to Table 30) together with the least MPC increase (refer to Table 31).

A further analysis shows the effectiveness breakdown for each retraining modality (figure 21).

Figure 21. Musician Rated Retraining Effectiveness



The results show that neuroplastic approaches to retraining produced the highest frequency of "extremely effective" outcomes at 28.6%. The data also confirms a broad spectrum of perceived effectiveness across different retraining types, with a strong tendency towards moderate efficacy (Somewhat Effective) for each retraining method.

Whilst some approaches have outliers indicating high satisfaction, the overall outcome reveals perceptions of moderate effectiveness across each retraining modality.

RQ3). What are their perceptions of their retraining experiences, and to what extent were their expectations met?

Survey Items 9-12

Participants were asked to evaluate the quality of their retraining, as well as the support that they had received during and following their experience. They were then requested to comment on how their overall retraining expectations were met.

Retraining Quality

The evaluation of quality (refer to Table 30) showed that neurofeedback retraining approaches received the lowest rating of 2.71, with all other modalities receiving ratings above the midpoint of 3. The highest mean rating of 3.79 for complementary retraining also stayed near the "neither high nor low quality" midpoint of 3, whilst the standard deviation of 0.86 showed moderate agreement amongst respondents. The self-developed retraining methods received a quality rating of 3.67 with a negative skewness of -.30 which indicated that participants gave higher ratings than the average. Sensorimotor retraining and psychological retraining data showed average scores near the midpoint with symmetrical distribution (3.50 and 3.23 respectively), whilst neuroplastic retraining received a mean score of 3.45 with significant negative skewness (-.69) indicating strong participant variability.

Table 30. Musician Rated Retraining Quality

	N	Min.	Max	Mean	Std. Dev	Skew.	Std.Error
How would you rate the quality of your Complementary retraining?	**19**	3	5	**3.79**	.86	.45	1.01

How would you rate the quality of your Self-developed retraining?	**36**	1	5	**3.67**	.96	-.30	.77
How would you rate the quality of your Cognitive/ Emotional retraining?	**14**	2	5	**3.50**	.76	.06	1.15
How would you rate the quality of your Neuroplastic retraining?	**29**	1	5	**3.45**	1.15	-.69	.84
How would you rate the quality of your Sensorimotor retraining?	**22**	1	5	**3.23**	1.02	.09	.95
How would you rate the quality of your Neurofeedback retraining?	**14**	2	4	**2.71**	.73	.52	1.15

Quality Rating:

5= Very High-quality 4= High-quality 3= Neither high nor low quality 2= Low Quality 1= Very low quality

A further categorical breakdown of each of the retraining types and their quality ratings is presented below (figure 22).

Figure 22. Perceived Quality of Retraining Methods by Category



Each column reveals how participants evaluated quality levels from very low to very high. A total of 52.6% of participants that utilised complementary approaches evaluated their experiences as high or very high quality, whilst 47.3% considered them of neither high nor low quality. Similarly self-developed approaches were considered of high or very high quality by 52.7% of those that utilised this approach, whilst 41.6% gave a neutral assessment. Neuroplastic approaches showed an average distribution with the smallest number of neutral responses at 32.1%. The method received positive

ratings from 53.7% of participants who considered it to be of high or very high quality, yet 14.2% of participants found it to be of poor or very poor quality. Sensorimotor retraining and psychological retraining received identical negative perception rates at 18.1% and 14.1% respectively which resulted in slightly lower mean scores. Neurofeedback received the most negative quality ratings with 61.5% of participants evaluating it as neither high nor low quality and 23% rating it as low quality. The lowest mean rating of 2.71 indicates that participants expressed significant dissatisfaction.

The results confirm that complementary, self-developed and neuroplastic retraining types receive positive evaluations from a large number of participants who rate them as high quality. Sensorimotor and Psychological retraining received the largest neutral quality ratings from participants which indicates potential quality issues or unclear assessment methods. Neurofeedback approaches received consistently poor responses which requires further investigation to understand the underlying reasons for these negative perceptions.

Quality of Retraining Support

Study participants were asked to clarify the levels of support they felt they had received both during and following their retraining. Paired T-Test results of support ratings during and following retraining are displayed in the following Table 31.

Table 31. Quality of Support Received During/After Retraining - Paired T Tests

		Mean	N	Std. Deviation	Std. Error Mean
Pair 1	How would you rate your support DURING Neurofeedback Retraining?	3.00	14	.88	.23

	How would you rate your support AFTER Neurofeedback Retraining	2.14	14	.77	.21
Pair 2	How would you rate your support DURING Neuroplastic Retraining?	3.68	25	1.03	.21
	How would you rate your support AFTER Neuroplastic Retraining?	2.72	25	1.05	.29
Pair 3	How would you rate your support DURING Sensorimotor Retraining?	4.00	13	.71	.20
	How would you rate your support AFTER Sensorimotor Retraining?	3.46	13	1.05	.29
Pair 4	How would you rate your support DURING Psychological Retraining?	4.10	10	.74	.23
	How would you rate your support AFTER Psychological Retraining?	2.90	10	1.29	.41
Pair 5	How would you rate your support DURING Complementary Retraining?	4.40	15	.63	.16

How would you rate your support AFTER Complementary Retraining?	3.47	15	1.12	.29

Each of the retraining methods (excluding self-developed retraining) received an initial support rating above the median level of (3.00). However, post-retraining support ratings were substantially lower. The results were significant at the p<.05 level refer to Table 32) and of particular significance for biofeedback, neurofeedback, and complementary retraining were of high significance. This demonstrates a substantial decline in post-retraining support across all modalities with only sensorimotor and complementary retraining experiences remaining above the median (3.46, and 3.47 respectively).

Support Rating:

5= Excellent, 4= Good, 3= Satisfactory, 2= Quite Poor, 1= Very Poor

Table 32. Retraining Support Significance Levels

SIGNIFICANCE		**DF**	**ONE -SIDED P-VALUES**	**TWO-SIDED P-VALUES**
Pair 1	How would you rate your support DURING Neurofeedback Retraining?	13	**.001***	**.003***
	How would you rate your support AFTER Neurofeedback Retraining			
Pair 2	How would you rate your support DURING Neuroplastic Retraining?	24	**<.001****	**.001***
	How would you rate your support AFTER Neuroplastic Retraining?			

Pair 3	How would you rate your support DURING Sensorimotor Retraining?	12	**.006***	**.01***
	How would you rate your support AFTER Sensorimotor Retraining?			
Pair 4	How would you rate your support DURING Psychological Retraining?	9	**.009***	**.02***
	How would you rate your support AFTER Psychological Retraining?			
Pair 5	How would you rate your support DURING Complementary Retraining?	14	**<.001****	**<.002***
	How would you rate your support AFTER Complementary Retraining?			

*. Correlation is significant at the .05 level (p <.05).

* * Correlation is significant at the .001 level (p <.001).

Effect sizes amongst all retraining approaches were considerable (refer to Table 33) with psychological retraining appearing to be the most impactful changes based upon the highest effect sizes.

Table 33. Retraining Support Level Effect Sizes

			95% Confidence Interval	
PAIRED EFFECT SIZES	**Standardised**	**Point estimate**	**LOWER**	**UPPER**

Pair 1	MPC before Neurofeedback retraining	Cohen's d	.86	.99	.33	1.62
	MPC after Neurofeedback retraining	Hedges Correction	.92	.93	.31	1.53
Pair 2	MPC before Sensorimotor retraining	Cohen's d	.66	.82	.17	1.43
	PC after Sensorimotor retraining	Hedges Correction	.70	.76	.16	1.34
Pair 3	MPC before Psychological retraining	Cohen's d	1.32	.91	.15	1.64
	PC after Psychological retraining	Hedges Correction	1.44	.83	.14	1.50
Pair 4	MPC before Neuroplastic retraining	Cohen's d	1.02	.94	.47	1.41
	MPC after Neuroplastic retraining.	Hedges Correction	1.05	.91	.45	1.36
Pair 5	MPC before Complementary retraining	Cohen's d	.96	.97	.34	1.58
	PC after Complementary retraining	Hedges Correction	1.02	.92	.32	1.49

Overall Expectations of Retraining

Finally, overall expectations of participants 'retaining were evaluated, showing variable results (refer to Table 34) with an average score of3.03, almost exactly at the midpoint of the 5-point Likert scale.

Table 34. Overall Expectations of retraining- Mean values

To what extent did your retraining live up to expectations?

N	Valid	70
	Missing	0
Mean		**3.03**
Std. Deviation.		.99
Minimum		1
Maximum		5

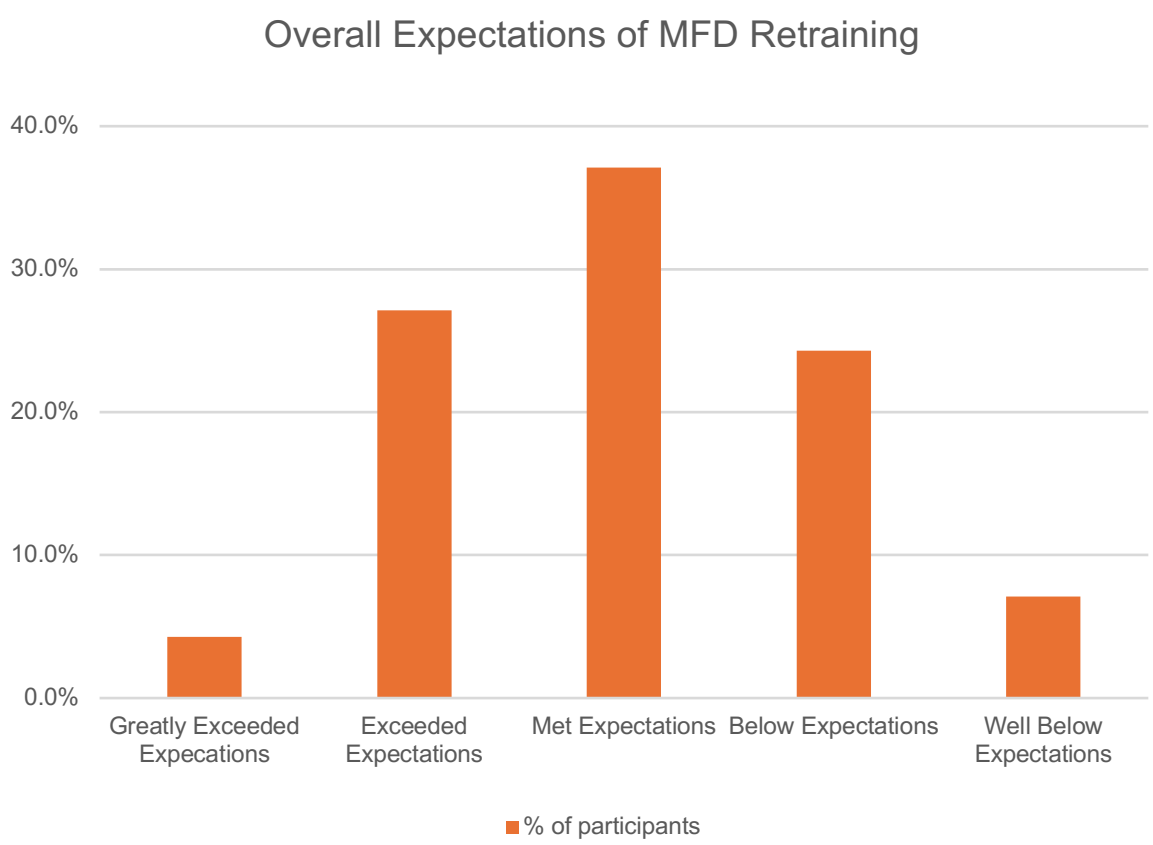
Expectation Rating:

5= Greatly Exceeded Expectations
4= Exceeded Expectations
3= Met Expectations
2= Below Expectations
1= Well Below Expectations

The average participant assessment indicates that retraining experiences were somewhat satisfactory but did not reach high quality standards. A standard deviation of 0.992 in participant responses confirms differing perceptions about to what extent retraining met expectations. The wide range of responses demonstrates that participants had varying levels of satisfaction, with some participants finding the retraining very effective, but others being considerably less satisfied.

Figure 23 emphasises the distribution of responses, with 27.1% reporting retraining exceeding expectations and 24.3% falling below. Greatly exceeded expectations accounted for 4.3% of responses, whilst 7.1% reported their retraining falling well below expectations.

Figure 23. Overall Expectations of Retraining Outcomes



The variability in the responses suggests that individual differences may significantly influence the perceived effectiveness of retraining programmes and re-emphasises the need for tailored retraining to meet the specific needs or circumstances of each musician.

5.5 QUALITATIVE FINDINGS

In the following section, thematic analysis of the interview data from the qualitative phase of the study participants (n=9) is presented, providing qualitative evidence to further substantiate each of the twelve survey items (refer to table 28). Each of the four themes are presented below together with their respective sub-themes, survey item numbers, and relevant research questions (RQs).

Theme correspondence to the relevant survey items is displayed in Table 35 displayed in 4 colours, blue/grey (Theme 1), peach (Theme 2), green (Theme 3), and blue (Theme 4).

Table 35. How themes correspond with survey questions.

Item no.	Research Question (RQ)	Survey Items
1	RQ1	How long did it take to get a diagnosis of focal dystonia after symptoms first appeared?
2		How long did it take to begin retraining after your diagnosis?
3		How long have you been using retraining for managing your dystonia in total?
4		Which of the following retraining methods have you used?
5		How long have you utilised this retraining method for in total?
6	RQ2	How able were you to play before the retraining?
7		How able are you to play after the retraining?
8		How would you evaluate the effectiveness of the retraining?
9	RQ3	How would you rate the quality of the retraining?
10		How would you rate the level of support provided during the retraining?
11		How would you rate the level of support received post-retraining?

12		To what extent did the retraining live up to your expectations?



Theme 1 - A Lack of Prior Awareness

Theme 2 - Retraining Journeys: Choices and Commitment

Theme 3 - The Perceived Impact of Retraining

Theme 4 - Perceptions of Retraining Quality and Support

Qualitative Findings

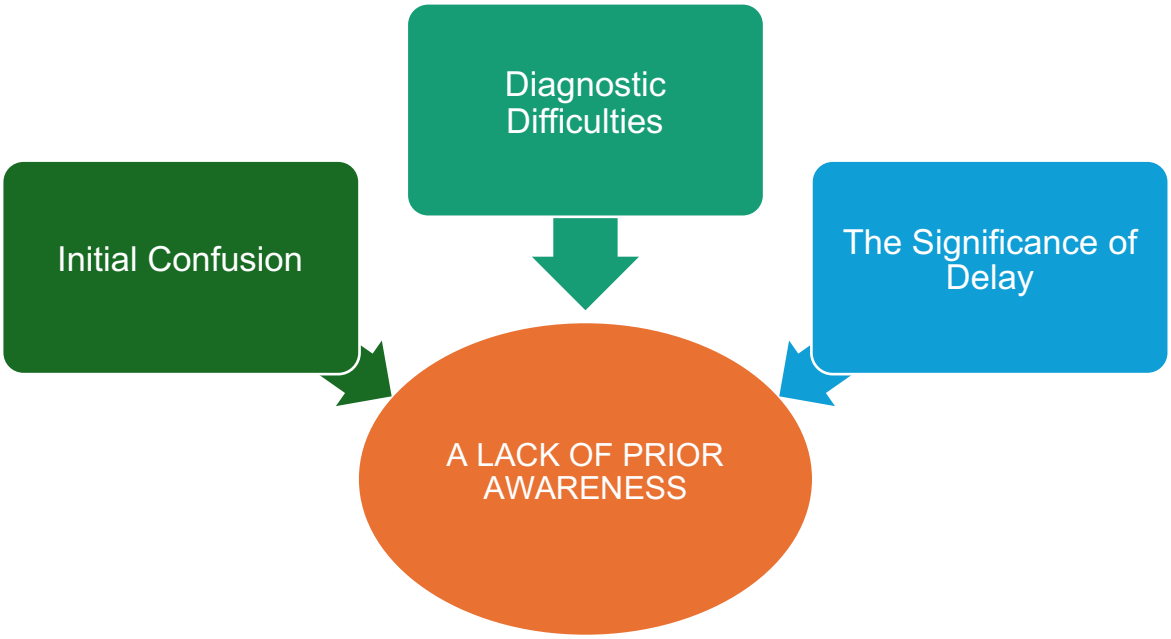
Similarities in the experiences of musicians were observed at particular stages during the initial phases of their retraining journeys. The average time between symptom onset and diagnosis was between two to three years (refer to Figure 11), and from diagnosis to the commencement of retraining between one and two years (refer to Figure 12). The quantitative data also revealed correlation between the time elapsed from symptom onset to diagnosis and the duration of retraining. The findings highlight the challenges of navigating retraining in the initial stages, specifically those that affect timing and decision making.

Theme 1: A Lack of prior awareness

(Survey Items 1-3)

The theme “Initial Confusion” explains these challenges whilst showing the complicated process musicians experience when starting their retraining journeys. A lack of awareness or understanding of MFD during the initial stages of managing the condition was frequently reported by study participants. Three sub-themes emerged, each representing a distinct perspective on the main theme, as presented in Figure 24.

Figure 24. Theme 1 – A Lack of Prior Awareness



The following table (Table 36) shows the frequency (n) of references recorded for each of the three sub-themes across all nine interviewees.

Table 36. Theme 1 – A Lack of Prior Awareness

Sub-theme	**Interviewee Number**									**References Total (n)**
	1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	
	Frequency of References									
Initial Confusion	4	3	2	4	3	0	3	4	2	25
Diagnostic Difficulties	2	2	4	2	0	4	4	2	3	23

The Effect of Delay in Initiating Retraining	2	0	3	2	1	1	2	0	3	14
Total										**62**

Sub- theme 1 – Initial Confusion

Initial confusion is a significant barrier to taking appropriate and timely first steps towards rehabilitation. Most interviewees (n=7) stated that they had no knowledge of MFD until after their symptoms had appeared. Participant 2 had thought that their symptoms might be a previously diagnosed tendinopathy, commenting, *"I had the same stiffness as before. [Instrumental teacher] thought it was that. I never even heard of focal dystonia until then."* Similarly, Participant 6 reported being completely unaware of what was happening to their embouchure: *"Nobody mentioned anything for a long time to me. I was not practicing right, and it was in my head. That's what I thought. A colleague of mine suggested it could be dystonia."* Participant 2 was an undergraduate student when their symptoms appeared and participant 6 was at the beginning of their career at 27 years old. The two examples show a common problem for dystonic musicians who are diagnosed early in their careers. At this point, they may have little awareness of what may be happening to them. If further complicated by diagnostic confusion, the initial symptoms are frequently overlooked or attributed to other causes, leading to diagnostic delay as the individual searches for answers on their own.

Participant 1, who finally received a diagnosis of MFD at 54 years of age had had "strange" symptoms for more than 15 years without relating them to dystonia, commenting, *"I had not a clue to be frank. I went to see doctors a few times. They had no idea, so I left it alone."* In this instance, in addition to being unaware of the possibility of having a dystonia, it was also difficult to find appropriate medical treatment. The participant also reported to have been living away from a major city for years prior to diagnosis and has had to rely on the local healthcare system.

Together, each of these examples demonstrate the haphazard and confusing way in which musicians search for answers when they have poor awareness of the condition. It also highlights that medical awareness of MFD may not always be sufficient, re-

enforcing the importance of musicians' awareness to minimise the risk of protracted periods of uncertainty or confusion.

Sub-Theme 2 – Diagnostic Difficulties

Most interviewees (n=8) also shared troublesome diagnostic experiences and the effects upon the initiation of their retraining. This sub-theme discusses the obstacles encountered during diagnosis by both musicians and clinical professionals.

1. **Difficulties Identifying Subtle and Instrument-specific Symptoms**: Focal dystonias and MFD in particular, have symptoms that are subtle and often very task-specific in nature, making them potentially difficult to correctly diagnose in a clinical setting (Beghi et al., 2015). Participant 4 describes an experience that illustrates this challenge, highlighting limited understanding of the condition from a medical professional: "*There was nothing showing on my MRI (magnetic resonance imaging) or blood tests, so I was basically told, 'it's nothing serious, it will probably go away over time'. I was given some muscle relaxants, referred for some physio and signed off."* In this instance, the musician sought a second opinion as they suspected they might have MFD. However, for a musician that has no awareness of MFD, this situation would inevitably lead to a delayed diagnosis.

2. **Variable Presentation of Symptoms**: Musicians can present with MFD in very different ways, and this can lead to inconsistent or conflicting diagnostic assessments. Participant 1, who had never heard of MFD and whose first symptom was finger tremors, was initially investigated for essential tremor and Parkinson's disease: *"The doc said he wanted to rule out Parkinson's as my dad had it, so I was really freaked. Looking back, I should have taken my [instrument] with me and shown him then. He might have picked it up sooner."* MFD was not suggested as a possible diagnosis in this case until a future consultation: " It took a year, but I found a neuro that got It ". This resulted in delay in both diagnosis and initiation of retraining.

3. **Misinterpretation of MFD as a Solely Psychological Issue**: The task-specific nature of MFD and the fact that the condition is not always evident to the naked

eye may sometimes be misinterpreted as a purely psychological problem or stress (Newby et al., 2017). Although neurological examination should prevent this assumption, musicians that are not previously aware of MFD are often consulting medical professionals who are not movement disorder specialists. In such cases, it is by no means a certainty that correct signposting to an appropriate specialist, or a correct diagnosis will be achieved, as the following excerpt demonstrates: "*I remember him looking blankly at me when I told him about my lip tremor only when I tried to play. I was actually sent away with diazepam to keep me calm the first time."* (Participant 4).

4. In addition to the diagnostic difficulties encountered by musicians due to misinterpretation on the part of medical professionals or procedural flaws, several instances of poor interaction between musicians and clinical professionals were also reported. Participant 1 described a particularly frustrating experience that was not only marked by a lack of formal diagnostic procedure, but also dismissive attitudes from a medical professional. "*I turned up at the clinic for an EMG (electromyography) but there.. the nurse or whoever, was not there, so obviously, go home. I already had a consultation booked on the Friday, so I ended up going with no EMG because it was too late to change it. The doctor basically just told me to come back when I had it."* A further comment that was mentioned independently by clinical professionals in their interactions with n=3 participants was, *"Have you thought of trying something else?"* This particular response clearly demonstrates a lack of awareness of the professional significance of MFD to musicians.

In each scenario, lasting impressions were made upon musicians and their relationships with clinicians, drawing attention to a clear need to improve awareness of the psychosocial impact of MFD on the welfare of musicians. It also highlights the importance of equipping musicians with the necessary tools to discuss their diagnosis with their health provider and to set the stage for a continuing dialogue, rather than one off consultations that frequently leave musicians feeling under-valued and under-supported.

Sub-Theme 3 – The Significance of Delay in Initiating Retraining

Delays in initiating retraining were frequently reported by interviewees. As confirmed by the quantitative data, delay in achieving a diagnosis, and subsequent delays in initiating retraining, were associated with longer retraining periods (refer to Figure 13). The significance of this delay was discussed several times by study interviewees, the majority of whom (n=6) reported having been in retraining for more than 5 years. The effects of delayed retraining identified by participants across the data set, are set out in the following table (Table 37).

Table 37. Effects of Delayed Retraining Initiation for Dystonic Musicians

Effects of Delayed Retraining Initiation for Dystonic Musicians **Description**	
Prolonged Retraining Periods	Delays prior to, and during diagnosis, may culminate in extended periods of retraining.
Psychological Distress	Feelings of confusion, isolation, and desperation may increase emotional distress, negatively affecting retraining.
Haphazard Retraining Choices	A lack of initial support may lead to poor retraining decisions, causing delay and confusion.
Worsening Symptoms	Symptoms may progress, adding complication to the recovery process.
Reduced Motivation	Declining motivation may contribute to extended and/or disrupted retraining.

Emotional Exhaustion	The stress of delays may reduce resilience to psychological effects including stress and anxiety.

Extended delays during the diagnostic process prior to retraining were of significant concern for musicians. *Participant 5 commented, "I don't know of anyone that just went straight into retraining. It took me ages to understand what I was really trying to achieve with it. I was on track after maybe a year or so?"* A similar experience was also recounted by Participant 8: *"I can remember having to undo a lot of compensatory movements I'd worked in when I didn't know what I was doing."* Both examples draw attention to the period between diagnosis and retraining, a moment where musicians frequently experience confusion and are unsure how to proceed with their rehabilitation. This further the highlights the importance of making musicians aware of holistic pathways to rehabilitation and providing clear signposting from the outset.

The emotional impact of delays in initiating retraining, including confusion, isolation, low confidence and feelings of desperation, was also commented upon frequently, as described by Participant 7: "*I didn't know what to do at the time. I would have tried anything by that point, laying of hands, or whatever. I just needed something to hang on to."* This position reflects a lack of initial support or signposting at the time of diagnosis and a sense of desperation. It also demonstrates the haphazard retraining choices made by musicians who may be scrambling to find solutions. This may also compound any pre-existing emotional issues, alluded to by Participant 8: *"I had panic attacks a lot. I didn't know how I was going earn any money, and I couldn't sleep properly"*.

Further detrimental effects attributable to delayed retraining initiation were reported in relation to worsening symptoms and reductions in motivation demonstrated by Participant 7." *By the time I went to see [redacted] I couldn't put one finger in front of the other which was just horrid.. I was about ready to quit already.*" Reduced motivation was also a concern as expressed by Participant 1: "*Thanks to my wife, I have to say because it was thanks to her that I found a possible treatment and... I don't know, I was just about to, you know, quit, and never play again. And she said no. You cannot*

do it, you must try this treatment, and if this treatment doesn't work, then you can give up." In addition to the negative motivational effects, a state of emotional exhaustion was also a common experience, as Participant 3 shared: "I was *just fighting to keep things going like that, I remember thinking, I need a positive right now or that's it. I was so low."*

The literature suggests that delaying treatment of MFD may worsen prognosis as stereotyped dystonic movements, when repeatedly practiced becoming encoded, as conscious control declines (Altenmüller & Ioannou, 2016; Sadnicka et al., 2018). Similarly, a lack of psychological support or emotional neglect reduces the capacity to deal with stress (Gowling, 2020). Both examples reinforce the need for timely intervention to aid the mitigation of symptoms, both physiological and psychological. The consequences of delayed rehabilitation impacts both the physical and emotional aspects of a musician's wellbeing, making timely interventions, including retraining, important factors in effectively managing MFD. The narratives of interviewees confirm a general lack of pre-existing knowledge that leads to confusion and misinterpretation of symptoms. Subsequent confusion contributes to significant emotional destress, reduced motivation, and the possible aggravation of symptoms. Therefore, the importance of mitigating and minimising delay is of upmost importance in advancing the quality of help and support for dystonic musicians.

Theme 2: Retraining Journeys: Choices and Commitment

(Survey Items 4-5)

The second theme, "Retraining Journeys: Choices and Commitment" contextualises the retraining strategies that musicians adopt and combine to find compatibility with their personal needs and circumstances. It also discusses the impact of personal beliefs, experiences, and instrument-specific demands on retraining choices. Social connections and the influence of peers further shape these decisions. It confirms the inherently personal nature of retraining, shaped by intrinsic motivation and a commitment to recovery.

A total of 60% of survey respondents confirmed that they had used more than one form of retraining to rehabilitate from their MFD (refer to table 24). Data also revealed that 51.4% of survey participants had developed and utilised their own methods as part of their retraining (refer to figure 14). With the exception of one interviewee, musicians confirmed that they had initiated retraining without specific medical recommendation or referral as the following example from Participant 4 highlights: *"[I] had to navigate the retraining and recovery process largely on my own without [any] help."* Participant 2 confirmed a similar experience, reflecting a sense of desperation to find a solution: "*I remember joining a Body Mapping class online on the advice of my wife. I was in the gym every day, doing Body Mapping 'things' when I could. I had to do something, so it went from there."* The unguided nature of these retraining decisions reflects a wider issue, one that highlights the lack of informed guidance, leading to haphazard decision-making, and poorly informed decisions.

However, more informed choices concerning retraining selection were reported as musicians began to seek answers, usually autonomously, as in the case of Participant 1: *"I started to look for alternatives and followed Nancy Byl's research."* Participant 5 also commented upon their experimentation with retraining approaches following their own research. *"I read various things, including the Leisner Method and Fabra's techniques."* Each case reflects a shift towards personal responsibility, indicating how musicians engage with available sources to find appropriate solutions. It also suggests that they seek out credible and established techniques, demonstrating a significant degree of autonomy in the process.

Quantitative data concerning retraining combinations (refer to tables 21 and 22) did not find any correlating patterns of retraining selection. However, a tendency towards instrument-determined retraining approaches was apparent. For example, the keyboard cohort reported the lowest utilisation of cognitive/emotional and complementary approaches (refer to figure 19, e and f), yet the highest utilisation of biofeedback, sensorimotor retraining. More strikingly, bowed strings had the highest utilisation of neuroplastic retraining of 70% (refer to figure 19 d), yet 0% of participants had utilised sensorimotor retuning (refer to figure 19d). Interviewees were asked to clarify their reasons for selecting their specific retraining approaches. A dichotomy of

beliefs regarding the root cause of MFD emerged, with the various cohorts of instrumentalists in the study also reporting selecting and utilising retraining due to a combination of instrument-specific demands, personal experiences, and the nature of available resources as described in the following section:

1. **Individual Experiences and Challenges:** Personal instrument history, specific symptoms, ontological position concerning MFD, and past successes or difficulties all influenced retraining selection. Psychological approaches were more suitable for some, resonating with their personal experiences with performance anxiety or stress-related issues, as expressed by Participant 4: *"For me it's always been a trauma response. It can't just be a physical thing; there's nothing to see. Dealing with my anxieties and stress has changed things so much."* Contrastingly, others consider the condition to be primarily a physiological issue, as described by Participant 8: "It's *all about muscle usage. If we block the movement somewhere by not moving properly, we break down right? In anything we do... I need tangible things to try; therapy sessions don't cut it for me."* A more extreme example recounted by Participant 7 further highlights the broad ontological differences: *"I think if you're going to be a professional musician, you should get your DNA checked, see if you have these genes. You do. Don't p*ss away 10 15 years of your life memorising a body of work that you suddenly can't use."* These exemplars highlight a division between those that follow physiological approaches to retraining and those who choose more psychologically focused approaches. It also highlights an often "blinkered" perspective on retraining that overlooks the multifactorial aetiology of MFD within the literature, re-enforcing the need to increase and expand MFD awareness.

2. **Autonomous Decisions and Peer Influence:** Autonomy in retraining was confirmed as a significant driving factor, in part by the high number of musicians that reported utilising their own, self-developed methods (refer to figure 18). Two distinct motivators were identified as catalysts. Firstly, as discussed in Theme 1, a lack of professional guidance or signposting to retraining options which prompted musicians to research the principles of retraining on their own, as described by Participant 3: *"I did my research, but yeah, still feels like being part of some*

underground movement most of the time. And nobody is there telling you which way to go, apart from yourself." Secondly, recommendations from peers were influential in retraining decisions. Participant 6 confirmed, *"A trumpeter friend of mine told me to give sensory retuning a go. An old teacher of his had dystonia and he got himself right again with that. It has worked pretty well for me".*

Both of these excerpts highlight and re-emphasise a recurring issue for retraining musicians: a lack of signposting from qualified professionals. In the absence of structured guidance, musicians are navigating often unguided paths to find solutions that work for them. Some may trust and follow their own research, whilst rely on the recommendations of peers or colleagues. Although for some musicians 'outcomes appear positive, the lack of professional guidance is worrisome and indicates that other musicians may be disadvantaged in their retraining by poor signposting and professional support.

Theme 3: The Perceived Impact of Retraining

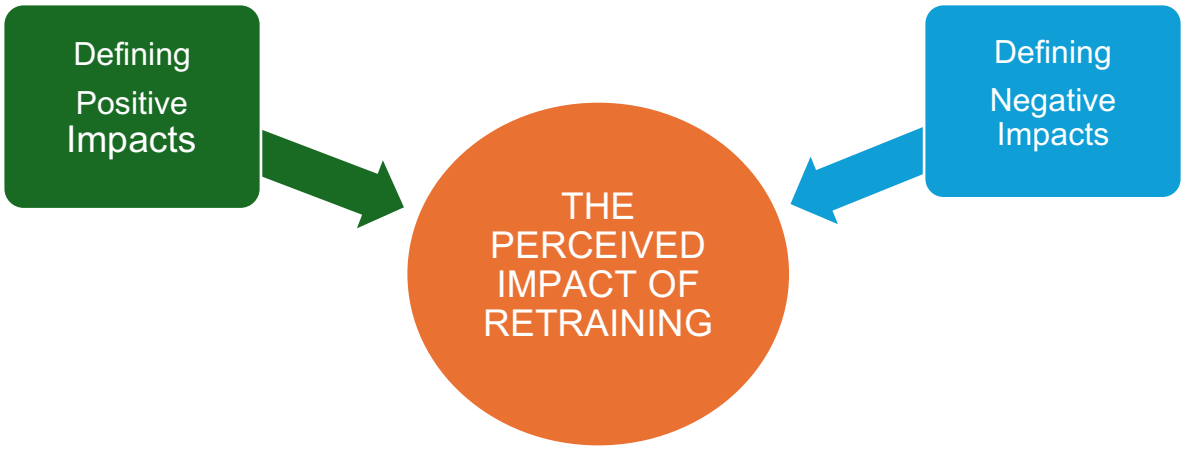
(Survey Items 6-8)

The third theme examined how musicians perceive the outcomes of their retraining. Across the survey group, 60% reported having undergone retraining for over five years (refer to Figure 19), and whilst this indicates that retraining can be prolonged and complex, the average perceptions of pre- and post-retraining outcomes were generally positive across all modalities (refer to Figure 22). What was commonly acknowledged by all participants was a change in their expectations of retraining. The complexities of the retraining process instigated a shift in outlook involving letting go of short-term goals and replacing them with longer-term objectives. Participant 1 commented, *"You can't just carry on as you were and expect it to go away. You have to accept the reality of it all and work it out slowly. It takes time to see progress, it's stressful and frustrating."* Participant 3 also confirmed this, stating, *"Where I'm at now is better psychologically but it took so long to feel the benefits. It's taken far longer than I thought it would, you know?"* This realignment of priorities signifies a fundamental shift in perspective, moving from the expectation of a swift recovery to a recognition of the complexities inherent in retraining and longer-term objectives. This raises the question

of how musicians themselves assess success or failure in the context of their retraining.

The following two sub-themes were developed, defining the positive and negative impacts of retraining as related by study participants (Figure 25).

Figure 25. Theme 3 – The Perceived Impact of Retraining



Sub- theme 1: Defining Positive Impacts of Retraining

Positive impacts of retraining were described by participants in a number of ways. Each of the reported outcomes reflect on retraining as part of a broader transformative process that not just addresses the immediate symptoms of MFD but also provokes changes in musical identity and professional outlook.

1. **Appreciating Incremental Progress**: Learning to valorise incremental improvements over quick fixes was commented upon frequently. Participant 1 reported, *"A lot of days it's hard to see much progress, but if something feels better, then I did something right, right? When I have more stamina on one day, or the hand doesn't shake for a bit longer, then yes, it's a good thing."* Recognising incremental improvements encourages greater concentration on the retraining journey itself rather than just the end goal, and a sense of continuing achievement

and motivation to persevere. It also reflects a more compassionate approach to retraining. *“My way of doing it is to enjoy things while they last and not panic if they fall apart. I don’t beat myself up about it.”* (Participant 8). The adoption of a mindset that accepts progress as a gradual and non-linear process re-affirms a shift from short-term fix to long-term gains.

2. **Consistency:** The ability to maintain improvements consistently over an increasing timescale is an important factor in gauging positive responses to retraining, as expressed by Participant 5. *“It’s one step forward two back mostly, but there are periods when things change and stick like that. Those days make it good.* “The importance of retraining regularly was also a key factor, as expressed by Participant 9. *“I need daily contact with the [instrument] even if I don’t play too much. When I leave it for any-time I feel it straight away”* (Participant 9*).* Both examples highlight the importance of consistent practice for musicians in maintaining retraining gains and improving self-assessment of their progress. Participant 5 confirms that although progress may be inconsistent, the moments when improvements "stick" contribute to psychological wellbeing as well as skill development. Participant 9 reinforces this, emphasising the need for regular interaction with the instrument, asserting that even minimal contact is beneficial.

3. **Quality over Quantity:** Avoiding excessive repetition and playing time is recommended within the literature to limit the reinforcement of stereotyped and inflexible movement sequences that may provoke symptoms of MFD. Knowledge of this was reflected in responses to retraining and changes in practice habits. Participant 6 commented, *“Yeah, I never do more than 30 minutes in one go anyway nowadays. I can do a lot more away from the [instrument], but not on it.”* The importance of mental practice was also expressed by Participant 2, *“I like to think more about the music. Mindfulness is all about visualisation, right? I get that right, then when I’m working at things on the [instrument], then I can get things working more quickly.”* Each excerpt describes strategic adjustment in practice habits as a result of retraining, demonstrating an informed approach that recognises the importance of intentional and mindful playing in facilitating recovery, actively avoiding un-necessary excesses.

4. **Psychological Resilience**: Participants frequently discussed the anxieties and frustrations associated with retraining, highlighting the importance of addressing mental resilience, as expressed by Participant 1: *"It's so tiring worrying about not being able to get back to playing fully. You have to find a way to take it one step at a time without freaking out over the future."* This account reflects the adoption of a patient mindset in which accepting gradual progress in retraining offsets anxieties about future outcomes. It also reflects the substantial mental strength that is required to navigate retraining, as expressed by Participant 4: "*It's a kind of slow torture, but you just have to do it. You can't give up on yourself, if I feel like that I just stop, do something else and carry on."* This highlights a critical coping mechanism, the ability to step back and shift focus when faced with negative emotions. They also acknowledge setbacks as part of the retraining process rather than indicators of failure, confirming that psychological resilience during retraining isn't just about enduring difficulties, but also actively choosing strategies that positively influence mental wellbeing. In turn, this enables musicians to move forward in their retraining with greater assurance.

Sub-Theme 2: Defining Negative Retraining Impacts

Negative outcomes of retraining were associated with loss of direction, the absence of significant improvement, as well as negative psychological states and feelings of disconnection from the retraining process. The following list outlines the most commonly cited negative impacts by participants:

1. **Lack of Direction:** A lack of retraining direction was a common issue described amongst participants as experienced by Participant 6. *"I didn't really know what I was supposed to do or feel after some time. We seemed to repeat a lot, but nothing was really working."* Unclear goals and planning were also associated with poor support and feedback from retraining professionals, further re-enforcing the necessity for improved support channels as emphasised by Participant 4. *"I couldn't' get any answers to my questions, and I lost interest quickly after that."* Each example captures the confusion and frustration that arises when there is no

clear path forward. The repetition without progress describes a feeling of stagnation, which can significantly affect motivation. They also point to an inadequacy of support and feedback from retraining professionals, resulting in barriers to effective learning and engagement, emphasising the need for clearer goals and better communication within retraining frameworks to provide more supportive environments.

2. **Stagnation in Progress:** Participants experienced periods of retraining where their recovery plateaued, leading to frustration and discouragement as experienced by Participant 2: *"I honestly had no idea if I was getting better or not. God knows what I was supposed to be feeling."* Similar frustrations were reported by Participant 6 who had also experienced a significant increase in anxiety as a result of their retraining stagnation: *"It's so hard when things aren't getting any better. It's like a feeling of total despair sometimes, you know?"* In each case, a sense of powerlessness was conveyed, outlining the significant resilience needed to maintain motivation and engagement with the retraining process.

3. **Feelings of Disconnection**: As confirmed in the quantitative data, the retraining process can be lengthy and, as reported by interviewees, often undertaken in isolation with limited levels of support. Consequently, as musicians progress in their rehabilitation, they report being disconnected from their peers and their identities as performing musicians: *"You need to change your perspectives when you're going through it. It's like you're now in the special club that no-one else is allowed into and yeah, nobody knows about it, or they don't want to know about it"* (Participant 9). There is also recognition of feelings of disconnection that can occur in direct response to the retraining process itself: *"I still feel like my playing is more superficial than before. If I just go for it then I forget what I shouldn't be doing, you know? I'm hopeful that that part will recover. I miss that a heck of a lot"* (Participant 2).

4. **Decreased Self-Esteem:** The impact of MFD on the self-esteem of musicians may be profound. The retraining process itself may also further compound feelings of low self-worth as the difficulties of achieving improvement become apparent, an experience expressed strongly by Participant 8*: "It's wild to think one day you're*

playing Brahms and the next you're trying to play two or three notes without splitting them. When it sinks in that you might not get it back if the retraining doesn't work, man you go low. I felt useless." In this account, a diminished sense of self-worth was also insinuated when comparing current playing ability to past achievements. An additional factor in low self-esteem repeatedly commented upon amongst participants was a lack of positive reinforcement from external sources, as described by Participant 6: *"You've really got to focus and see the wood for the trees when you're doing the exercises. No-one's there to cheer you on and most of the time you just feel like cr*p."* As with the previous section, feelings of disconnection and isolation were associated with decreased self-esteem, pointing to the effects of poor support as a central factor contributing to negative retraining impacts.

In conclusion, the examination of the perceived impact of retraining revealed several positive and negative aspects for musicians. As reported within the quantitative data, retraining periods were extensive, with processes of more than five years reported by 60% of participants. These extended periods give musicians time to gradually reassess their expectations from short-term targets towards pursuing long-term objectives, demonstrating the extent to which the process of retraining can positively affect the ability to adapt to, and endure, significant physical and psychological challenges. The development of psychological resilience, utilising coping mechanisms including redirecting focus and taking deliberate breaks, can also reduce the impact of setbacks during retraining. Musicians also recognise the importance and value of incremental progress during the retraining process, acknowledging the need for patience when faced with unpredictability. Maintaining consistency and daily contact with their instrument through mindful and intentional practice was also recognised as being associated with sustaining skill retention and reducing maladaptive muscle patterns.

Negative impacts of retraining stem from both psychological and structural obstacles. Musicians experience confusion and stagnation due to unclear retraining goals and a lack of clear direction in their retraining. Insufficient support from retraining professionals can worsen these problems, suggesting the need for improved

communication and more structured guidance. Retraining frameworks require improved communication and structured guidance systems. Musicians also experience frequent feelings of isolation demonstrating the impact of retraining on their personal identities and emotional states. They may also experience diminished self-esteem due to their perceived shortcomings and absence of external recognition during their retraining. The analysis demonstrates the dual impact of retraining by revealing how musicians develop and display significant resilience to navigate its challenges, whilst also highlighting the importance of comprehensive support systems to facilitate positive outcomes and mitigate negative experiences.

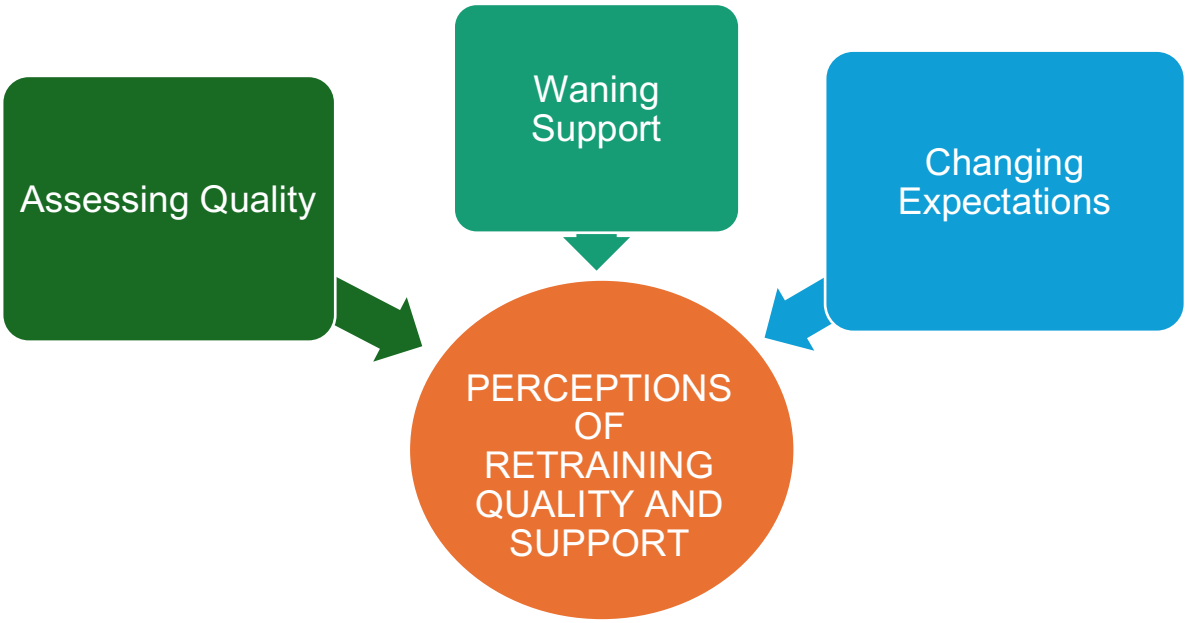
Theme 4: Perceptions of Retraining Quality and Support

(Survey Items 9-12)

The fourth theme contextualises how participants perceive the quality of their retraining and the support they received during and after the process. Most participants rated the quality of retraining methods favourably (refer to figure 22) with mean scores above the neutral midpoint, although neurofeedback approaches did fall below this threshold. Levels of support were perceived as being considerably lower following retraining across all modalities, and overall experiences of retraining exceeded and fell below expectations in roughly equal measure (refer to figure 24).

The following sub-themes further elaborate on these aspects (Figure 26).

Figure 26. Perceptions of Retraining Quality and Support



Sub- theme 1: Assessing the Quality of Retraining

The following section (Table 38) contains the positive and negative quality indicators reported within the qualitative data together with exemplars to support each criterion.

Table 38. Positive and Negative Retraining Quality Indicators.

Concept	**Positive Quality Indicators**	**Negative Quality Indicators**
Communication with Retrainer	Supportive and responsive retrainers, available to answer questions.	A lack of responsiveness from retrainers and perceived lack of interest in maintaining relationships post-retraining.

Retraining Goals	Clearly explained, specific objectives within defined timeframes.	Vague and poorly communicated goals and unclear objectives, leading to confusion and lack of direction.
Emotional Connection to Retraining	Positive and affirming emotional connection with the retrainer.	Impersonal connections with retrainers provoking feelings of isolation and frustration.
Communication of Retraining Content	Well-articulated and structured retraining content.	Poor clarity and poorly elaborated content.
Long-term Retraining Sustainability	Clear, long-term retraining goals reflected in techniques and strategies that are clear, effective, and easily implemented.	Unclear, short-term goals without clear technical or strategic direction, provoking feelings of being adrift and without a plan.

Positive quality evaluations were primarily associated with attentive and supportive retraining experiences, as confirmed by Participant 9: *"I would recommend [redacted] to anybody. They always reply if I need to chat about something, that's the difference."* Conversely, unsupportive retraining experiences were unsurprisingly associated with negative quality evaluations, as described by Participant 3: *"I had so many questions when I got back, but nobody answered them. I was disappointed, yeah... really disappointed with that."*

Unclear objectives and goals were also significant negative factors, particularly when participants did not have a clearly defined way to measure progress or modify strategies in response to rates of progress, as Participant 6 describes*: "It's difficult to*

know what to do next, that's the thing. I definitely needed more guidance." Increased retraining satisfaction was reported when given clear benchmarks to measure advancement, as in the case of Participant 8: *"[Retrainer] was always really attentive with me, right from the start we had targets to get to. We learned a lot together as well, which was rewarding to experience. I learnt so much from [them]."* Collaborative retrainer interaction with the musician, positioning themselves as learner as well as mentor, also contributed to positive evaluation of quality.

Emotional and psychological support from retraining professionals is also considered a benchmark of quality. Negative or sterile emotional experiences were associated with negative quality evaluations. Describing an experience with neurofeedback during their MFD retraining, Participant 9 commented, *"You need somebody there that understands the musician. If it's too clinical then you're just waiting for results and not questioning or feeling anything. For me that's the whole point."* This reinforces the importance to musicians of recognising the impact of psychological stressors upon retraining productivity. In this case, the participant had directly attributed their incompatibility with a retraining approach to a lack of emotional connection. Similarly, Participant 5 recounted their positive experience of a psychological approach to retraining, attributing their continued utilisation of brain-spotting to their emotional connections: *"[Retrainer] is just marvellous to work with. I always feel the improvement after a session; you just feel so supported through the process there's nothing negative about the process at all."*

A further significant negative impact on retraining quality evaluation was poor communication from retrainers during the process. Participant 1 commented on a particularly frustrating experience: *"There's a lot of money that went into not very much really. There was never a clear endgame, so all the exercises were just ongoing in my head. It's weird, I learnt a lot, definitely, but it always felt like I was being told things generally; there wasn't much detail."* Contrastingly, positive communication was associated with accounts in which participants had received clear short- and longer-term guidance that was more personalised and tailored to their individual circumstances, as described by Participant 8: *"One-on-one sessions are so much better. You take in so much more and it's about you; it's not just stuff to listen to and try to absorb."*

Finally, the perceived sustainability of retraining during the longer term was commented upon. In addition to clarity and direction, the memorability and ease of execution of retraining was associated with positive quality assessment, confirmed by Participant 9: *"We build simple exercise daily routines of about twenty/thirty minutes or so. Every now and again we meet and change if necessary."* Together with the ongoing collaboration and support of the retraining professional, this excerpt highlights an example of retraining considered to be sustainable and of high quality. Contrastingly, Participant 3 recounted an experience that they considered to be of low quality and with no longevity: *"I was pretty diligent for a while, but I was stuck with what I had. I hit a wall and left it pretty quickly, to be honest."* The sense of commitment and progression experienced by Participant 9 exemplifies how structured and flexible retraining routines help musicians to remain focused on their goals whilst also encouraging effective and positive retraining experiences. Inflexible and monotonous retraining routines, on the other hand, as recounted by Participant 3, contribute to unsatisfactory experiences and waning motivation. The "hitting a wall" sentiment confirms the need for retraining to be adaptable to personal development and changing requirements. The continuous exchange between retraining professionals and musicians establishes a flexible and creative dynamic, confirming that adaptable and personalised retraining is associated with positive experiences and higher quality ratings amongst musicians.

Sub-Theme 2: Waning Support

As reported in the qualitative results, substantial decreases in post-retraining support were noted across different retraining modalities (refer to Table 26), implying that musicians regularly find themselves processing their retraining with limited advice or guidance. Causes of waning ongoing support were attributed to the following factors:

1. A Lack of Structured Follow-up: The absence of protocols for maintaining ongoing support led to communication breakdowns between retrainer and client. Participant 3 reported, *"I didn't speak with [redacted] again. I was just sort of left to figure it out by myself, which was really not what I was expecting. I was really disappointed not to meet again."* Feelings of abandonment and resentment were also

evident, as described by Participant 8: *"It doesn't take much to answer an email, right? Everything was so impersonal afterwards. No-one appreciates that, right?"*

2. Resource Constraints: The significant client load of some retraining professionals can result in limited availability. Participant 4 reported, *"There were a lot of us just in our group. Multiply that several times, there's no way [retrainer] could respond to all of us."* Additionally, a lack of prompt response may demotivate some musicians, as demonstrated by Participant 9: *"I had so many questions but that's not working via email. I needed one-to-one meetings which wasn't going to happen any time soon."* Financial constraints are also a factor, as described by Participant 8: *"I would like to keep working and discuss how things have gone but I simply can't afford it. There's no other way though."* Musicians may have invested considerably to consult or work with a particular professional, but high retrainer demand may limit availability without further investment.

3. Poor Support Effectiveness: Limited support effectiveness makes musicians feel that they do not need to seek continued help, as experienced by Participant 9: *"I got instructions on how to do some of the exercises we learnt, but it doesn't help that much without being there in person."* Again, a lack of effective signposting to alternative support sources was also cited by Participant 6: *"I made solid contacts from the [retraining] sessions. We talk sometimes and swap our tales, and that helps some, but no-one has had any more contact with [retrainer]."*

Restricted access to post-retraining support reveals a significant barrier to maintaining the benefits of retraining. Ensuring that care and post-retraining engagement continues is fundamental to sustaining the long-term benefits of the process. Therefore, improving support following retraining through structured channels of communication and correspondence is a fundamental step in improving the quality and effectiveness of the retraining experience.

Sub-Theme 3: Changing Expectations

Coming to terms with the time frame of the retraining process was the principal factor affecting retraining expectations, with musicians re-evaluating their personal goals to

fit with their reality, as described by Participant 5: *"I pretty quickly realised how long it would take and what I was in for. There is no quick-quick way out, but you have to go for it if you want to improve."* In addition, high expectations of retraining, including expecting complete symptom resolution, prompted fundamental shifts in thinking and understanding towards the process, as experienced by Participant 8: *"For the money I was expecting more. What, I don't know really. I know that it's not a magic bullet or anything, but I wish I'd known that in advance, you know?"* Each example confirms a lack of prior understanding of retraining that reflects broader deficiencies in awareness, highlighting the need to provide musicians with clear information about the processes they will undertake and their aims and objectives.

Participants who reported retraining experiences that exceeded their expectations during the qualitative phase (n=3) were extremely positive about their retrainers, as recounted by Participant 1: *"[Retrainer] had me playing again in the first session. [Redacted] told me to let the tremor happen. It was such a relief to hear that. It was a magical experience for me and I'm so grateful for it."* Similarly, the following quote describes an almost reverential account of brain-spotting: *"It's wonderful, really. Every time I played I'd find another spot, work through it, and I'd be freer. [Redacted] has been my saviour"* (Participant 7). Contrastingly, those who had had experiences of retraining that had fallen short of their expectations were particularly critical of their retrainers: *"Everything is just a repeat of something else really, that's the problem. You end up knowing a lot about not a lot"* (Participant 7).

What is clear from the data is that retraining both exceeds and fails expectations in similar quantities amongst musicians. The overall perception is neither overwhelmingly positive nor negative, confirming that rehabilitation utilising retraining is clearly beneficial, yet there is room for improvement. There is a clear need to accurately define the aims and objectives of retraining, to improve support throughout the process, and to continue to acknowledge the highly individualised nature of retraining and the need for bespoke approaches to its implementation.

5.6 DISCUSSION

As musicians with dystonia rehabilitate, it is important to understand the challenges that they face and how we can mitigate the barriers that exist, maximising their chances of achieving positive outcomes. The first, and arguably one of the most significant obstacles for musicians, is the process of diagnosis, as confirmed by participants in this study. The literature confirms frequent misdiagnosis of dystonias due to factors including confusion with other co-morbid conditions such as depression and anxiety, neck sprain or whiplash (in cases of cervical dystonia), or unrelated orthopaedic pathologies (Beghi et al., 2015; LaHue et al., 2020). Difficulties are also reported in the absence of clearly identifiable biological markers for idiopathic focal dystonias (Beghi et al., 2015), and limited information sharing concerning rare diseases between specialists and general practitioners (Smit et al., 2021). This is further compounded by limited professional training in occupational health problems (Bertram & Williams, 2016), including those of performing musicians.

The diagnostic process is therefore frequently confusing, and protracted delays are common. Considering the association between symptom onset and retraining duration reported in this study, together with the time-sensitive progression of symptoms for musicians confirmed within the literature (Altenmüller & Ioannou, 2016), this makes the situation particularly concerning, as delay directly disrupts rehabilitation and the chances of resuming playing careers. Maximising the potential for recovery requires early intervention (Altenmüller et al., 2014) in order to reduce delays and improve recovery processes. Therefore, increasing awareness and understanding of the condition is a necessary step in improving rehabilitation. This study advocates for increasing awareness of MFD and treatment options beyond medication-based care for both musicians and medical professionals. In the case of the medical community, this would necessitate improving and expanding a working knowledge of idiopathic dystonias amongst non–movement disorder-specialised physicians. For musicians, the development and careful inclusion of MFD-specific information within educative programmes of performance-related health (PRH), and within professional performance organisations. In both cases, clear and prompt signposting to relevant

sources of information and help, including PAM institutions, could help to reduce delays in diagnoses and improve long-term retraining outcomes.

A further concern for musicians during the diagnostic process, also reported in this study, is a lack of professional recognition of the psychological and psychosocial implications of MFD. The literature confirms significant psychological effects on musicians that include anxiety (Enders et al., 2011; Jabusch & Altenmüller, 2004), stress (Gowling, 2020; Ioannou et al., 2016a, 2016b), depression (Lewis et al., 2008) and trauma (Détári et al., 2022; Schneider et al., 2021). The diagnostic process is a pinch point for these effects and highlights the pressing need for medical professionals to be more aware of, and sensitive to, the significant psychological and psychosocial effects of a diagnosis of focal dystonia upon patient wellbeing (Gowling, 2020; A. Lee et al., 2015; Morgan et al., 2021). It also confirms the need for clear signposting to, or referral for, psychological evaluation and support at the time of diagnosis.

Supporting Retraining Selection

Stimulating self-agency during retraining is also an important step in improving rehabilitation outcomes. Self-determination theory states that people are inherently driven to grow and evolve. For this to occur, people need to feel in control of their actions (autonomy), be effective and capable in their actions (competence), and have meaningful connections with others (relatedness) (Ryan & Deci, 2002). Musicians facing MFD are, by the condition's definition, suffering from a loss of physical control and autonomy. Their competence is also directly affected by the physical effects of their MFD, as are connections with employers and colleagues. Therefore, musicians are understandably at a psychological low as they begin to assess their retraining options, and it can be assumed that considerable intrinsic motivation is required to navigate the initial stages of rehabilitation. Mitigation of negative effects upon intrinsic motivation—such as pressure and stress (Eubank & Gilbourne, 2003), comparison and competition (Garcia et al., 2013), or incompatibility with personal values (Appelgren et al., 2019; Matschke & Fehr, 2017)—are therefore important elements in helping musicians navigate the process. This once again emphasises the importance of providing psychological support to newly diagnosed musicians and also draws

attention to the importance of clear guidance and shared experiences in encouraging and motivating musicians in their retraining selections.

Utilising Retraining Combinations

Current studies into the utilisation of multiple retraining methods include the effects of constraint-induced therapy and motor control retraining (Berque et al., 2010), and combinations of mirror therapy, sensory feedback, constraint-induced therapy, sensory motor retuning, differential learning, and slow-down movements (Ackermann & Altenmüller, 2021; Butler et al., 2025). A large proportion of participants (80%) reported the utilisation of one or two retraining methods (40% for one method, and 40% for two methods), with an average of 1.94 methods being utilised across the sample, suggesting a tendency amongst participants for dual-method approaches. Although no correlations were statistically confirmed, the quantitative results showed favourability towards the inclusion of self-developed approaches in conjunction with either neuroplastic or psychological approaches. Similarly, complementary forms of retraining were also utilised more frequently with these two approaches. This is in contrast to sensorimotor retraining and neurofeedback, both of which were utilised in combination to a far lesser extent.

The quantitative data also confirmed considerable instrumental group preferences for particular retraining approaches, also confirmed in the literature (Catellani et al., 2024). For example, keyboard instrumentalists were associated with the lowest utilisation of psychological approaches at 15.3%, compared to 35.7% of brass instrumentalists (refer to Figure 17e), and brass instrumentalists were associated with the lowest utilisation of neuroplastic retraining at 21.4% compared to 70% of bowed strings (refer to Figure 17b). However, qualitative data also confirmed clear differences in retraining preferences connected with the ontological position of musicians towards the causes of MFD. Although the qualitative sample was small, a tendency to pigeonhole the condition into either being a physical or mental problem, rather than acknowledging the interaction of both, was observed. Additionally, participants reported frequently investing financially and emotionally into the approaches of particular practitioners and therapists, contributing to the possibility of cognitive dissonance, or a “guru” effect, limiting their receptiveness to other retraining possibilities.

Retraining Quality, Support, and Managing Expectations.

Each retraining modality examined within this study, with the exception of neurofeedback approaches, registered average quality scores slightly above the midpoint value of 3 (neither high nor low quality). Musicians gauged the quality of their retraining upon factors including their working relationship with a retrainer, clarity of aims and objectives, and levels of support. Several studies have confirmed the benefit of utilising constructivist learning theory in the delivery of health-related interventions (Areskoug Josefsson & Andersson, 2017; Patton et al., 2013; Rojas et al., 2022). As reported in this study, similar person-centred approaches to retraining are also associated with positive experiences of retraining and higher quality ratings. Therefore, it can be inferred that more impersonal or formulaic approaches to retraining are perceived as being of lower quality and associated with less satisfactory levels of ongoing support.

A lack of post-retraining session support experienced across each of the retraining modalities examined in this study also draws attention to a further area of concern. Musicians frequently report feeling lost, or even abandoned, following retraining, experiencing isolation, confusion, and disappointment. There are practical reasons as to why this may occur, including high client turnover amongst retraining professionals or unviable financial requirements. What is evident is that there is a need for improved ongoing support following retraining. As reported in this study, to mitigate the effects of isolation and confusion, musicians frequently engage with online groups and communities. The benefits of these include learning coping strategies, overcoming isolation, learning from successful role models, building support networks, feeling more in control, and learning about available services (Tanis, 2007; Worrall et al., 2018). However, the negative effects of misguided, unhelpful, or even harmful statements cannot be underestimated (Galinsky & Schopler, 2013). To the author's knowledge, as of 2025, online social media platforms including Facebook and Instagram remain the principal channels of general discussion or chat for musicians with dystonia. To address the question of improving ongoing support, this study advocates for the creation of an official MFD discussion or chat forum that is affiliated with a recognised PAM organisation. In doing so, this would permit musicians to

actively engage with colleagues and PAM professionals, to share their experiences and concerns, whilst also minimising the effects of false or misleading information.

(For Study Limitations please refer to section 7.7 – Study 2)

5.7 Conclusions

This research demonstrates the many challenges that dystonic musicians face during their retraining journeys, highlighting an urgent need for better diagnostic experiences, retraining methodologies, and improved psychological support. The complexities of diagnosing movement disorders that can contribute to delayed or repeated misdiagnosis demonstrate the need for medical professionals and musicians to increase their awareness of the condition. Enhancing training amongst non–movement specialist physicians and incorporating MFD-specific education into performance-related health programmes are important steps in overcoming current barriers to achieving clear and prompt diagnosis and signposting to appropriate forms of rehabilitation.

The psychological impact of a diagnosis of MFD also requires improved understanding amongst professionals, enabling them to handle the emotional and psychosocial aspects of the condition with sensitivity, safeguarding musicians' mental health. This study advocates for proactive measures to ensure that musicians have access to psychological support from the moment of diagnosis, helping them to develop resilience and a sense of agency throughout their rehabilitation.

The research also indicates that musicians increasingly prefer dual method retraining strategies, demonstrating the need for ever more personalised approaches to retraining. Standardised retraining programmes must reflect this need and adapt to incorporate the individual needs of both the physical and psychological perspectives of musicians. Strengthening the retrainer–musician partnership enables the creation of more effective personalised retraining experiences that address individual requirements and preferences.

Finally, the study promotes the creation of official support and discussion forums for musicians with dystonia. Such platforms, affiliated with recognised PAM organisations, would create spaces for productive exchanges whilst also improving resource sharing and minimising misinformation. By addressing this gap, stakeholders can substantially enhance the rehabilitation outcomes for dystonic musicians, enabling them to restore their artistic profession and identity. The research provides essential insight into the musicians' experience of retraining, guiding future research and interventions towards improving the care and support of musicians confronting MFD.

CHAPTER 6 - Study 3:

Investigating the Impact of Self-Developed Retraining in Musicians' Focal Dystonia Rehabilitation: An In-Depth Thematic Analysis

6.1 ABSTRACT

This qualitative study explores the experiences of musicians who utilise self-developed approaches to retraining for rehabilitation from musicians' focal dystonia (MFD). In-depth thematic analysis of study participants' accounts reveals the complexities of dealing with diagnosis and the resourcefulness of affected musicians as they navigate their retraining processes. The findings are organised into four main themes which explore: (1) "Personal Journeys of Adaptation", highlighting musicians' commitment to MFD rehabilitation through self-developed approaches to retraining; (2) "Innovation and Creativity in Retraining", demonstrating the combination of physical and psychological strategies incorporated into the retraining approaches of participants; (3) "The Emotional Impact of Self-Developed Retraining", which demonstrates how emotional resilience functions as a vital element in the retraining process, and; (4) "Retrospective Insights", presenting musicians' reflections upon their experiences, insights into their retraining and lessons learnt. Findings confirm the importance of acknowledging and supporting the autonomous rehabilitation efforts of musicians with MFD, promoting a broader understanding of the retraining experience and the development of more dynamic, personalised retraining approaches and interventions.

6.2 INTRODUCTION

Musicians' focal dystonia (MFD) is a focal form of the hyperkinetic movement disorder dystonia, affecting an estimated 1% of professional musicians worldwide (Altenmuller

& Jabusch, 2009). Symptoms manifest as involuntary muscle spasms, sometimes accompanied by dystonic tremor (A. Lee, K. Tominaga, et al., 2015), leading to impairment of the fine motor skills required to play an instrument. In turn, this leads to a reduction in performance capabilities and disruption in musical careers. Standard medical care for MFD includes botulinum toxin injections or anticholinergic medications that offer palliative relief of symptoms. However, for many, undesirable side effects, including excessive muscle weakness often become intolerable, causing many to cease treatment over time (Ackermann & Altenmüller, 2021; Schuele et al., 2005).

As the multi-factorial nature of MFD has been revealed, management of the condition has led to a shift from primarily pharmaceutical intervention towards more integrated and holistic treatment approaches. Consequently, the search for effective MFD management has drawn considerable attention from researchers across various fields and disciplines. Studies address the correction of maladaptive motor patterns (Prudente et al., 2018), sensorimotor retuning (Candia et al., 2002; Yoshie et al., 2015), orthotic splinting (Kenny, 2014; Schuele & Lederman, 2004), psychological interventions (Aman et al., 2015; Chiaramonte & Vecchio, 2021; van Vugt et al., 2014), and programmes of specific movement exercises (Butler & Rosenkranz, 2016; Furuya & Altenmuller, 2015). More recent research advancements also advocate for ever more personalised approaches to retraining (Butler et al., 2025), acknowledging the role of physiological, psychological, and psychosocial factors in the manifestation of the condition (Détári et al., 2022), and suggesting the need for a more streamlined path to rehabilitation that attends to the individual needs of the musician.

Understanding how dystonic musicians develop and adapt their bespoke retraining methods to fit their specific retraining needs remains largely unexplored. As musicians are increasingly empowered to explore rehabilitation methods that match their individual physical needs and psychological settings (Altenmüller & Jabusch, 2010; Détári, 2023), investigating what drives and sustains the self-developed retraining approaches that dystonic musicians use, becomes increasingly important. To address this question, this study utilises in-depth thematic analysis (Braun & Clarke, 2021) to develop a narrative of the combined experiences of musicians, expanding the

knowledge about musician-driven retraining methods, whilst also providing educational and health professionals with insights into how musicians with MFD currently execute and experience their bespoke retraining.

6.3 RESEARCH AIMS

The research investigates musicians' strategies, perceptions and experiences with their self-developed retraining methods for MFD, exploring implications for the development of more bespoke retraining approaches. The study contains four main objectives which are as follows:

i. To examine the methods, strategies and motivations of dystonic musicians as they navigate self-developed retraining.

ii. To explore perceptions of self-developed retraining amongst dystonic musicians.

iii. To understand the barriers and enablers experienced during self-developed retraining.

iv. To gain insight and discover lessons learnt by musicians through utilising self-developed approaches to retraining.

(Please refer to Chapter 3, Section 3.5 for the study methodology.)

6.4 FINDINGS

The findings of the thematic analysis are presented within four interconnected themes. A brief overview of each theme follows, before presenting the thematic framework for the research (Table 39). Following this, a thorough analysis of the data set is conducted, contextualising each of the themes and connected sub-themes.

Introduction to the four main themes:

1. **Personal Journeys of Adaptation**

   This theme reveals how dystonic musicians adapt during their self-developed retraining journeys, examining diagnostic experiences and the strategies employed to deal with delay and confusion during the rehabilitation process. Participant accounts confirm significant resilience to setbacks and the development of a broader understanding of MFD and its mechanisms. Creative problem-solving and adjusting to longer-term retraining goals emerge as significant aspects of the retraining journey.

2. **Innovation and Creativity in Retraining:**

   Dystonic musicians that implement self-developed retraining approaches adapt and combine both psychological and physiological methods to produce individualised mind-body approaches to their retraining. This theme examines how they are used within the make-up of participants' retraining approaches and contextualises the rationales for their integration.

3. **The Emotional Impact of Self-Developed Retraining:**

   Emotional factors of MFD are directly linked to the process of retraining. This theme presents accounts of the significance of both positive and negative emotions upon retraining efforts, highlighting the importance of emotional resilience. It also reinforces the need for more robust psychological support systems for dystonic musicians as they navigate their retraining.

4. **Retrospective Insights:**

   This theme examines reflections of dystonic musicians towards their self-developed retraining, highlighting changes in professional and personal outlook towards music-making, and a broader understanding of MFD. It also discusses lessons learnt during the retraining process and how participants' experiences serve as guidance for others. A collective desire to share acquired knowledge of managing MFD becomes evident through participants' accounts.

Table 39 outlines the thematic framework of the research, presenting the four themes, their sub-themes, and how their relations to each other within the framework.

Table 39. Thematic Framework – Study 3

Main Themes	Sub-Themes	Related Themes	Description of Interconnections
Personal Journeys of Adaptation	The Impact of Diagnosis	The Emotional and Psychological Impact	The process of receiving a diagnosis can significantly influence musicians' emotional health and coping mechanisms.
	Coping Strategies	The Emotional and Psychological Impact	Musicians develop coping strategies based upon their emotional responses to MFD, which shape their journeys of adaptation.

Innovation and Creativity in Retraining	Psychological approaches in Self-Developed Retraining	Personal Journeys of Adaptation	Emotional responses to MFD both hamper and enhance the willingness to experiment with multiple retraining methods.
	Physiological approaches in Self-Developed Retraining	Personal Journeys of Adaptation	Musicians' personal experiences inform the techniques they develop to retrain and are reflected in their adaptation.
	Integrating Approaches	Personal Journeys of Adaptation	Autonomy in retraining allows musicians to combine different retraining approaches to produce their own, unique approaches.

The Emotional Impact of Self-Developed Retraining	Emotional Transition	Personal Journeys of Adaptation	Retraining stimulates emotional transition, working towards less competitive and more holistic approaches to music making.
	Effects on Wellbeing	Innovation and Creativity in Retraining	A positive emotional state enhances creativity in developing personalised retraining approaches, as musicians are more open to experimentation.
Retrospective Insight	Self-Reflection	Personal Journeys of Adaptation	Musicians reflect on their retraining journeys, considering their previous training methods and how they might have approached their playing differently.

	Lessons learnt	The Psychological Impact of Self-Developed Retraining	Insights gained from musicians' experience with MFD can lead to personal growth and a better understanding of neurological playing health.

6.4.1 Theme 1 - Personal Journeys of Adaptation

Flexibility in coping with both the physical and psychological challenges of MFD is reported as a necessity by musicians. The diagnostic process often provokes negative experiences which impact motivation, but in dealing with these issues, participants develop resilience, resulting in frequently positive long-term motivational effects. The following three sub-themes detail the most commonly discussed topics related to adapting to MFD and rehabilitation, including the impact of diagnosis, issues of motivation, and coping strategies.

Sub-Theme 1 – Impact of Diagnosis

The diagnostic process is considered a significant "pinch-point" in the retraining journeys of musicians. As reported in Study 2 of this PhD, musicians frequently describe their diagnostic experiences in unsatisfactory terms, encountering numerous problems and obstacles. The following table (Table 40) shows the frequency of comments shared across the data set concerning the diagnostic process.

Table 40. Commonly Reported Issues During the Diagnostic Process

Diagnostic Experiences	Citations (n)
Delay	14
No prior awareness of MFD	11
Negative Interactions with Medical Professionals	10
Confusion about Next Steps to Take	10
Lack of Support	7
Lack of Follow-up	6
Misdiagnosis	5
Unsatisfactory Treatment Plans	5

Musicians describe frequently troubling interactions with healthcare professionals including incorrect diagnoses and limited interest or engagement with their problems. Significant diagnostic delays were reported together with accounts of unsatisfactory treatment plans and poor follow-up procedures. Participants conveyed frustration and powerlessness during the process, culminating in resentment and apathy.

The following interview excerpts demonstrate the negative encounters that musicians can experience with medical practitioners during the process of diagnosis. Participant 2 expressed their frustration at the absence of diagnostic consensus and the subsequent confusion this provoked: *“I was actually only diagnosed last year. I have had so many tests over the past few years, and I was repeatedly told I was physically fine- that it was psychological. I kind of found out first on my own that it wasn’t.”*

Two main points are highlighted: Firstly, that dystonic musicians can face prolonged and confusing routes to diagnosis; and secondly, that the effects of diagnostic

uncertainty and subsequent delays significantly undermine rehabilitation efforts. In this case, intuition prompted further medical investigation and an eventual diagnosis, but only following a considerable period of confusion and inaction.

An account from Participant 7 demonstrates a further troublesome scenario in which musicians receive little or no signposting to non-pharmacological treatment approaches for their MFD: *"I finally saw a neuro [neurologist] who told me what it was, but then she lost interest. I didn't want Botox, so she suggested I do some physio or something. That was it."* Experiencing medical disinterest, including inactivity in helping to find management solutions effectively closes the medically signposted route to retraining. The casual suggestion of physiotherapy, creates an impression of disengagement, dismissing the specific needs of the musician in favour of a "one-size fits all" generic approach to treatment.

Even more profound accounts of disengagement were also reported, creating situations of disappointment, anxiety, and even despair, as described by Participant 9: *"He just said to do something else. I thought to myself, 'Get me out of here.' It's humiliating, you know. To them, it's like playing is a hobby. They suggest you do something else and stop complaining."* In this instance, the medical professional not only demonstrated a dismissive attitude towards the professional work of a dystonic musician but also displayed a failure to understand the central role of music-making in musicians' identities, which devalues and, to some extent, dehumanises the situation of already potentially anxious individuals.

Medical signposting to treatment and therapies is often limited not only due to professional disengagement with the condition, but also in part, due to a lack of awareness. Several participants in the study reported experiencing lack of awareness from medical professionals during their diagnostic process as the following excerpt from Participant 1 illustrates the issue: "The family doctor had no idea what was going on, so I got a referral to an orthopaedic specialist. I wasted a lot of time for nothing." This confirms the problem of information sharing between professionals, which can frequently leave musicians with no clear signposting to treatments or therapies. In turn, this obliges musicians to engage in autonomous research into their condition, creating

delay, exacerbating emotional distress, and potentially aggravating symptom development, as described by Participant 2: “The only suggestion at the clinic was Botox [botulinum toxin injections]. No one was there to do it, and I was quickly going downhill, so I left. I thought, ‘Sod it; I’m on my own.’” Participant 7 echoed this sentiment and also experienced significant effects on their self-esteem: “I had no guidance and felt desperate; my confidence was totally shot at this point. I wasn’t convinced retraining was for me and was really reluctant, to be honest.”

For many musicians, the diagnostic stage represents a moment of fragility which may compound feelings of negativity. Participants commented upon experiencing a range of negative emotions including desperation, isolation, confusion, and frustration which can significantly affect both motivational drive and the capacity to successfully engage with retraining. The current lack of structured guidance leaves musicians feeling professionally under-supported, frequently navigating retraining decisions via trial-and-error methods. This lack of certainty also creates discouragement which can significantly diminish musicians' confidence and self-esteem as well as being emotionally debilitating to musicians, as described by Participant 4: *“Every time I played; I was expecting it to fail. Musically, I was empty really, no idea what to do at the time. Like a student again with shaky fingers, I suppose.”*

However, as confirmed by contrasting accounts, being subject to emotional distress, and an absence of professional support during diagnosis also had an paradoxically positive effect on motivation, incentivising the initiation of self-developed retraining rather than being seen as a hindrance, as the following excerpt from Participant 3 describes: “*Waiting for my doctor wasn't helpful. Feeling useless doesn’t help either. I just got my f*** you hat on and went for it.”* This conveys proactivity instigated by negative diagnostic experience and assuming ownership and positive control of rehabilitation. Resilient mindsets transform bad experiences into opportunities, but the incidence of profound frustration and emotional distress recounted during the diagnostic phase highlights significant shortcomings that exist in the initial phase of rehabilitation for dystonic musicians.

Sub-Theme 2 – Coping Strategies

The lack of emotional support encountered along the retraining journey timeline means that robust personal coping strategies are necessary. The following sub-theme reports how musicians cope with the process and the barriers that they face.

1. **Acceptance and Resilience:** The shift to proactive action requires musicians to both understand and work through their emotional responses to diagnosis, whilst also accepting the reality of rehabilitation. Actively controlling stress and anxiety despite uncertainty and concerns over recovery, is demonstrated by Participant 1: *"I think that we all have a sink or swim moment, right? I just cancelled all performances and started playing from scratch really. It's a leap of faith, but what's the alternative?"* This demonstrates the abrupt and profound changes that musicians are forced to accept as they adjust to their dystonic states.

2. **Self- Developed Exploration and Innovation:** Musicians that develop their own approaches to retraining consistently demonstrate initiative in searching for solutions. Trial-and-error approaches, adaption of previously utilised methods and the introduction of self-developed exercises were repeatedly related by study participants, as described by Participant 12: *"I'm always changing things up. Sometimes I change a fingering or work with a new position. It might work, who knows? If I do the same thing though every day, then I feel things start to drop off."* Avoiding excessive repetition is a key element for dystonic musicians as they retrain, developing more flexible nervous system responses to movement patterns and reducing stereotyped responses (Rosset-Llobet & Fàbregas-Molas, 2018). Experiencing improvements such as these was mentioned frequently, with musicians describing, "mixing things up" and "keeping myself guessing" as they gain understanding that repeating set patterns of retraining, whether in the form of instrument-specific exercises, or the use of other holistic approaches such as meditation or tai chi, should be fluid, rather than a study "regime." Reacting with proactivity, researching extensively and experimentation were also traits common to participants in the study.

Musicians who develop their own strategies are predominantly independent thinkers, as demonstrated in the following excerpt from Participant 11: *"I work a lot at improving muscle chain connections. I read a lot about that from [redacted], but there's not much that focuses on dystonic musicians. I've spent a lot of time working on reconnecting big muscles to small ones when I try and play."*

Examples such as these show commitment to the retraining process as well as reinforce the importance of autonomy and self-agency. The motives for the substantial levels of self-agency demonstrated by musicians as they develop their retraining can be described in two categories. Firstly, there is frequent disappointment or distrust attached to previous retraining efforts. Study participants describe previous retraining experiences with specific methods, programmes, or retrainers in both positive and negative terms. However, negative experiences were associated with scepticism and perceptions of poor support and feedback, as described by Participant 5: *"There was no follow-up really. Nothing was really made clear, and I ended up filling in the gaps on my own anyway."* A similar experience was related by Participant 2: *"There was no two-way contact really. You need to take a big leap of faith to believe it'll work."* Secondly, in addition to reacting negatively to experiences of limited emotional connections with retrainers, participants also commented on the limited financial resources and logistical difficulties of retraining, as described by Participant 13: *"I don't have money to burn, and I feel like I wasted a lot for very little. I was doing most of it myself anyway."* Both of these motives for turning to self-developed approaches reflect aspects of dissatisfaction with existing retraining methods. They reflect the personal drive of musicians to find solutions to their MFD and confirm the proactive and motivated attitudes they possess in the face of challenges.

3. **Setting Realistic Goals and Expectations:** The unpredictable nature of retraining requires musicians to establish realistic goals and expectations. A significant step in achieving this was described by Participant 9, commenting, *"I can tell when I'm going in the right direction. I think, why didn't I always do this? You know? I've learnt to enjoy those moments; it's managing the ups and downs that is hard."* Dividing the retraining process into smaller steps, acknowledging the non-linearity of progress, and celebrating incremental achievements were repeatedly commented

upon. Participants described “ignoring the noise” or “keeping your head down” when attempting to effectively ignore long-term, focusing instead upon short-term gains.

Self-awareness and patience are also important elements of successfully adjusting retraining goals. Gradual, subtle changes are internalised and difficult to perceive from the outside. Therefore, external validation of improvement or experiencing clear and dramatic improvements in playing through retraining is infrequent, requiring significant patience and acknowledgement of subtle changes. Participant 9 commented, “*Retraining myself has been like watching my child grow. It’s happening, I know, but most of the time I can’t tell. It’s a very proximal thing.”* The incremental improvements described by participants express the importance of setting realistic expectations. In doing so, musicians reduce the emotional burden of setbacks, acknowledge the non-linearity of retraining, and facilitate positive responses to retraining which facilitate the development of bespoke approaches.

Musicians also acknowledge changes in positionality towards themselves as musicians, as confirmed in this excerpt from Participant 6: “*I can observe myself as I play now without worrying what anyone else thinks. When I was at rock bottom, I could see what I needed to do without freaking out.”* Both excerpts reveal a process of “letting go” to some extent. They also describe pragmatism in response to challenge which reflects the world view of participants in this study. Redefining identify can potentially relieve past pressures, creating new purpose, and a sense of new beginnings. In facing this challenge, musicians demonstrate, and draw upon, significant motivation and resilience, embracing changes in perspective and identity as they retrain.

5. **Developing A Sense of Non-judgemental Self-Observation:** The development of non-judgemental self-observation emerged as a significant coping strategy during retraining, with heightened self-awareness, sensitivity to physical and emotional sensations, and enhanced understanding of mental states all contributing significantly. During this process, compassionate relationships with the self, and non-judgemental observation facilitated the capacity to cope with the complex emotional and physical problems and frustrations of retraining as demonstrated by the following exemplar from Participant 12: “*Practicing self-observation felt like*

taking a step back and becoming my own witness. I stopped judging every mistake as a failure. Instead, I saw them as moments of data. It made the whole endless journey a bit less daunting." Musicians describe learning to understand their present state, recognising to what extent it involves frustration, tension, or physical discomfort without passing judgement, as further elucidated by Participant 5: *"I started by just watching how my body reacted in different playing situations. At first, I was quick to criticise myself, but then I realised that simply noticing what happens in my hands or my breath was powerful. It helped me know when to stop or adjust without feeling guilty."* The practice of mindful observation creates a neutral space which helps musicians recognise patterns and triggers related to their dystonia. Through non-judgemental self-observation, musicians establish a base to experience their retraining with both understanding and gentleness. It develops emotional strength whilst also encouraging a compassionate, patient, and positive mindset towards their rehabilitation. In utilising this approach, musicians can progress in their retraining with more confidence, less anxiety, and the ability to add all experiences, good or bad, to their knowledge base.

Dystonic musicians' journeys of adaptation reflect the difficulties of the diagnostic process and the subsequent development of resilient coping strategies. Study participants expressed various negative emotions and experiences during diagnosis which included frustration, confusion and despair, aggravated by perceptions of insufficient professional help. These adversities motivate engagement with self-developed retraining efforts. Musicians develop acceptance and resilience which enables them to explore new paths of self-discovery whilst also experiencing transformations in their musical identities. The development of personalised strategies combined with realistic goal-setting and non-judgemental self-observation empower musicians, whilst positively transforming negative experiences. The reports demonstrate both the weaknesses in present diagnostic and support systems, and the considerable ability of musicians to develop innovative solutions for themselves. Future supportive frameworks need to establish structured systems, which acknowledge the importance of self-agency in retraining outcomes and emotional health for musicians with dystonia.

6.4.2 Theme 2- Innovation and Creativity in Self-Developed Retraining

The second theme discusses participants' approaches to self-developed retraining, describing the integration of both established methodologies and personal solutions. Both psychological and physiological approaches are adopted, their inclusion reflected in aetiological assumptions made about MFD. The subsequent sub-themes present these approaches, and report how musicians integrate them into their personalised retraining.

Sub-Theme 1: Psychological Approaches to Self-Developed Retraining

Two distinctive psychological approaches to retraining for MFD appear within the literature, those that facilitate calm and relaxed bodily states, and those that address trauma responses. Both were utilised by participants in this study, demonstrating a robust understanding of the mind-body connection as conveyed in the following excerpt from Participant 9: *"I think there is a psychological component as well. I've never really thought that it's a physical thing only."* A similar quote from Participant 3 also describes changing opinions concerning their MFD, gradually acknowledging the psychological effects of the condition during their retraining: *"I started noticing; there was also an emotional connection that had to be addressed. Without getting into that, I was up against it, I think."*

The two prominent strategies utilised by participants in this study, representing both approaches, were brain-spotting and meditation. The following table (Table 41) presents a breakdown of how they were utilised.

Table 41. Commonly Used Psychological Approaches to Self-Developed Retraining

Retraining Type

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	Total (n)
Brain-spotting				X		X	X	X	X	X	X		X	X	9

Meditation	X	X	X		X						X	X	6
Both Approaches					**X**						**X**	**X**	**3**

Brain-Spotting

Brain-spotting aims to process and release trauma by selecting a specific eye position or “spot” to activate areas of the brain that are involved with remembering and processing emotional distress. Positive effects of trauma resolution on rehabilitation from MFD have been shown within the literature (Détári, 2023), and several participants within this study reported symptom improvements that they attributed to brain-spotting techniques. However, empirical studies to measure real effects on MFD, are as of 2025, yet to be conducted.

Accounts of positive effects of brain-spotting were shared by participants, suggesting that for some, the effects of addressing trauma though “spots”, stimulate the physical release of movement, as described by Participant 6:

> *It's helped me discover some difficult things in my past that maybe I was holding on to that kind of like, were maybe tangentially related to the dystonia. I'm not physically blocked when I do some of the exercises now. When I apply the brain spot to the rest of my movement exercises, I usually feel freer movement.*

Participant 11 recounted a similar outcome, experiencing an immediate physical response:

> *My body vibrates when I get a spot. Once or twice, it's lasted for at least twenty minutes or so. I remember regaining trill speed for the first time from one of those. It was like someone had taken the handbrake off in the car or something.*

Both accounts describe significant changes in dystonic symptoms through the focused release of trauma and tension, conveying the importance of brain-spotting in improving their emotional state and playing ability. The literature confirms the reduction of Post-

Traumatic Stress Disorder (PTSD) symptoms using Brain-spotting (Hildebrand et al., 2017), and the role of trauma in as a non-organic factor in the onset of MFD (Détári et al., 2022).

However, musicians also report negative brain-spotting experiences, investing considerable time and money with no perceptible gains, as described by Participant 9: "*I was expecting a magic bullet, I suppose. That hype was short-lived in my case. It's interesting as a therapy looking back after a year of it. It helped with my anxiety I think, but it did nothing for my playing."* Expectations of a "magic bullet" highlight the potential vulnerability of musicians as they search for retraining solutions. Although there are potential benefits, outcomes and experiences vary significantly. This reinforces the fact that retraining needs to be highly individualised, with awareness of a range of options key to building personalised plans of recovery. It also confirms that practitioners and researchers should maintain realistic expectations when utilising or investigating innovative therapies and to reinforce to musicians that recovery is non-linear and strongly influenced by individual circumstances.

Meditation

Two variations of meditation were discussed within the data, mindfulness and guided meditation. Mindfulness focuses upon mentally observing what is happening in the present and observing bodily sensations and state without judgement. It also incorporates breathing control exercises for regulating stress and anxiety. For participants in this study, mindfulness was associated with producing calm mental states prior to practical retraining sessions as described by Participant 3: "Doing *twenty minutes of it [mindfulness] before my slow exercise work, and there you go. I can play stuff better. It makes a big difference."* It also facilitated non-judgemental reactions to retraining, allowing musicians to observe changes in their playing, whilst minimising emotional responses to inadvertent events, as described by Participant 6: *"I easily get frustrated if I think, or maybe over think things, it stops me from ruminating too much and going down rabbit holes, so it's perfect for me."*

Guided meditation on the other hand, involves progressively relaxing muscle groups whilst in a state of rest with the objective of achieving a deep physically and emotionally relaxed state. Participant 11 reported using guided meditation before a retraining session as a pre-cursor to their physical retraining: *"It's pretty time-consuming, I admit. I probably do around an hour a day thereabouts. It's the most important thing for me. A lot of the embouchure work is TMJ [temporomandibular joint] based and it's so good for getting release prior."* In both instances, the technique is clearly understood and utilised to prepare mental state to then facilitate practical retraining. They are incorporated as central elements in retraining rather than as alternative approaches.

Cross utilisation of psychological approaches

Across the data set, n=3 participants confirmed having utilised both approaches in their retraining. Participant 6 offered an interesting insight into their motives for doing so: *"I do mindfulness and mental imagery work first. Then, when I do the practical session afterwards, I brain-spot together with the exercises which focuses everything together."* Participant 13, who also implemented both approaches, commented on the significant effect of working on their emotional response to improve focus: *"Get your mind right and your body responds better. It's not a cure but you feel so much more in control of things. I'm sure that I'm less dystonic now because I think better and don't stress out."* Both exemplars demonstrate the significance that musicians attach to addressing the psychological aspect of their MFD. They also reveal now musicians tailor and adapt these approaches to reinforce their practical retraining, clearly acknowledging their understanding of the condition as multi-factorial.

Sub-Theme 2: Physiological Approaches to Self-Developed Retraining

Physiological approaches to self-developed retraining consisted predominantly of individualised instrument-specific movement exercises (ISMEs). Further techniques were applied to either compliment exercise regimes or as stand-alone approaches used in parallel to exercise regimes. The interview data for utilisation of these approaches amongst participants is displayed in Table 42.

Table 42. Physiological Approaches to Self-Developed Retraining

Retraining Type	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**11**	**12**	**13**	**14**	**Total (n)**
* ISME	X	X	X	X	X	X	X	X	X	X	X	X	X	X	14
Tai Chi		X	X		X	X				X		X			6
Body Mapping				X					X		X				3
Feldenkrais				X										X	2
Alexander Technique												X		X	2
Splinting													X		1

**ISME Instrument-specific Movement Exercises*

Instrument-specific movement exercises (ISMEs) were central to how all participants approached their retraining. The content of these exercises, although specific to the individual instrument of the musician, also had common factors. Firstly, the utilisation of slow-down exercises was reported by all participants. Participant 9 stated, *"I spend a lot of my time always playing things as slowly as I can stand. I get the fingers to react as little as I can."* When asked to suggest as to why this was important to them, they also responded**,** *"I need to think through the whole movement, visualise the joints and muscles and I feel the whole arm not just the hand."* The musician had previously reported having studied Body Mapping during a period of their retraining and was keen to integrate this approach.

Similarly, Participant 14 commented on utilising a slow-down exercise approach, this time including principles of both Alexander technique and the Feldenkrais Method. *"Yeah, it's changing movement patterns when I do the slow work, you know, to stop always doing things the same way, breathing properly as well is a massive help."* In addition to slow-down exercises, two further types were identified within the data,

tension release exercises, and finger pressure discrimination exercises. Participant 2 described utilising both of these approaches in the following excerpt:

> *Just relax doesn't mean a lot. When you go part by part though then you see where you're holding tension. The goal is to not hold down the fingers and freeze, and for me, control string pressure, but I do remember getting cramp in my left leg for a while when I was working on my thumb tension. I was so tense.*

Participant 7 also demonstrated particular understanding of their need to "feel the keys" again, by re-learning to be able to discriminate the pressure they were putting on the keys: *"I realised for myself early on that I couldn't tell how hard I was pressing my fourth finger and when I was releasing it. When you start from minimal touch then you feel the key again which is what I couldn't do."* Three participants reported only using ISMEs as physiological approaches to their retraining. Interestingly each of these participants commented particularly strongly on their utilisation of Brain-spotting as their primary strategy, as commented upon by Participant 7. *"If I don't brain-spot first then I get less out of a session. It's definitely a combination of the two but brain-spotting is a powerful thing for me."*

Amongst the participants that reported using Tai chi together with ISMEs (n=6), integration of approaches was not reported. Commentary concerning the use of Tai chi described a parallel process of learning how to "rebalance" muscles in order to then facilitate their other retraining elements, as described by Participant 2. *"We need to know where our centre is and be balanced inside, then you can start working properly on the playing."* Participant 3 also commented on practicing Tai Chi on a daily basis, whether or not they would be playing their instrument. "*I practice [Tai Chi] almost every day. If I don't, then I don't play that day."* These accounts suggest that for musicians utilising self-developed retraining, ISMEs are integral to the process and are treated both as standalone elements, and incorporated into other body awareness approaches, being considered of particular benefit in combination.

A further common thread that ran through the accounts were the motivations that had led to the inclusion of retraining methods that accompanied ISMEs. A principle factor

was frustration with slow progress as described by Participant 7, discussing their experience with a specialist that had previously prescribed a series of movement exercises: *"Every week I had more questions than answers. It was the lack of clarity, and I really felt underwhelmed by my progress. I was always suggesting things to [retrainer] and I knew that this was a real problem."* In response to this, the participant had independently undertaken a programme of Body Mapping to help them answer their questions. *"I found out about Body Mapping by accident when I was looking for information about thumb joints. I went from there really. If you know how a thumb works, you're halfway there already with the right exercises."*

Participant 1 also shared similar frustrations with their initial training experiences., commenting: *"I need to feel fully connected to my movements, not just going through a sequence of exercises. You don't cure yourself by just treating symptoms."* Having previously practiced tai chi independently of their MFD retraining, they had carried out considerable personal research into developing their exercises for their MFD by adapting exercises from their tai chi:

> *I can really connect the body, so I feel strong. One example that's good to do, balancing work like the "single whip", moving outwards, every limb It's a common tai chi sequence. Then I sit at the piano, repeat and then I play. It lets you feel all the sensations of the hands and fingers on the keys.*

In these cases, previous unsatisfactory experiences had sparked initiative to look into adapting and developing ISMEs to increase their potential effects. Neither participant had abandoned their previous retraining approach but had instead, adapted and extended their utility.

In contrast, others reported developing their retraining without previous experience of organised forms of retraining whatsoever, as described by Participant 6: *"I was just doing everything slowly, by myself. I probably spent a year really going slow at things. It seemed like the right thing to do, oh, and I was also tying fingers together with lollipop sticks and shoelaces."* Participant 13 had also begun alone by implementing slow-down exercises, in this case with no perceived benefit: *"I played everything so slowly,*

it was soul destroying, but I did it anyway, for months at a time, getting nowhere fast to be honest. I wasn't convinced it was a physical problem for me anyway."

These accounts highlight the significant intrinsic motivation of musicians required during the development of their retraining approaches. They demonstrate that musicians that have both undertaken prior retraining and those that have not, are motivated and resilient to setbacks and continue to look for solutions, autonomously. In doing so, they develop a personal understanding of MFD that focuses on their individual needs, rather than investing in approaches to retraining that may not be suitable for them.

Sub-Theme 3: Integrating Approaches

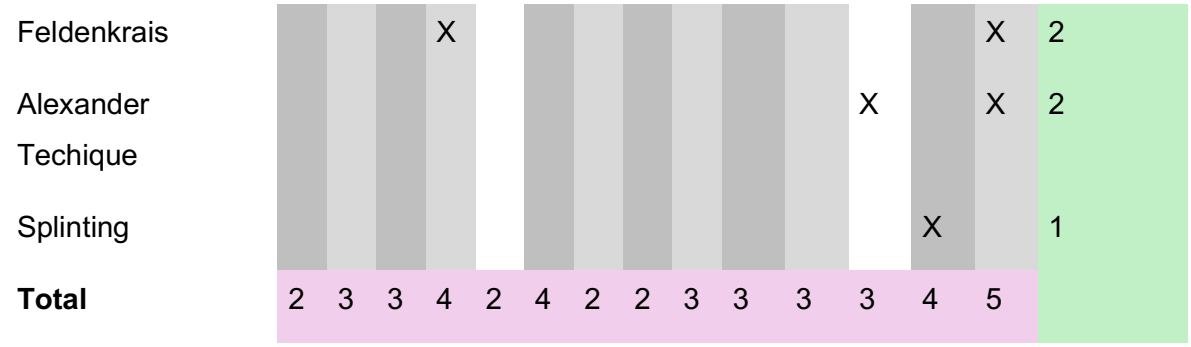
The integration of physiological and psychological approaches to retraining was reported by the majority of participants (n=12). This was encouraging and reveals that musicians that follow their own approaches are particularly open-minded to the inclusion of different strategies, rather than being restricted to specific types of retraining or the influence of a particular practitioner.

The following table (Table 43) shows the combined reported utilisation of retraining across the data set:

Table 43. Combined Psychological and Physiological Approaches to Self-Developed Retraining

Retraining Type

	1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**11**	**12**	**13**	**14**	**Total (n)**
* ISME	X	X	X	X	X	X	X	X	X	X	X	X	X	X	14
Brain-spotting				X		X	X	X	X	X	X		X	X	9
Meditation	X	X	X			X							X	X	6
Tai Chi		X	X		X	X				X		X			6
Body Mapping				X					X		X				3



**ISME Instrument-specific Movement Exercises*

The large number of accounts of the inclusion of brain-spotting in retraining approaches (n=9) is notable and warrants further investigation. So too does the comparatively low reported utilisation of other established methods, including splinting (n=1). The blanket utilisation of ISMEs and their differing modes of inclusion in participants 'retraining reflects the considerable initiative that musicians demonstrate in addressing their MFD. The results from the sample group in the study suggest that musicians that follow self-developed approaches to retraining, approach the process from a standpoint of, "let's see what works for me" rather than having a preconceived notion of what will and will not work, as described by Participant 2: *"I'll give most things a try, really. My thoughts are, there's no cure out there for me, so I'll stir the pot until there is."* A similar mindset was also described by Participant 8: *"If A plus B plus C equals Z, then so be it. I will find a way through it though."*

The selection and adaptation of retraining methods in self-developed approaches to retraining reinforces the notion that personal motivation and resilience drive the process. It also confirms that musicians who retrain in this way think critically about retraining and move away or avoid being exclusively attached to any particular method or philosophy.

6.4.3 Theme 3 - The Emotional Impact of Self-Developed Retraining

The emotional and psychological risk factors associated with MFD onset including heightened anxiety and stress, are widely acknowledged within the literature (Gowling,

2020; Ioannou et al., 2016a, 2016b). Pre-existing emotional and psychological issues were similarly reported by participants in this study. However, emotional changes were also described by participants as their retraining impacted their psychological states. Although the diagnostic process and pre-retraining phases are associated with accounts of emotional distress, anxiety and uncertainty, subsequent stages of retraining revealed emotional positivity and reconciliation. The following two sub-themes present firstly, the emotional transitions reported during the retraining process, and secondly, the emotional support systems utilised to respond to these experiences.

Sub-Theme 1: Emotional Transition

As reported in Theme 1, musicians that undertake self-developed approaches to retraining are well motivated and show considerable resilience to setbacks and challenges. During the initial stages of their retraining processes, anxiety and stress remain significant factors, as the following excerpt by Participant 4 expresses: *"I was [still] really confused after deciding I needed to retrain myself. I needed a quick fix. I remember being so worried all the time. Obviously, this was counter intuitive."* Recognition of an anxious state being "counter intuitive" to their retraining, alludes to a wider understanding of the negative impact of their excessive worries and concerns. The significant impact of stress at the outset of retraining is also described by Participant 7: *"It made me feel so low. The whole experience was horrible for me. I couldn't sleep, I was losing all my work, and my hand wasn't working properly. I wanted to run and hide, let alone confront it."*

In each case, the considerable psychological burden that musicians face at the outset of their retraining is significant. None of the study participants reported receiving emotional support for their concerns at this stage, instead conveying a sense of isolation, as described by Participant 9: *"Nobody knows what you're going through, really. That's life though; what doesn't kill you makes you stronger, right?"* As participant accounts of their retraining moved past the initial stages, reports of heightened states of both anxiety and stress decrease. Accounts of beginning to overcome negative psychological effects emerge, signalling a shift towards motivated and resilient mindsets as described by Participant 2: *"When you can see the big*

picture, that's when all the bad days start to mean less and less." Accounts of gaining wider perspective of the retraining process also reflect the changes observed in participants 'acceptance of short-term setbacks and recognition of longer-term goals. Consequently, more relaxed outlooks emerge as retraining processes progress, as expressed by Participant 1: *"I like to make quiet time to think about what I'm doing or it's just too stressful to focus. When I'm in that state I can try things out without overthinking things."* The importance of calming stressful states for musicians is emphasised and describes a process of letting go and allowing themselves to try things out without judgement.

A further emotional transition reported by musicians is a stage of eliminating self-comparison with peers and colleagues as part of a phase of shedding negative emotional "baggage" as described by Participant 1: *"I compared myself to others and was [always] getting down about it. Then this [dystonia] just slaps you in the face. It's such a waste of time, nobody cares how you play anyway, let's be honest."* A similar realisation was shared by Participant 7: *"We're conditioned to compete and when you can't, you realise it's part of the problem."*

This reflects a "paradigm shift" for many musicians as they describe creating more introspective and relaxed emotional attitudes to their playing. As they reassess their music-making within the context of dealing with MFD, a process of focusing upon retraining and recovery replaces negative external influences. The positive effects on drive and motivation are described by Participant 1: *"When I'm not thinking so much, as if the world just stops speaking for a while, that's when I usually make some real progress."* The "filtering" out of negative distractions is also elaborated by Participant 9: *"I feel a lot more confident in my ability to recover when I don't focus on what's not working, more on the small wins over time."*

The recognition of the value of small gains also represents a process of minimising circumstances or mindsets that disturb the incremental progress of retraining. Although participants entered the retraining process with long-term aims, objectives, and targets, a more measured approach emerged as their work progressed,

suggesting that musicians undergo a significant emotional transition during self-developed retraining, irrespective of their individual methods.

The result of this process of emotional transition is increased self-confidence and a positive environment in which self-developed approaches are utilised. Whereas initially, retraining accounts are associated with a tendency towards negative psychological states, as retraining processes proceed, more positive accounts are evident, reflecting a common transition amongst musicians towards positive psychological outlooks, as confirmed by Participant 14. *"I really worked at getting my head right. There's no point in trying to improve if you're always doubting yourself. I wish I'd had the same outlook before to be honest."* This exemplar is also suggestive of a desire to have changed their emotional connection to their playing prior to their dystonia, which is expanded upon in Theme 4.

The stages of emotional transition discussed in this section are presented in the following table (Table 44).

Table 44. Timeline of Emotional Transition During Self-Developed Retraining Processes

Stage	Description
Initially High Anxiety and Stress	High levels of anxiety and stress upon entering retraining. Feelings of confusion and frustration, leading to worry and fear. Isolation due to lack of emotional support.
Recognising the Importance of Resilience	Strong motivation and resilience despite emotional turmoil.
Shifts Towards Motivation	Decrease in anxiety and stress as retraining progresses. Consistent determination to overcome setbacks and focus on long-term goals.

Development of a Relaxed Mindset	Emergence of a more relaxed outlook. Practicing stress management and experimentation. Reflection becomes a helpful strategy.
Reassessing Self-Comparison	A shift away from comparing themselves to others. Reducing competitiveness with others and focusing on personal recovery.
Improved Self-Confidence	Filtering out negative distractions, gaining confidence in recovery ability. Appreciation of small victories and steady progress.
Emotional Transition Summary	**Significant emotional transitions from anxiety to resilience and motivation.**

The findings of this sub-theme highlight the transformation that musicians undergo emotionally as they progress through their retraining. Significant motivation and resilience are consistently observed, suggesting that musicians that engage in self-developed approaches are able to manage stress and anxiety particularly effectively. The pressure that musicians may feel to find a “quick fix”, and the recognition that such worries may be "counter-intuitive", indicates an awareness of how anxiety can undermine the retraining process. Developing a more introspective, relaxed mindset, that filters external distraction and acknowledges the importance of short-term achievement over long-term goals to improve outcomes, are key factors in dealing with the psychological stressors of MFD. Recognition of these factors is an important step in improving the emotional support that dystonic musicians receive during their retraining.

Sub-Theme 2: Effects on Wellbeing

Positive and negative effects of self-developed retraining on wellbeing were repeatedly reported by participants. An improved sense of mind-body connection, self-confidence

in retraining approaches, and strengthened emotional resilience were associated with positive wellbeing effects, whilst frustration with setbacks, isolation, and inconsistent outcomes were associated with negative effects. The following table (Table 45) presents a list of the commonly cited wellbeing effects before contextualising them within the data.

Table 45. Positive and Negative Wellbeing Effects of Self-Developed Retraining

Positive Wellbeing	Frequency of Comments
Improved Mind-Body Connection	14
Strengthened Emotional Resilience	12
Consistent Motivation	10
Personal Agency	10
Clear retraining goals	6
A sense of Community	4
TOTAL	**56**

Negative Wellbeing	Frequency of Comments
Feelings of Self-Doubt	11
Struggling to Maintain Focus	8
Mental Overload	6
Worrying about the Future	6
TOTAL	**44**

Positive Wellbeing Effects

References to the mind-body connection were the most frequently reported positive wellbeing effects of participants' retraining, associated with improved awareness and understanding of the connection to more favourable emotional states as described by Participant 4: *"When you think about it, you can't separate the two things. When I stopped fighting symptoms and started looking after me as a whole person, I begin to feel better. If I feel better, then I retrain better."* They were also associated with developing positive emotional responses, particularly when dealing with setbacks or periods of stagnation during retraining, as described by Participant 1. *"When I'm calm then I work things out well. I always try to be in a calm state. If I can't then I do something else. I need a positive experience when I play or there's no point."* Recognition of the importance of both the body-mind connection and strengthening emotional resilience to setbacks are both central features of retraining experiences. This confirms the importance of creating a sense of positive wellbeing in order to extract positive outcomes from retraining. It also ensures that the retraining experience is enjoyable to a greater or lesser extent, which is also necessary to maintain motivation throughout the process.

Personal agency and ownership of the retraining process are also consistently described by musicians as a positive wellbeing effect of self-developed retraining. Although the initial motives for this type of retraining may be due to negative events (as referred to in Theme 1), the outcomes demonstrate the value of autonomy and its importance in retraining from MFD. Participant 3 confirms: *"You have to be your own guide and don't rely on anyone else."* The positive effects on self-confidence and motivation are also highlighted by Participant 8. *"I know me. I know I can do and what I can't. It's frustrating sometimes, but I know what I'm doing, I think. I quite like the way I play now."*

A final positive wellbeing effect of self-developed retraining was the development of a sense of community with fellow dystonic musicians. Although not frequently commented upon by study participants, inclusion as participants in this study was reliant upon their engagement with an online group of dystonic musicians. Participant 9 described their online connection to fellow dystonic musicians as, *"an important place to eave drop or share a question or two."* For many, online resources provide information, guidance, and provide signposting. Online discussions, chat boards or

personal connections are also tools for maintaining connection with other musicians, serving to support emotional wellbeing for some, as reported by Participant 1: *"I like to keep connected to people online otherwise I can get pretty fussed up on my own. I like to share my ideas as well."* Acknowledging the importance of community for dystonic musicians, especially those approaching retraining alone, is crucial, for both emotional support and information sharing reasons.

Negative Wellbeing Effects

Four commonly cited contributing factors to negative effects on wellbeing during retraining were identified across the data. Self-doubt during the retraining process was of particular concern to musicians. Self-developed retraining approaches imply individuality. Therefore, external validation of a particular approach to retraining may be neglected, as described by Participant 14. *"I second guess myself a lot of the time. I think that's just part of the process, but when you feel like you don't know what you're doing and there's no-one to ask, it's a lonely place."* Experiencing self-doubt was also associated with thoughts of not being able to "recover", and not understanding "how" to improve, as related by Participant 3: *"It's hard to deal with the dead ends or things that don't work. That's when I'm thinking, should I just give up?"* Other participants remarked on feeling "useless", "feeble" or "not good enough" in response to setbacks in their retraining. To negate feelings of self-doubt, participants also referred to their connections with on-line groups and communities, as expressed by Participant 14. *"I share a lot of my thoughts and ideas online. I get a lot of feedback which I need to have. I'm less unsure about things then"*. However, the possible negative effects of such engagement were also highlighted by Participant 6: *"I need to know what others are doing, especially when I start to lose it. The problem is that there's a lot of pseudo-science out there. You get the "I'm cured" brigade as well. That can be depressing."* Recognising the validity or relevance of shared information or experiences is important and re-enforces the need for accredited sources of science-based information that minimises the possible negative effects of online connections and protects the emotional wellbeing of musicians.

A second negative effect discussed in the data is the ability to maintain focus during retraining. Participants describe situations in which they "overthink" and become

"overwhelmed" by their retraining, as confirmed by Participant 4: *"It's easy to go off-track sometimes. When you have lots of ideas, it's impossible not to."* This stresses an important point, that rather than following instructions or working towards completing prescribed tasks, self-developed approaches represent self-led, autonomously guided processes. that require a great deal of knowledge and drive to execute, as emphasised by Participant 11: *"It's simple getting confused about what to do or which way to go next. It can be exhausting until it's sorted."* As well as highlighting the tiring effects of losing focus, this example also hints at the mental overload that the process can trigger. Altogether, the negative effects of self-developed retraining point to the need to monitor feelings of self-doubt, and to be aware of diminished focus and mental overload.

The overall reported effects on wellbeing of self-developed retraining are positive. They confirm positive effects on resilience, a thorough understanding of the mind-body connection, positive effects on motivation including a greater sense of agency and the ability to set personalised, clear retraining goals.

6.4.4 Theme 4 - Retrospective Insights

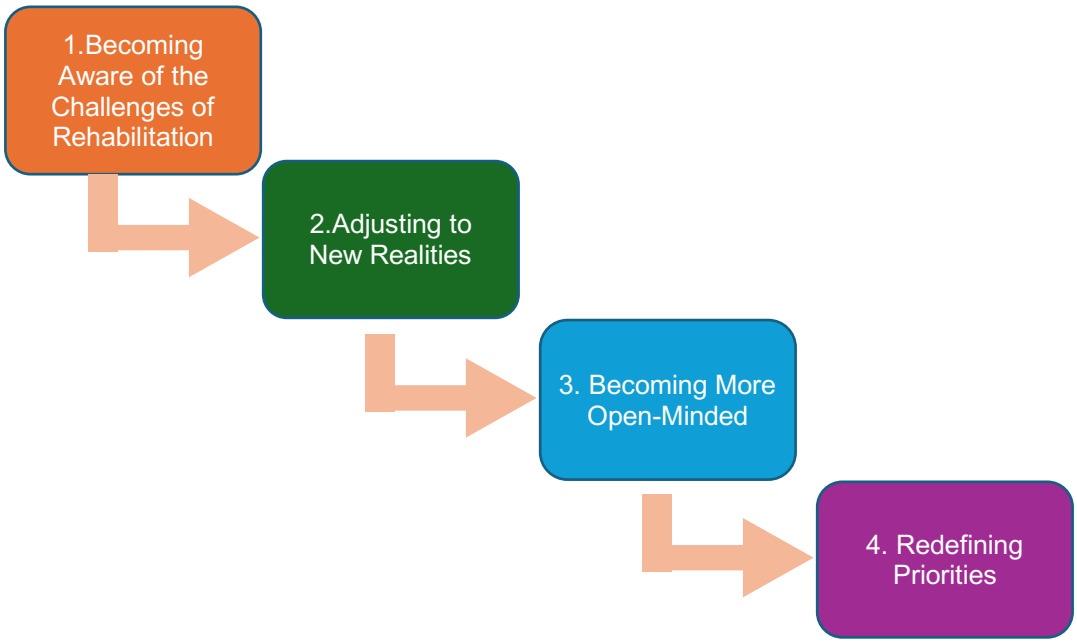
Study participants revealed insights they had gained during their self-developed retraining. The following two sub-themes contextualises their reflections and common lessons learnt from undertaking the process.

Sub-Theme 1: Self-Reflection

Reflection generates deeper understanding of the retraining process, driving further recovery efforts and clarifying methods. Four stages of self-reflection were identified across the data set (Figure 27)., each representing a significant point in the retraining

process. The following section presents the observations of musicians during these reflective stages, drawing attention to commonly shared experiences and perceptions.

Figure 27. Four Stages of Self-Reflection Identified During the Retraining Process



1.Becoming Aware of the Challenges of Rehabilitation

Following diagnosis, musicians report limited awareness of approaches to rehabilitation, including retraining options. Study participants reflected upon difficulties encountered in obtaining appropriate information and guidance after diagnosis, as expressed by Participant 10: *"You're on your own at the beginning. That needs to change. I had no idea what to do, who to turn to."* Participants also discussed the process of taking agency over their situations in the absence of any source of guidance: *"For me, I don't know. I had to be my own boss; I had no choice. In my situation, there was nothing else to do"* (Participant 5).

Reflecting on gaining insight into the challenges of the retraining process itself, participants described significantly underestimating the task at hand, as recounted by Participant 8: *"For me, I don't know. I had to be my own boss; I had no choice. In my situation, there was nothing else to do."* The need for awareness of the complexity of retraining was also reflected upon, as related by Participant 13: *"We should be aware*

of what to expect at the outset. I think about how much time I wasted and sometimes I think, maybe it made me worse".

Poor awareness, as discussed in Theme 1, is attributable in part, to inadequate signposting during the diagnostic process. In addition to reflecting on the personal difficulties they encountered, study participants also commented upon measures they thought could be taken to improve awareness and signposting for others, as described by Participant 4. *"We have to be more open about dystonia and talk about it, particularly in orchestras. When you find out that people knew and didn't think to tell you about it, that's makes my blood boil really."* Participant 13 shared a similar sentiment stating, *"Just get it out there. People that need-to-know ought to know, period."* Both of these excerpts convey the strength of feeling amongst dystonic musicians. It also suggests that the issue of raising awareness of MFD should include consultation with dystonic musicians, particularly those that have experienced and navigated a difficult diagnostic process.

2. Adjusting to New Realities

Changes in mindset experienced during retraining processes were also reflected upon. The central theme was a shift towards more holistic views of rehabilitation, moving away from a single-minded symptom resolution mindset, as confirmed by Participant 8: *"You treat the cause not the symptom. We should do the same with all illnesses, I think."* Participant 2 also commented on the ineffective experience of focusing on a single problem: *"I spent hours, days, trying to get my finger to lift up as it used to. It was so inconsistent as well. It's a whole-body issue, so you treat that then the finger responds."*

A further point of reflection concerning timelines for recovery was commented upon by Participant 1: *"I took six weeks off at the beginning expecting to be back at work for the start of the season. You just have no notion of how long this stuff takes until you're in it."* Not being able to estimate retraining timescales and becoming aware of the long-term nature of the retraining process prompts the removal of time pressures, which also acts to reduce anxieties and stress, as related by Participant 6. *"If you try*

to work to a return date it just gets more and more stressful. You have to let go of time limits. You can't improve under duress."

In addition to letting go of competitive mindsets (as discussed in Theme 3), adopting a position of humility was also reflected on as achieving the same reduction in anxiety and stress, as the following excerpt from Participant 3 suggests: *"You have to be humble. Dystonia doesn't have room for ego."* Participant 7 also reflected the same sentiment: *"If you can't play then your ego is going to take a hit anyway. Just be nice to others."* Confronting MFD obliges musicians to consider their professional position in respect to others. Adopting a less judgemental and more sympathetic stance acts to further reduce pressure, which in turn may positively influence increased personal focus.

3.Becoming More Open-Minded.

As new realities of living with focal dystonia are absorbed, musicians also become more open-minded in their approaches to their music-making. Motives for these changes include several factors including repertoire or genre changes, physical limitations, instrument or technical changes and the retraining process itself. Reflecting on these changes, study participants discussed letting go of previous expectations, as described by Participant 2: *"I am a perfectionist. Letting go of that has been such a relief. Dystonia taught me that."*

A further powerful reflection upon opening the mind up to change through a transformative process was presented by Participant 6: *"I call it ego death. It was really like mourning a real death, and once I got over old "me", things started to work out. It was a necessary process for me; I needed to do it a long time ago."* The process of "ego death" describes a significant period of adjustment and letting go of previous assumptions tied to their musicianship. It demonstrates the extent to which retraining can provoke fundamental and sometimes profound changes in outlook. In this case, this involved a particularly positive transformation reflected upon post-retraining, were changing musical relationships with instruments, as shared by Participant 13: *"I've stopped thinking 'why me?' or 'if only' all the time. If I play some wrong notes I don't care. I enjoy making music for me now for the first time in years."*

Each of these excerpts describe significant positive changes in perceptions towards playing experienced during or following retraining. As observed within the data set, there was little reflection on technical improvement or specific details of the retraining process. Instead, reflection encompasses a broad, more fundamental positive set of changes in attitude and approach, that in turn are attributed to changes in symptoms.

4. Changing Priorities

Participants were asked to reflect upon how their musical priorities had changed following their retraining. More open-minded approaches to music involved fundamental shifts. For example, Participant 7 reported, *"I don't play for everyone else now, I play for me. I know my limits and I'm ok with saying no to things."* Participant 9 also commented on their self-focused approach to performance: *"I really don't care what anybody else thinks nowadays. If I'm making music and enjoying it then that's ok."*

However, musical priorities did not only change for positive reasons. Participant 2 shared how their dystonia had negatively impacted their musical expression: *"The output feels superficial I suppose, like I can only play if I hold back, somehow…but if I become too involved emotionally, the problems come back right away."* Participant 1 also described feeling as though they had sacrificed a degree of musical expression to facilitate the physiological changes of their retraining: *"When I have to think about how I move, I lose the expression. Sometimes I'm playing and then realise that I have no idea what I'm trying to say, musically. That is still the worst thing for me sometimes".*

These negative reflections highlight that for some that return to performance, changes in how they perceive the transmission of their musical expression may feel unsatisfactory, creating a paradox. On the one hand, there may be significant physiological improvement in symptoms, yet on the other, a sensation of superficiality or less ability to produce satisfactory musical interpretation. It suggests a trade-off, in which improved motor control coincides with decreased spontaneity or depth of expression. This indicates that technical change alone is insufficient, suggesting that

the retraining process is not only about restoring technical ability but also reconstructing the musical voice of the musician.

This sub-theme presents reflection as a central pillar and driver of change in self-developed retraining. Musicians progress from limited awareness, signposting and the underestimation of challenges to a more realistic, holistic appraisal of the task, less perfectionistic tendencies, and a reordering of priorities. Common threads emerge including recognising the complexity and duration of retraining, letting go of rigid timelines, and adopting humility to reduce pressure and sustain focus. Participants describe significant shifts in identity and musical relationships with gains in acceptance and enjoyment, offset by perceptions of a reduction in spontaneity or depth of expression as motor control improves. Early signposting, realistic pacing, and shifts in priorities are central to converting difficult changes into long-term improvements.

Sub-Theme 2: Lessons Learnt

This section reflects upon the lessons learnt by musicians during their self-developed retraining. Five recommendations were drawn from the data, each reflecting a repeatedly cited topic reported by study participants. Table 46 presents these recommendations before contextualising them within the data set.

Table 46. Key Insights from the Retraining Journey: Lessons learnt

Lesson Learned	Recommended Action
1. Progress is unpredictable and non-linear.	Concentrate on achieving short-term improvements when developing approaches to retraining, rather than focusing on long-term outcomes.
2. Flexibility and adaptability of retraining is required consistently.	Be aware of, and open to, changes in approaches to retraining throughout the process.

3. Perseverance and motivation are pre-requisites for navigating personalised retraining.	Be persistent, particularly when facing retraining challenges and setbacks and focus upon elements that positively influence motivational.
4. The Mind-Body connection is central to the process.	Acknowledge the multifactorial nature of MFD and explore both psychological and physiological approaches to retraining.
5. Creative Experimentation is Essential	Embrace innovation and experimentation as essential components of retraining.

1. **Unpredictable Progress**: The path to improvement was often described as unpredictable and haphazard by participants who commented repeatedly on the need for patience and preparedness to face unexpected challenges, as confirmed by Participant 8: *"You have to let go of any expectations of getting back [to playing] quickly. The goalposts always need to be nearer, small steps and expect the ups and downs all the time."* A further observation by Participant 6 also framed the unpredictable nature of the process, re-emphasising the need for long-term perseverance: *"I couldn't get anything to stick from one day to the next for a long time. You always stick at it until it comes right."* The importance of appreciating small gains, whilst also persevering in the face of setbacks, were repeatedly commented upon in the data. The accounts confirm the need to accept the complexity of the retraining process, and to adapt responses to both success and failure, accordingly.

2. **Retraining flexibility and Adaptability**: Unpredictability requires substantial adaptability, flexibility, and open-mindedness, as reflected upon by Participant 10. *"I had a lot of false start[s]. Some lasted for ages and ages. It's hard to know when you've got something right, but I've an open mind to most things nowadays to be honest."* Adopting flexible approaches to retraining also permits the inclusion of a

wider range of strategies, as described by Participant 13: *"If something stops working or doesn't work, it's ok. Try something else. You have to know when to stop and step back, but when you have, then try another way."* Achieving this position reflects the stages of transformation commented upon previously within the study, principally the ability to calmly observe, and assess retraining outcomes in the absence of negative emotional responses.

3. **The Importance of Perseverance and Motivation**: Participants repeatedly mentioned the need for sustained effort and determination to overcome setbacks. As discussed previously, consistent motivation is considered vital in achieving meaningful progress. Perseverance was also commented upon within the context of maintaining belief in the implementation of self-developed approaches to retraining. The following excerpt from Participant 2 describes their struggle to filter out unwanted information or guidance that was distracting or counterproductive to their own strategies. *"The problem is that when you talk about your stuff everyone has an opinion. Do this, don't do that…Try this. You have to really stay focused on you and what you're trying to achieve which might not always be clear at the time".* Managing information overload requires mental focus, again drawing attention to the need for psychological preparedness to maintain motivation when confronted with possible distractions or doubts. It also reinforces the importance of clarity of thought and maintaining autonomy and self-agency throughout the process.

4. **The Mind-body Connection:** The mind-body connection in MFD was commented upon frequently as participants navigated their retraining. Despite division in opinion between musicians as to the physical or psychological nature of the condition, participants in this study consistently demonstrated understanding of its multifactorial aetiology. Participant 13 reflected on the need to maintain an open mind as they incorporated brain-spotting techniques into their retraining approach: *"I was always very sceptical of anything like that [Brain-spotting]. I wish I'd understood why it's important to look inwards at yourself, and work on yourself. Otherwise, you're just treating symptoms."* A further example of recognising the importance of being open to the mind-body effects of retraining, was also provided by Participant 10: *"When you learn to deal with your stress, then you can deal with*

the dystonia. The two walk hand in hand in my opinion." The importance of this connection was repeatedly acknowledged and actively addressed by study participants. Further comments included. "getting the head to set up the body properly' and a need to, "understand my emotional reactions to dystonic movements."

Learning to maintain a calm mental state to improve physical responses to retraining was also reflected upon by Participant 3: *"It's no fun worrying about things you try not working out. I always make sure I begin exercise sessions in a calm state. It makes a lot of sense to me nowadays. If I'm feeling stressed out, there's no point."* Participant 12 described their personal difficulty in achieving a calm state prior to retraining but reflected upon the importance of their meditative practices in the process: *"I meditate most days. My challenge has always been to play without losing the effects. There's a lot of discipline needed to do that."* Recognition of mental preparedness prior to retraining sessions demonstrates considerable personal understanding of the effects of psychological states on their retraining processes. It also reflects a broader understanding of the central role of the mind-body connection that develops during the self-developed retraining processes of musicians.

5. **Creative Experimentation:** Each account of creative experimentation within the dataset referred to an autonomous process rather than relying on external guidance or recommendation. Participant 8 commented, *"I spent six months or so studying Moshe's, 'The Feldenkrais Teaching by Handling Method'. We need to wake up all the circuitry before we start to play so that we can really feel movements when we're working on them."* Creativity in approaches to retraining was also discussed by Participant 2. *"Trying new things all the time just keeps me fresh. Even if something works, I'll keep mixing it up. I don't give the dystonia time to catch up anymore."* A*wareness* of the importance of maintaining variance and minimising repetitive practice were understood by participants who also commented on the inclusion of "fluid" and "unplanned and free" retraining sessions. The excerpts demonstrate how musicians develop understanding of the role of creative experimentation during their retraining. This insight is particularly useful when considered within the context of developing approaches to retraining that

reflect understanding of the risk factors of MFD and the need to continually mitigate those risks.

In conclusion, the lessons learnt by musicians during self-developed approaches to retraining reflect processes of self-discovery, resilience, and adaptability. The insights gathered from the participants show a clear understanding of the unpredictability of the process and the importance of having a flexible mindset. The importance of perseverance, sustained motivation, and consistent effort in the face of setbacks is key to achieving meaningful improvement.

6.5 DISCUSSION

This study utilises in-depth thematic analysis to examine the perceptions and experiences of dystonic musicians as they navigate MFD retraining using self-developed approaches. Findings highlight the challenges faced by musicians along these journeys and shed light upon how they navigate the barriers and enablers that they encounter during the process. Interpretations are discussed along a timeline of the retraining process, drawing together elements from the four themes identified during analysis of the data set.

Navigating the diagnostic Process.

Several notable studies examine the effects of emotional state on MFD including stress, anxiety, and trauma, (Schneider et al., 2021) (Ioannou & Altenmuller, 2014; Ioannou et al., 2016a), as well as its effects on wellbeing (A Lee et al., 2015). How these states are affected during the retraining process is less clear. The findings draw attention to the psychological distress that musicians report in response to either misdiagnosis, unclear signposting to treatment, or unsatisfactory/uninterested interactions with medical professionals.

The challenge of dystonia diagnoses for neurologists is acknowledged within the literature (Beghi et al., 2015), as are the limitations of information sharing between doctors and specialists when treating rare conditions (Jog et al., 2011). The limited psychological support and treatment advice offered to musicians in this study also

reflect a wider concern of medical professional understanding of the impact of MFD on careers and wellbeing. It highlights the need for improvement in awareness of the condition amongst medical professionals, recognition of the potential psychological effects of diagnosis, and improved signposting to appropriate sources of emotional support. This particularly important given that positive association has been established between emotional neglect and lower stress resilience in dystonic musicians (Alpheis et al., 2022). It further emphasises the need to evaluate and support the psychological wellbeing of musicians at the point of diagnosis, equipping them with the emotional tools to begin their retraining on the right footing.

Motivation and Resilience

Although emotional neglect during diagnosis is concerning, musicians that follow self-developed approaches demonstrate inherently high levels of both motivation and mental resilience. Resnick et.al describe motivation as the need, drive, or desire to act in a certain way to achieve a certain end (Resnick, 2018). Retraining for MFD is a complex process with no guarantees of success, requiring musicians to adopt strategies and methods that may or may not produce positive outcomes. In response, people facing uncertainties in resolving a problem may engage in meaning-based coping (Folkman et al., 1997), reflecting the emotional development observed in participants from this study as they shift from expectations of short-term symptom resolution to longer-term transformative processes. Retraining becomes part of a more fundamental change in musical identity and professional outlook, involving significant changes in understanding of the process. Meaning-based coping was also central to participants ’accounts of these processes, further highlighting the importance of supporting ongoing resilience and motivation in maintaining musicians ’confidence in the approaches they develop.

Why do Musicians Choose Self-Developed Retraining Approaches?

Financial restrictions and logistical limitations were cited by musicians as barriers to following established programmes of retraining. Unfavourable geographical location and prohibitive travel expenses were also restrictive factors. Consequently, self-developed approaches emerge in part, in response to having restricted access or opportunity to follow structured programmes of training. A further factor to consider is

an inherent understanding by musicians that personalised and self-developed retraining is needed to maximise positive outcomes. Established programmes of retraining may offer generalised, more impersonal approaches, catering for significant numbers of clients. The absence of clear retraining aims and objectives, together with unclear paths to rehabilitation contribute to musicians taking charge of their situation, rather than relying on external instruction.

There are comparisons to be made between the skills acquired by healthy musicians as they develop their playing autonomously following their formative training (without professional instruction), and the autonomous retraining decisions of participants in this study. As musicians transition from student to professional, they increasingly depend on their self-motivation to continue to develop their skills and musical knowledge (Creech et al., 2008). Likewise, study participants demonstrate considerable self-motivation, seeking out learning resources that match their individual goals and needs, reflecting the autonomous decisions made by musicians in this study as they navigate retraining. As autonomous learning is linked to improved knowledge retention (Bonneville-Roussy & Evans, 2024) and enhanced critical thinking (Cheng et al., 2020), it suggests that strategies for MFD retraining that encourage autonomy and support critical thinking, may be increasingly beneficial in comparison to those that offer more formulaic and impersonal approaches.

What Methods do Musicians Follow in Their Self-developed Approaches?

Participants in this study reported using a mixture of both physiological and psychological methods in their approaches to retraining, demonstrating awareness of the mind-body connection of MFD (Bradnam et al., 2021). From the psychological perspective, brain-spotting was of particular interest. Studies comparing brain-spotting and other forms of trauma therapy have shown similar effectiveness in post-trauma symptoms and better longitudinal improvement over time (Bianco, 2010; Hildebrand et al., 2017). Although empirical studies into the effects of brain-spotting on MFD rehabilitation are yet to be undertaken, subjective reporting by musicians confirms positive effects on their condition. The significant utilisation of this approach merits further investigation to document effects, particularly when incorporated with instrument-specific music exercises (ISMEs).

From the physiological perspective, the uniform utilisation of ISMEs was also noteworthy. There were particular similarities in approaches to these exercises including focus on “slow-down” approaches, progressive muscle relaxation, and finger pressure discrimination. Studies have previously reported the effectiveness of slow-down exercises (Butler et al., 2025; Chiaramonte & Vecchio, 2021; Sakai, 2006; Yoshie et al., 2015), progressive muscle relaxation exercises (Ackermann & Altenmüller, 2021), and finger pressure discrimination exercises (Ackermann & Adams, 2005; Butler, 2010). However, the effectiveness of Tai chi techniques on MFD rehabilitation, frequently included in the retraining approaches of participants, is far less clearly understood.

Meditation was also consistently utilised by participants. Mindfulness intervention studies involving musicians that include validated measures have shown positive effects on body awareness, reductions in self-criticalness, and more efficient and creative practice (Czajkowski et al., 2022). Accounts recorded in this study also reflect these findings, confirming musicians’ understanding of its benefits to both their physical and emotional states.

The considerable cross-utilisation of both physiological and psychological approaches suggests that musicians who implement their own retraining approaches demonstrate similar profiles in the way they are constructed. Maximising the effects of core retraining exercises (ISMEs) with the addition of further physiological and psychological approaches produce a bespoke combination that best fits with the individuals’ particular needs. The literature confirms the need for such an approach to maximise retraining outcomes (Butler et al., 2025), re-emphasising the need to listen to the experiences of retraining musicians, particularly those from outside of controlled clinical settings to guide future interventions that are both practical and accessible to the wider dystonic population.

Non-Judgemental Self-Observation

A self-critical mindset is inherent to the ways in which musicians approach their playing, marked by several negative traits including self-denigration, and feelings of

failure, fear and shame (Johnson, 2016). These markers of perfectionism (Alpheis et al., 2022; Liliana S. Araújo et al., 2017) are established risk factors in the development of MFD (Altenmüller & Ioannou, 2016) and also accompany musicians as they embark on their retraining. A noteworthy observation from this study is recognition by musicians of the development of non-judgemental self-observation during their retraining (refer to theme 4), and the positive effects they reported on their process of rehabilitation and musical and professional outlook.

Self-criticism and competitiveness are acknowledged as job-related stressors of instrumental musicians (Vervainioti & Alexopoulos, 2015) and have been shown to have negative effects on goal progress amongst both musicians and athletes. Self-critics can be more focused on avoiding failure and preventing potential loss of approval than on effective goal pursuit (Powers et al., 2009; Shahar et al., 2003). The negative effects on motivation and autonomous learning are also well documented (Powers et al., 2007) confirming that a shift in mindset away from these traits elicits positive effects on motivation and retraining goals.

The highly autonomous experiences of retraining examined in this study confirm the importance of maintaining motivation, therefore it is imperative that musicians are made aware and encouraged to recognise unrealistic expectations of retraining and be aware of the negative impact of critical, judgemental observation on their retraining processes. Mitigating the unpredictability of retraining is partially achieved through increasing personal agency and autonomy. This process involves improving the ability to self-correct during retraining, requiring both reflection and action (Sanfey, 2017). As musicians develop their own approaches to retraining, they too reflect and act upon their experiences, demonstrating a qualitative shift from focus on performance perfection to a more complex understanding of their abilities and limitations. The research also emphasises the adaptability and perseverance of musicians as they employ their retraining approaches, demonstrating considerable self-efficacy, resilience, and non-judgemental attitudes in the process.

For study limitations, please refer to Chapter 7, Section 7.7 - Study 2.

6.6 CONCLUSIONS

This study provides a comprehensive analysis of the self-developed retraining strategies employed by dystonic musicians. It highlights the benefits of musician-led approaches that combine both practical and psychosocial elements, calling for rehabilitation programmes that address psychological resilience and equip musicians with the tools to maintain motivation and effectively manage emotional responses. Improving community support networks and peer collaboration that can mitigate the isolating effects of MFD, are also recommended.

The psychological challenges faced by musicians during the diagnostic phase, including instances of misdiagnosis and troubling interactions with healthcare professionals, indicate the need for improved understanding of MFD amongst the medical community. The development of psychological support frameworks is needed to mitigate these effects and allow musicians to manage the emotional impact of MFD more effectively.

The study also reveals the significant motivation and resilience of musicians that utilise self-developed approaches. Significant autonomy is also demonstrated, in part due to financial and logistical constraints. This further emphasises the value of personalised retraining approaches that require independent learning, critical thinking, and offer effective alternatives to more standardised approaches. The combination of instrument-specific retraining exercises with additional interventions including Brain-spotting, and mindfulness meditation highlights the significance of addressing the mind-body connection in MFD management. It suggests a need for further investigation into tailored interventions that are informed by the subjective experiences of musicians. Additionally, the shift towards non-judgemental self-observation can positively affect motivation providing musicians with a broader perspective on their rehabilitation and professional outlook.

In summary, the study highlights the importance of developing autonomous, resilient, and adaptable retraining strategies that incorporate the lived experiences of dystonic musicians. Directing future interventions towards the specific needs of the musician

can contribute to a more nuanced understanding of effective retraining practices and support systems for musicians within this context.

Implications for Practice and Future Research

For Musicians and Music Educators:

- Encourage self-awareness and creative problem-solving in MFD rehabilitation.
- Integrate mindfulness and psychological support frameworks into retraining protocols.
- Create an accredited, accessible resource that provides accurate information on retraining options and improves access.

For Healthcare Professionals:

- Recognise the value of patient-led approaches to MFD rehabilitation.
- Develop more patient-led treatment plans for MFD.

Future Research Directions:

Longitudinal studies on the effectiveness of self-developed retraining methods.

Examination of the cross-utilisation of retraining strategies in self-developed approaches to retraining.

6.7 RESEARCHER POSITIONALITY STATEMENT

It is important to acknowledge the inherent subjectivity in qualitative research and the potential influence of researcher positionality. To maintain transparency and clarify interpretation of the data, the following section discusses possible biases and assumptions that may have influenced the researcher during the research process.

Researcher Background:

- **Professional Background:** The researcher is a professional cellist and teacher currently employed within Higher Education and actively engaged in the implementation of playing-related health education.
- **Personal Experience with Musician's Dystonia:** The researcher was officially diagnosed with MFD in 2005.

Acknowledgement of Researcher Biases and Assumptions:

1. **Rehabilitation Bias:** As a dystonic musician that has experience with retraining methods for MFD over a considerable time period, this may subconsciously influence engagement with more familiar challenges or experiences.
2. **Musician-Centric Perspective:** As a professional musician, the researcher may subconsciously prioritise musicians' experiences of MFD over other stakeholders.

Reflexivity Measures:

To mitigate the impact of these biases and ensure the study's credibility:

1. **Selected Member Checking:** Preliminary findings were shared with a small number of participants to validate the applicability of their accounts to the developed themes.
2. **Audit Trail:** A historical record of the research process including methodological decisions, coding processes, and theme development was maintained to facilitate transparency and respond to academic questioning.
3. **Self-Reflection:** Regularly reflecting on the positionality of the researcher was maintained throughout the research process to acknowledge and address any emerging biases or assumptions.

Trustworthiness of the Research:

Acknowledging and addressing researcher positionality enhances the study's trustworthiness by:

1. **Contextualising Findings:** Identifying and commenting upon potential researcher bias in the interpretation of themes.
2. **Encouraging Critical Engagement:** Discussing findings of the research having fully disclosed researcher positionality.

3. **Discussing Future Research Possibilities:** Highlighting areas where future studies could build upon or diverge from this research when considered from alternative perspectives or utilising alternative methodologies.

CHAPTER 7: Discussions/Future Directions

This chapter begins with a brief summary of the objectives and findings of each study in the research. It then discusses, synthesises, and interprets the findings, drawing together the three studies and interpreting them within the context of the research field. Limitations and future directions are then discussed.

7.1 - SUMMARY OF INDIVIDUAL STUDY OBJECTIVES AND FINDINGS

This PhD reframes musicians' focal dystonia (MFD) across the three studies, as a journey shaped by educational, clinical, and personal systems. The principal objective of the research is to highlight this journey through the experiences of musicians as they encounter MFD and progress through the process of retraining, providing insight into the current scenario of MFD navigation, from pre-diagnosis to post-retraining.

1. Study 1 confirms poor levels of awareness MFD amongst conservatoire students and limited levels of awareness amongst teachers, drawing attention to discrepancies in performance-related health issues (PRHIs) and discourse within the one-to-one teacher/student environment. This is despite continued expansion of PRHI education within conservatoire curricula. Although awareness of MFD amongst conservatoire teachers is moderate, there is very limited understanding of associated risk factors between both stakeholders. This highlights a broader issue: the continuing prominent position that instrumental teachers hold as guides and sign posters for their students, alongside an apparent blind spot in PRHI education within UK conservatoires. It indicates the need for improved teacher training and more effective communication channels that permit the careful dissemination of relevant information concerning MFD. Enhancing health discourse between teachers and students could facilitate earlier recognition of potential PRHIs including MFD, improving health signposting and facilitating more timely interventions.

2. Study 2 revealed haphazard experiences of retraining for musicians. Protracted delays, both in achieving a diagnosis and initiating retraining reflect the lack of awareness of MFD confirmed by Study 1. Subsequently, decisions concerning retraining selection were often arbitrary, with little or no guidance from medical professionals, who routinely failed to recommend holistic therapies, including retraining, as potential treatment options. The average retraining period exceeded 5 years, revealing the complexities of rehabilitation. Association was also found in delay between diagnosis and retraining initiation and extended periods of retraining. Together these findings emphasise the need for improved signposting from professionals and improved information and access to retraining for musicians. Instrument families tended to favour certain retraining approaches whilst neglecting others, suggesting the need for a unified framework for guiding musicians as they retrain, incorporating both instrument-specific and general approaches, and clearly defining the goals and theoretical foundations of individual retraining methods. A lack of direction, and clear retraining goals, combined with declining levels of post-retraining support contributes to negative perceptions of retraining quality and perceived effectiveness. Although positive retraining gains were reported across retraining methods, the overall perception of musicians is that retraining does not exceed expectations, suggesting that there is significant room for improving the retraining experience for musicians.

3. Study 3 revealed the lived experiences of musicians utilising self-developed retraining for their MFD. This research focus was informed by findings of Study 2, which revealed that over half of survey participants (51.4%) had developed and adapted retraining to cater for their individual circumstances. As revealed in Study 2, troubling diagnostic experiences had created delay, confusion and frustration, with further accounts of poor professional support and follow-up highlighting a significant point of weakness in musicians' retraining journeys. Significant levels of motivation and resilience were observed amongst the sample group throughout their retraining processes as they took personal agency of their rehabilitation. Autonomous retraining decisions, although frequently lacking in professional guidance, triggered improved awareness and understanding of a broad range of retraining methods. Emotional transformation was observed, including the

development of open-minded, less competitive approaches to music-making, changes in musical priorities, increased self-care, non-judgemental self-observation, and prioritising the mind-body connection. A range of both psychological and physiological strategies were adapted or integrated into study participants' retraining, reflecting highly adaptive and flexible approaches to rehabilitation. This highlights the importance of supporting bespoke approaches to retraining and providing the necessary individualised support to musicians as they navigate their individual retraining processes.

7.2 SYNTHESIS OF KEY FINDINGS

The findings from the PhD move towards advancing the field in the following areas:

1. Reframe MFD as both a neurological and educational/relational issue that is influenced by the instrumental teacher/student context.
2. Advocate for earlier detection of MFD which is in part, dependent upon improving the culture of health awareness within the music profession, expanding professional performance-related health issue (PRHI) training for music educators, as well as clinical expertise.
3. Assert that support for dystonic musicians should be multidisciplinary, goal-led, sustained, and include structured space for supervised self-developed retraining.
4. Encourage a move towards proactive pathways to reduce MFD risk-factors, including the integration of neurological playing health (NPH) into training, rather than following the current practice of late-stage responses.

The following section presents a complete synthesis of the findings of the research across the three papers of the PhD.

7.3 Discussion 1 - The Case for Increasing Awareness of MFD

Awareness of MFD remains low due to several factors. As revealed in Study 1, understanding of discourse surrounding PRHIs, including MFD, remains limited. For music students, existing health education within Higher Education music institutions is predominantly a modular or optional component of curricula (Matei & Ginsborg, 2022).

The centralisation of health education as a core component of learning within conservatoires would involve fully integrating PRHI literacy into performance elements of the curriculum, and also formally acknowledging the importance of the instrumental teacher/student setting in guiding students through PRHIs. Results from Study 1 highlight significant discrepancies concerning how students and their teachers perceive the quantity and frequency of current PRHI conversations that they engage in during individual lessons, with teachers overestimating engagement, whilst students report significantly lower levels. When considering MFD, the considerably higher levels of awareness of MFD and its risk-factors amongst teachers compared to students reflects this fact, highlighting a possible generational gap that maintains MFD as a poorly understood and frequently “taboo” subject.

The sensitive nature of MFD is of course, a significant concern when discussing raising awareness. For many musicians, intense competition and pressure to perform to the highest level may dissuade them from seeking prompt treatment (Baadjou et al., 2021), preferring instead to remain in silence. Studies also indicate that awareness efforts can lead to exaggerated symptom interpretation, resulting in undue anxiety and potential misdiagnosis (Foulkes & Andrews, 2023). This heightened scrutiny might convince musicians they are suffering from a serious condition when experiencing mere stress or fatigue-related issues. Also, increased self-reporting of MFD without clinical validity could undermine legitimate cases, posing challenges for healthcare providers.

However, the data from Study 1, reporting positive responses to questions of levels of concern for MFD and discussing MFD with students (Q9 and Q10), supports the case for increasing MFD awareness within undergraduate level programmes of instrumental study. The literature confirms the involvement of teacher/student relationships as potential contributors to cases of MFD (Détári et al., 2022). Therefore, considering the relatively high levels of existing awareness of MFD amongst teachers currently teaching within UK conservatoires, this PhD advocates for delivering more detailed information about the condition to teachers (particularly its modifiable risk factors), facilitating the dissemination of knowledge to students through the one-to-one lesson setting.

A further argument for raising awareness of MFD arises from the diagnostic experiences of dystonic musicians, as reported in both Study 2 and 3. A persistent lack of awareness or specialism amongst medical professionals contributes to deficiencies in identifying and diagnosing dystonia (Bradnam et al., 2021; Smit et al., 2021; Tedeschi, 2024). Younger musicians in particular, may struggle to recognise symptoms, which may exacerbate diagnostic delays, similar to the challenges of diagnosis associated with other forms of dystonia (Tadic et al., 2012). Bridging the awareness gap for both musicians and health professionals is therefore a key element for improving early detection and intervention for those at risk of MFD.

Reframing Awareness of MFD

A further possible “on-ramp” to raising awareness of MFD, particularly for younger musicians, is to reframe awareness of the condition, concentrating instead on the positive benefits of improving modifiable risk-factors as elements of good practice. Reframing MFD as part of the broader picture of neurological playing health (NPH) may also encourage engagement with strategies and techniques that can potentially improve playing ability and address the modifiable risk factors of MFD concurrently, without necessarily confronting the condition directly.

Many of the philosophical underpinnings of retraining for MFD are relevant to all musicians in their day-to-day practice. For example, the role of neuroplasticity and sensorimotor/somatosensory processing (Byl et al., 2009), the importance of avoiding excessive repetition (Cadwallader et al., 2018), and regulation of stress and playing fatigue (Ioannou et al., 2016a), can benefit all musicians, not just those that are dealing with a diagnosis of MFD. They promote general neurological playing health, and whilst not focused directly on MFD, draw upon research in the field and the experiences of dystonic musicians undertaking retraining in some form. Integrating neurological playing health (NPH) techniques into established practice routines encourages deeper understanding of neurology's role in instrumental performance, whilst also re-enforcing techniques that may inadvertently reduce certain risk factors associated with MFD onset.

The following section sets out a framework for introducing NPH to stakeholders that is centred upon the introduction of the concepts of neuroplasticity and sensorimotor/somatosensory processing. It considers an approach that can inform instrumental students, instrumental teachers and performers in similar measure. The theoretical underpinning for the framework is derived from the COM-B (Capability → Opportunity → Motivation → Behaviour) framework (Michie et al., 2011), that asserts that behavioural change occurs in response to the "COM" factors. In the context of the proposed NPH framework these are considered within the following contexts:

1. Capability - The skills and knowledge required to implement NPH would involve improving both psychological and physiological capabilities. From a psychological standpoint, this involves gaining knowledge of key concepts of NPH including neuroplasticity, sensorimotor mapping, attentional control, playing variability and management of stress and fatigue. From a physiological standpoint, it involves developing techniques that address fine motor skill and control such as slow practice techniques, tactile/proprioceptive drills, avoidance of excessive repetition, and the inclusion of regular breaks. Students gain knowledge and skills to change their practice whilst teachers develop both observation and conversational skills to guide behavioural change.

2. Opportunity - The opportunity to implement NPH lies within educational institutions and their proximity to accredited sources of performance arts medicine (PAM) assistance. Institutional support requires the development of clear signposting protocols for students and teachers, establishing referral pathways to appropriate PAM professionals, and appropriate documentation to substantiate and validate the procedures. Achieving these objectives would enable students to follow clearly set out practice protocols and have access to resources to perform the behaviours in real time, whilst teachers would have a recognised role and pathway to act without overstepping clinical boundaries.

3. Motivation - Reframing MFD within NPH emphasises performance gains and modifiable risk instead of pathology, strengthening understanding that change is worthwhile and possible. Achieving this could involve the implementation of short-

term NPH goals that include valued outcomes including observing positive changes in sound quality, or improved accuracy/relaxation in response to specific practice interventions. In turn, brief drills may become integrated into practice routines, as could anxiety reduction elements including relaxation or mindfulness.

The long-term objective of a NPH framework would be to encourage young musicians to feel safe and motivated to adopt and maintain NPH routines and for teachers to feel confident that such an approach can help rather than harm. It also aims to address the question of stigma that surrounds MFD, instead re-enforcing a message that skilled musicians use health tools, including those that address NPH, to preserve their playing. The framework outline is presented in the following table (Table 47).

Table 47. Neurological Playing-Health Framework

1.	**Stakeholder Identification**
i.	Primary Audience: Music students, instrumental teachers, and professional performers.
ii.	Secondary Audience: Music education institutions, performing arts healthcare professionals.
2.	**Key Message Development**
i.	The significance of neuroplasticity in playing an instrument.
ii.	The importance of maintaining good sensorimotor function.
iii.	The importance of recognising and addressing psychological issues and their potential effects on playing.
iv.	The neurological implications of excessive repetition.
v.	The importance of slow practice for the brain.
vi.	The neurological benefits of taking regular breaks when practicing.
vii.	The neurological impact of excessive practice.
3.	**Modes of Delivery**

i.	Workshops and Seminars: The introduction of NPH sessions at conservatoires/music schools or professional orchestras.
ii.	Webinars: Online NPH sessions to ensure accessibility for a broader audience.
iii.	Collaborations: Partnerships with PAM organisations.
iv.	Digital Platforms: Websites and social media posts to disseminate ongoing research findings concerning and practice tips.
4.	**Educational Content**
i.	Interactive Learning Modules: Development of online modules exploring neuroplasticity and practices for neurological health.
ii.	Video Resources: The production of educational videos demonstrating effective practice strategies to improve NPH.
iii.	Case Studies and Testimonies: Real-life accounts from musicians utilising NPH techniques to illustrate practical applications.
5.	**Integration into Curricula**
i.	Encourage musical educational institutions to integrate NPH discussions into existing PRHI courses or modules as part of their content.
6.	**Professional Development Initiatives**
i.	Introduction of NPH sessions for instrumental teachers that focus upon integrating the principles of NPH into their teaching methods.
ii.	Multi-disciplinary seminars integrating educators, performers, healthcare professionals, and neuroscientists to discuss the intersection of music performance and NPH.
7.	**Feedback and Evaluation**
i.	Surveys and Feedback Tools: Implementation of systems to gather feedback from participants after sessions to assess understanding and effectiveness.

ii.	Review Sessions: Follow-up meetings to evaluate the implementation of suggested practices and make necessary adjustments to the framework.
8.	**Continuous Engagement and Updates**
i.	Research Collaborations: Maintenance of partnerships with ongoing research initiatives to ensure the framework remains current and evidence based.
ii.	Community Engagement: Creation of online forums and discussion groups for musicians to share experiences, insights, and support in applying recommended practices.

Incorporating this framework into PRHI seminars, workshops, courses, and existing curricula within conservatoires would effectively extend its reach across diverse sectors of the music profession. This approach would present stakeholders with all known modifiable risk factors of MFD, thereby offering musicians the chance to experience and comprehend the significance of NPH. As a result, musicians would be better equipped to recognise potential issues both in themselves and in others and to incorporate strategies for improving NPH into practice routines and training.

ii. Developing Awareness of MFD In the One-to-One Teacher-Student Setting, Within Conservatoires

The one-to-one instrumental teaching environment within music conservatoires is a unique moment in the formative training of an instrumental musician. The relationship between conservatoire students and their instrumental teacher is central to developing students' belief and self-efficacy (Gill et al., 2024). Teachers often see themselves as primarily accountable for their students' academic wellbeing, with one study indicating that almost three quarters (72%) of educators share this belief (Wijsman, 2023).

For many musicians, initial signs of MFD appear during periods of intense stress, work, or technical change (Altenmuller & Jabusch, 2010). The conservatoire environment offers an ideal opportunity for this to occur. Therefore, discussing MFD alongside other performance-related health issues (PRHIs), particularly in a one-to-one setting, should

be of considerable importance. However, existing training approaches to PRHIs within conservatoires are student centred, do not consider the role of the teacher, and remain largely optional rather than core elements of curriculum, reflecting a continued lack of integration into the teaching of music performance at tertiary music institutions (Clark & Lisboa, 2013; Shoebridge & Osborne, 2025) meaning that many students remain unengaged with PRHIs.

In light of this context, this PhD documented considerable discrepancies in how PRHI discourse was perceived between stakeholders, with teachers currently suggesting far more engagement with their students' playing health than the students themselves perceived from their teachers. Consequently, when problems do appear, musicians are frequently unsure of the appropriate steps to take in order to receive prompt attention and/or advice (Matei, 2019). For those experiencing possible symptoms of MFD, the situation may be even more confounding due to low levels of awareness, resulting in further delays and confusion. This issue was emphasised in Study 1, which showed that conservatoire students had a low level of MFD awareness compared to their teachers. Yet, both groups displayed limited understanding of the risk factors, reinforcing the need for heightened awareness. This is particularly important, as for students their instrumental teachers are typically their main point of reference, and the first people approached when potential problems surface.

This highlights a potential point of action in which instrumental teachers could be better provided with the resources necessary to guide and direct their students through enhanced discourse when faced with PRHIs, including MFD. Therefore, this PhD advocates prioritising awareness and improved understanding of PRHIs amongst conservatoire teachers. Given the high incidence of PRHIs amongst tertiary instrumental students, ranging from 62% to 88% (Árnason et al., 2014), it is imperative that conservatoire faculty possess the skills necessary to identify potential problems, clearly signpost their students, and engage in knowledgeable and supportive discourse.

To confront this issue, a first clear step for both students and their teachers would be for conservatoires to formally acknowledge the importance of PRHI discourse within

the instrumental student/teacher setting. For conservatoire instrumental teachers, there are currently no known mandates for either formal education or qualifications in PRHIs when contracted. Therefore, a significant step in raising awareness of MFD for both students and their teachers would be for conservatoires to formally recognise the importance of the student/teacher relationship in managing PRHIs. This could be addressed by considering the inclusion of the approaches suggested in the following section (refer to Table 48).

Table 48. Steps for improving PRHI discourse

1. Incorporate Health Awareness into Recruitment Procedures:
Include PRHI specific questions in interviews for prospective faculty members to assess existing awareness, understanding, and approaches for managing student health concerns.
Evaluate candidates on their approaches to dealing with PRHIs in their students, ensuring that they are adequately prepared to support wellbeing as part of their teaching responsibilities.

Justification: Currently, conservatoire instrumental teachers are not required to have formal education or qualifications in PRHIs when contracted. The significance of the one-to-one teacher-student relationship is well-documented, with teachers often serving as confidantes for PRHI issues. Therefore, embedding health awareness in recruitment ensures that faculty are adept at managing the overall wellbeing of their students from the outset.

2. **Mandatory PRHI Professional Development (PD) for Teachers:**
Provide training for faculty members with PAM professionals, focusing upon recognising the early signs of PRHIs in students and equipping them with tools to address issues of concern.

	Include workshops with physiotherapists, psychologists, and medical professionals that specialise in recognising and treating PRHIs in musicians.
	Invite PAM researchers to present the latest research and advice concerning musicians' health.

Justification: Vocal and instrumental teachers are typically recruited on the basis of their skills as performers, rather than as teachers, despite the skillset required for each of these roles being vastly different (Carey & Grant, 2021). Ensuring that teaching staff are skilled in supporting students' playing health and wellbeing is crucial for effective safeguarding. Implementing PRHI-focused professional development across the faculty ensures that all staff maintain a consistent level of health awareness.

3. **Clarify PRHI Signposting Protocols:**	
	Clarify institutional protocols for signposting students to performance-related health services and resources within and outside the conservatoire.
	Review and update protocols to ensure that they remain relevant to the requirements of both students and teachers.

Justification: The boundaries of health signposting for instrumental teachers remain unclearly defined. Whilst general guidelines advise against providing medical diagnoses or treatment recommendations such as the use of non-steroidal anti-inflammatories or TENS units, they do emphasise the importance of urging students to seek advice from healthcare professionals for ongoing pain (Palac, 2018). However, for this to be clearer and more effective, conservatoires must clarify their protocols and make them clear to both students and faculty.

4. **Facilitate Open PRHI Communication Channels:**

	Schedule regular discussion sessions with students and faculty concerning PRHIs.
	Establish mentorship programmes for PRHIs to support new students and teachers, guided by faculty members and students with experience in dealing with PRHIs.
	Develop feedback channels where students and teachers can share their experiences and suggestions concerning PRHIs.

Justification: Effective health communication remains a barrier to discourse within tertiary education (Evans et al., 2024). Establishing regular PRHI discussion sessions between faculty and students can encourage an open exchange of information and experiences. Designating experienced students and staff members to act as mentors and health sign posters could also stimulate a broader engagement across the conservatoire community.

The multifaceted responsibilities of one-to-one teachers in the modernday conservatoire are being increasingly recognised across the tertiary music education community (Guillaumier et al., 2025). This includes the intimate role of PRHI discourse facilitator and advisor to their students. The aim of these guidelines is to move towards officially recognising the importance of the student/instrumental teacher relationship as a pinch point for discussing and identifying potential PRHIs. The objective would be to improve discourse and communication amongst stakeholders whilst also providing students and teachers with an environment that requires open PRHI dialogue, ultimately reducing confusion and delay in receiving appropriate help when required. Implementation of these guidelines would reflect a further shift towards a more integrated conservatoire environment that brings together academic and performance faculty, sharing information and experiences, and placing teachers in a stronger position to support their students when confronted with PRHIs, including MFD.

7.4 Discussion 2 - Improving the Road to Retraining

i. Navigating Diagnosis

Within the literature, common misdiagnoses of focal dystonias include Parkinson's disease (PD), essential tremor, myoclonus, tics, functional ("psychogenic") dystonia, headaches, and scoliosis (Stephen et al., 2023). One study even reports that the incidence of false negative diagnoses of dystonia amongst a cohort of physicians was as high as 33% (Beghi et al., 2015). This is exemplified by diagnostic confusion experienced by several musicians in studies 2 and 3, reaffirming a wider challenge faced by the medical field, a requirement for more comprehensive, specialised training programmes for enhanced training in movement disorders for medical professionals (Tamás et al., 2020).

Diagnostic delay was also a significant factor for participants in this PhD, with the average duration between the onset of symptoms and a diagnosis of MFD being between 2 to 3 years. However, this is relatively brief compared to the average time taken for diagnosing other types of focal dystonia. For example, achieving a diagnosis of cervical dystonia takes an average of between 3.7 and 6.8 years. (Smit et al., 2021). The shorter diagnostic delay in comparison to cervical dystonia could imply that musicians are more informed about this condition, potentially through industry discussions or peer experiences, prompting them to seek appropriate treatment more quickly. It suggests that although awareness may remain limited within the musician profession (as discussed in the previous theme), there are positive effects upon diagnostic timelines, compared to similar dystonic conditions.

A significant concern that emerged during the research was a consistent lack of guidance provided by medical professionals at the time of diagnosis. Limited information sharing between doctors and specialist consultants (Morgan et al., 2021) reflects the sometimes, limited awareness of holistic treatment methods demonstrated by medical professionals. For musicians, this contributes to unsatisfactory consultations and emphasises the importance of signposting to performance arts medicine (PAM) associations and specialised support groups that can advise and

guide musicians through the diagnostic process. It also highlights the importance of raising awareness of MFD and its holistic treatment options amongst physicians through continuing professional development (Dick et al., 2022).

However, diagnostic challenges were not the only issues reported by musicians in this research. A second concern was with unsympathetic and/or dismissive interactions with physicians that transmitted a lack of understanding or compassion towards their situation. Although dystonias are recognised as provoking periods of psychological distress, compounded by social isolation and stigma (Morgan et al., 2021), MFD can often be treated as more of a professional inconvenience rather than a career and livelihood altering event. Therefore, this research calls not only for improved information sharing between physicians in the identification and the treatment options for MFD, but it also advocates for more awareness of the occupational significance of diagnosis, and recognition of the psychological impact that diagnosis provokes.

ii. Improving Signposting

Improving signposting to available treatments and therapies for MFD is a crucial step in improving access to appropriate care and support. From a medical standpoint, this involves recognising the multifactorial nature of the condition and acknowledging the role and importance of holistic treatments and therapies in rehabilitation. Although limited empirical evidence and the lack of rigorous, large-scale studies present clinicians with difficult decisions when considering non-pharmaceutical approaches, many neurologists and movement disorder specialists recognise the benefits of such approaches, particularly regarding their impact on mental health, stress management, and overall wellbeing. The trend towards patient-centred care and the acknowledgement of “perceived” benefits in developing treatment programmes further encourages the integration of multidisciplinary approaches that align individualised pathways with somatic, sensory, psychological, and psychosocial presentations of MFD (Collett et al., 2000; Sadnicka et al., 2022; Smit et al., 2021; Liwinski et al., 2024).

Non-clinical signposting via accredited websites, musicians’ associations, and PAM organisations is also critical to the rehabilitation process, and as such should deliver

standardised, comprehensive, and impartial guidance to counter the haphazard, poorly informed retraining choices observed in Study 2. Information sources that reflect the current landscape of retraining approaches, outline typical timelines and costs, and clarify the competencies of different providers can reduce trial-and-error and prevent delays, and the negative effects of cycling through incompatible methods. Embedding signposting within a multidisciplinary framework also creates opportunities for the development of clearly defined roles for stakeholders in the rehabilitation of dystonic musicians.

The implementation of effective signposting can normalise access to holistic, multidisciplinary options, including medical, pedagogical and psychosocial approaches, rather than defaulting to narrow, biomedical pathways. It reinforces the notion that retraining as an active, staged process, clarifies what “good” care looks like, and potentially shortens the time between diagnosis, informed choice, and meaningful rehabilitation. When delivered through standardised information and coordinated pathways, signposting offers a pragmatic route to earlier, more effective recovery and a safer return to performance that is transparent and provides feedback opportunities.

In summary, retraining for musicians with focal dystonia is shaped as much by the quality and timeliness of diagnosis as by the care that follows. Persistent misdiagnosis and variable diagnostic delay point to a clear training gap in movement disorders and to the need for more consistent, compassionate communication that recognises the occupational stakes for musicians. Addressing these issues requires better information flow between primary care, neurology, and specialist performing arts medicine, alongside explicit acknowledgement of the psychological burden that often accompanies MFD.

7.5 Discussion 3 - Redefining “Success” in Retraining

For many dystonic musicians, successful retraining outcomes may appear remote, whilst others may continue their playing careers without further disruption. Recovery may mean a return to pre-dystonic state, where movement filters produced by MFD

are reduced, and normal movement patterns are restored (Frucht, 2025), or more commonly, a more subtle transition towards new priorities and musical goals.

Across Studies 1–3, “success” appears multi-dimensional. including several factors in addition to motor improvement including improved wellbeing, steady participation in valued musical activities, an increased sense of being in control, and renewed professional identity in response to retraining. Study participants described success as being able to play in a meaningful way whilst also managing symptoms, having increased confidence and self-awareness, and improved coping mechanisms. These outcomes should be treated as equally important as motor changes.

The Transformative Aspect of Retraining

Interviews with musicians in both studies 2 and 3 recounted perceptions of retraining for MFD as a transformative process, not solely as vehicles for reducing motor symptoms. The multitude of non-motor symptoms that accompany dystonias (Bradnam et al., 2021), including trauma response (Détári et al., 2022), anxiety and depression (Lewis et al., 2008), mental and physical fatigue (Jirásek et al., 2025), were also central to their experiences. Instead of evaluating success simply as a question of “can I play like I did before?” a deeper and more fundamental transformation takes place, including paradigm shifts in both the physiological and psychological perspectives of being a musician, changing priorities, and the integration of holistic practices.

As reported in their 7-year follow-up study of multiple approaches to sensory-motor rehabilitation, Butler and colleagues confirmed that musicians often expressed a newfound sense of empowerment and control over their condition, attributing this shift to the comprehensive and tailored strategies provided by the combined treatment approaches (Butler et al., 2025). This PhD also independently reports similar findings, drawing attention to the reflections of musicians concerning their retraining. The prolonged recovery times and uncertainties of the process, provoke changes in musical and professional outlook. The concept of “ego death” described by a dystonic musician in study 3, even goes so far as to describe the profound process of letting go of previous self, in this case in response to the utilisation of brain-spotting for trauma

resolution. What consistently emerges throughout the qualitative data in both studies 2 and 3, is an intense introspection, and periods of time in which retraining musicians are obliged to abandon or de-prioritise their day-to-day career concerns, aims and objectives.

7.5.1 Choosing to Retrain

For musicians that have been formally diagnosed with MFD, standard medical care may satisfactorily resolve the condition. However, as reported within the literature (Butler et al., 2025; CF Chang & J. Frucht, 2013; Jankovic & Ashoori, 2008), side effects may be intolerable, providing limited or no benefits and requiring repeated applications over extensive time periods. Many dystonic musicians therefore choose to retrain. As previously discussed in this chapter, retraining choices and decisions are frequently made in the absence of professional orientation. Musicians are mainly reliant upon pre-existing awareness, individual research efforts and peer recommendations.

Choosing to retrain from MFD therefore involves a frequently haphazard process of decision making, requiring key factors to be in alignment. Firstly, sufficient awareness of the particular treatments and therapies that are available to the musician, and secondly, a sufficient understanding of the aims and objectives of the retraining method being considered. This remains problematic. Consequently, retraining choices and decisions are made following protracted periods of time (as confirmed in Study 2), often at considerable personal expense, (as described in Study 3), and with no guaranteed outcomes.

To address this question, this PhD advocates for the implementation of a multidisciplinary framework that addresses the lack of standardised retraining information available to musicians. The principal objective of such a framework would be to mitigate confusion and delay through careful signposting, information delivery, and multi-disciplinary support. Multi-clinical approaches to rehabilitation permit a range of treatments and therapies to be introduced, facilitating the construction of highly individualised medical and sensory-motor rehabilitation packages for musicians (Butler et al., 2025). The multifactorial nature of MFD and recognition of the importance

of personalised approaches to rehabilitation (Butler et al., 2025; Butler et al., 2018; Catellani et al., 2024), emphasise the potential impact that such a framework could have in shaping future retraining approaches.

The following multi-disciplinary framework (Table 49) presents a progression of standardised steps to facilitate signposting to retraining and provide access to appropriate channels of support during the retraining process.

Table 49. Framework for a multi-disciplinary approach to MFD retraining

1. SIGNPOSTING
Description: Signposting to an accredited source of MFD information affiliated with PAM organisations or associations.
Justification: The inclusion of a PAM accredited general source of MFD information minimises misinformation or retrainer bias, helping to clarify and encourage informed retraining decisions.
2. **MFD INFORMATION CONTENT AND DELIVERY**
i. General Information Overview :
ii. Treatment Options Overview :
Description: The publication of a complete list of available treatments and therapies for MFD including pharmaceutical and non-pharmaceutical options, clearly explaining their effects, aims and objectives.
Justification: To the researcher's knowledge there are currently no sources of information for musicians that present the available treatments and therapeutic options for MFD rehabilitation. Dissemination of this information in a centralised way provides musicians with sufficient knowledge and awareness of their

treatment options. (For a screen shot of the researcher's website www.musiciansdystonia.net, please refer to Appendix P)

3. INDIVIDUAL ASSESSMENT AND CUSTOMISATION

i. Physical Evaluation:

Description:

A physical assessment of diagnosed musicians by a PAM accredited physical therapist to identify specific motor problems and to guide musicians towards appropriate retraining, or combinations of retraining.

Justification:

Following initial diagnosis, there are no mechanisms currently in place to assess symptoms and signpost newly diagnosed musicians to appropriate treatments and therapies.

ii. Psychological Evaluation:

Description:

A psychological assessment by a PAM accredited psychologist or councillor to assess the impact of mental and emotional health conditions including anxiety or stress.

Justification:

Psychological assessment is not a recognised part of the diagnostic process. Therefore, for many musicians, there is no awareness of the influence of emotional factors on their condition. A psychological evaluation prior to commencing retraining would equip musicians with understanding of the importance of maintaining their emotional health and enable psychologists/councillors to produce reports that can help to guide and tailor retraining decisions for individuals.

ii. Customised Retraining Plan:

Description:

The development of an individualised retraining plan that aligns with the musician's physiological and psychological presentation, and their rehabilitation goals.

Justification:

The multifactorial nature of MFD is well understood, and the literature confirms the preference for individualised retraining approaches to maximise potential positive outcomes.

4. MULTI-DISCIPLINARY TEAM FORMATION

Description:

The formation of multidisciplinary teams of professionals affiliated to PAM associations to facilitate the development of bespoke approaches to retraining that account for the physiological, psychological, and psychosocial profiles of the individual.

1. Neurologist (Diagnostic Confirmation)
2. Physical Therapist (Motor assessment)
3. Psychologist or Counsellor (Psychological Assessment)
4. Occupational Therapist (Treatment plan development)
5. Retraining Specialists (Execution of retraining plan)

Justification:

To maximise the physiological, psychological and psychosocial benefits of retraining it is necessary to assemble a team of professionals that can collaborate to produce recommendations and execute bespoke retraining plans.

5. IMPLEMENTATION OF RETRAINING

i. Physiological Approaches:

Targeted exercises to improve neuromuscular control, strength, and flexibility. Ergonomics training (proper posture, instrument handling).
ii. Psychological Approaches:
Cognitive Behavioural Therapy (CBT) to address the emotional aspects of performing under duress. Mindfulness and relaxation techniques.
6. **CONTINUOUS EDUCATION AND SUPPORT**
i. Ongoing Workshops and Seminars:
Regular engagement opportunities with professionals and fellow musicians.
ii. Peer Support Groups:
Facilitate connections among musicians with similar experiences to share strategies and provide mutual support.
7. **FEEDBACK, EVALUATION, AND ADJUSTMENT**
Regular assessments of the effectiveness of the retraining strategies. Feedback mechanisms for musicians to communicate the effectiveness of interventions. Adjust and refine the retraining plan based on feedback and progress.
8. **REINTEGRATION INTO PERFORMANCE**
Gradual reintegration into performing with support.

7.5.2 Retraining Decisions

Decisions as to which retraining approach to follow, particularly in the absence of prior information about potential options, is frequently shaped by a particular retrainer or method centred loyalty, as suggested by the two' "psychological" or "physiological" retraining approach camps described in Study 2. It suggests that a master/apprentice model of retraining exists, one that can successfully organise and provide identity, but may also risk narrowing options, discourage criticism, and even restrict progress when a given approach does not fit the individual (Gaunt, 2011; Leech-Wilkinson, 2020). Researcher/clinician "allegiance" also predicts both uptake and reported success of branded methods (Wampold, 2015; Munder et al., 2013), suggesting that loyalty itself can shape judgments about what "works."

In contrast, musicians that follow self-developed approaches to retraining, naturally break this pattern and develop their own, critical appraisal of retraining. Somatic and motor-learning inherently requires self-observation, experimentation, and function over doctrine. Interventions emphasise individualised, feedback-rich behavioural retraining rather than one-size-fits-all recipes (Candia et al., 1999; Jabusch & Altenmüller, 2004; Ioannou & Altenmüller, 2014). More broadly, self-regulated learning research in music shows that autonomy, personal goal-setting, and systematic monitoring, predicts better adaptation and persistence (McPherson & Zimmerman, 2011). Schön's concept of "reflection-in-action" further emphasises the importance of iterative testing and revision or "a reflective conversation with the situation" over non-critical adherence to rules (Schön, 1983, p. 79).

Making dystonic musicians aware of the various retraining pathways available to them is fundamental in strengthening critical thinking and the ability to evaluate the potential benefits and appropriateness of one approach over another for an individual. This aligns with the concept of "preference-sensitive" decision making where there is "more than one reasonable option" (Elwyn et al., 2012, p. 1361).
When musicians receive condition-specific information and support to compare options, they are less likely to default to charismatic authority and more likely to make "autonomous, informed choices aligned with their preferences" (Elwyn et al., 2012, p. 1361). In short, awareness plus navigation preserves the motivational benefits of

mentorship whilst also countering the structural pull towards particular retraining approaches.

Taken together, these arguments suggest a practical stance that retains the motivational and informational benefits of expert mentorship whilst also scaffolding reflective practice. Making retraining decisions (including experimentation, modification or discontinuation), that are based upon the individual experience rather than the reported success rates of a retraining approach for example, is critical to the further development of personalised approaches to retraining that allow musicians to make informed and personally appropriate retraining decisions.

7.6 Discussion 4 - Empowering the Musician and the Importance of Self-Developed Retraining

It is imperative that the voice of the musician remains central to the development and refinement of rehabilitation from MFD. Empowering musicians to speak up and be heard as they retrain is integral to achieving this. This section considers what "empowerment" means practically for musicians living with focal dystonia, and how and to what extent self-developed retraining is a sustainable and invaluable route within rehabilitation. It considers the structures, skills, and measures that enable musicians to lead their own recovery and the appropriate channels of support to achieve this.

Why is Empowerment Important for Retraining Musicians?

Empowerment is more than the sum of encouragement or positive messaging. Awareness of MFD significantly contributes to empowerment, as naming the condition helps musicians to make sense of their symptoms and minimise self-blame. Early, accurate information about what MFD is, and is not, allows musicians to take a more active role in decisions about their care. Within the context of MFD retraining, it means that musicians are enabled to understand their situation, make informed choices, experiment with retraining methods under non-challenging conditions, and self-evaluate their effectiveness. Consequently, they are less dependent on sometimes unsatisfactory encounters with retraining specialists, and less vulnerable to long delays during the diagnostic process. The uneven access to specialist services

reported during studies 2 and 3 of this PhD, together with the often-erratic pathways to retraining reported by study participants, further reinforces the need for greater autonomy in rehabilitation, accompanied by independent, guided support.

Core Principles of Empowerment

Constructivist approaches to MFD rehabilitation are increasingly recognised as an important step in the development of more bespoke retraining strategies (Détári & Altenmüller, 2025). Part of the course for achieving this is treating rehabilitation as a partnership, rather than a prescription (Bond et al., 2012). In this scenario, health and education professionals provide both expertise and options, as the dystonic musician sets their retraining priorities, enabling them to follow the most realistic path to rehabilitation. A plan is formed in collaboration rather than isolation and is negotiated rather than imposed. This partnership model depends on clarity and transparency, also crucial elements in empowering musicians. For example, a clear understanding of basic health literacy empowers individuals by helping them to understand and act upon health information (De Jesus et al., 2025), and it is the responsibility of specialist professionals to provide clear information about the risks, benefits, and the uncertainties of retraining upfront, together with a realistic expected time course and commitment expectations.

Constructing Empowerment in Rehabilitation

Constructing empowerment in rehabilitation requires sustained, coordinated support that keeps musicians engaged, from diagnosis to conclusion of the retraining process. Current levels of support during retraining wain over time (as confirmed by participants in Study 1), and the current model of retraining support relies on the support of the retraining specialist and the self-supporting abilities of the musicians themselves. To potentially counteract this effect in a simple, practical way, this PhD advocates for the assignment of a patient navigator as third-party support for dystonic musicians following diagnosis. The role of patient navigators for people with chronic illnesses is well documented within the literature, acting as sign posters and guides for patients as they assess and choose treatment options (Natale-Pereira et al., 2011; Wells et al., 2008). In practical terms, a navigator could help with scheduling, coordinating between specialists, and signposting financial or workplace support. A navigator could also

check in at agreed intervals, take notice of early signs of frustration or disengagement, and prompt adjustments to a rehabilitation plan, helping to reduce gaps in care that currently suggest waning levels of support. The complementary role of a navigator would facilitate the creation of clear communication between specialist and musician, whilst also improving goal alignment and expectations. The model could potentially offer a simple, structured way to sustain support across the full course of retraining.

Co-produced, Self-developed Retraining

Self-developed retraining permits the musician to integrate contextual knowledge of their body and personal constraints and goals, into strategies that align favourably with their unique situation. Methodological or pedagogical elements of retraining however, require time and understanding to implement, potentially restricting access to beneficial retraining techniques and increasing total retraining duration. Collaboration and co-design of personalised retraining with patient navigators, can mitigate this effect by distributing expertise appropriately, moving towards more structured retraining decisions that provide musicians with the necessary information and support from the outset.

The following list describes the key potential benefits of such collaborative self-developed retraining approaches:

- **Improved motivation and adherence:** Musician-led retraining decisions executed within an agreed framework encourages both autonomy and ownership which are both linked to improved engagement and persistence in behaviour changes (Knowles, 1984; Ryan & Deci, 2024; Vallerand, 2000).

- **Improved contextual fit:** Co-design and shared decision making can align goals and methods with the musician’s repertoire, schedules, and resources, increasing feasibility and transfer to real-world performance (Elwyn et al., 2012; Levack, 2018).

- **Adaptive progression:** Two-way feedback enables timely adjustments to be made to retraining quantity, technique, and pacing, reducing the risk of negative physical effects or of overuse, whilst maintaining progress (Bate & Robert, 2006; Carman et al., 2013).

- **Development of self-regulatory skills:** Self-monitoring, reflection, and iterative problem-solving contribute to the development of skills that the musician can apply beyond the initial retraining period (McPherson et al., 2017).

- **Equity and trust:** Sharing decisions and valuing lived experience redistributes power, which can enhance trust and surface tacit knowledge that standard protocols may miss (Grasswick, 2010).

- **Innovation and field advancement:** Co-produced projects generate practice-based evidence and novel hypotheses grounded in real conditions, complementing controlled trials and accelerating learning across settings (Bolt & Barrett, 2014).

In addition to the significant benefits and empowerment that the inclusion of patient navigators could bring to musicians undertaking retraining, the effects of two-way knowledge can also not be underestimated. Collaborative contributions provide frameworks for iterative knowledge building that turn individual data into collective learning. They increase expertise of practice-based elements of retraining, where particular cases can inform methodological refinements and then be objectively tested (Reason & Bradbury, 2001). The sharing of effective strategies and nomenclature to describe problems and progress can also accelerate the dissemination of information across the broader population (Lang et al., 2012).

Empowerment through Autonomy

Although there is a strong argument for the importance of co-produced approaches to self-developed retraining, increasing autonomy and the capacity to self-manage is also fundamental to the retraining process. Studies suggest that many musicians develop these skills by necessity, particularly when access to specialist care is uneven or

delayed ((Baadjou et al., 2019). Findings from Study 3 also confirmed this, with participants assuming responsibility for their retraining and adjusting their own practice in response to waning levels of external support.

Autonomy is a crucial factor that motivates knowledge seeking and the skills to acquire and maintain retraining levels, especially when external support or intervention may be scarce. Bandura describes self-efficacy as “beliefs in one’s capabilities to organise and execute the courses of action required to produce given attainments” (Bandura, 1997). Similarly, patient empowerment focuses on “knowledge, skill, and confidence for managing one’s health,” considered a predictor of stronger self-care and follow-through (Hibbard et al., 2004). The converging message is that when musicians feel empowered to act, they are more likely to initiate, adapt, and sustain retraining autonomously.

Finally, learning science explains why autonomous self-management can work. Specific, timely feedback accelerates improvement (“the power of feedback”; Hattie & Timperley, 2007), while graded challenges and high-quality repetitions support neuroplastic change in motor skills (Guadagnoli & Lee, 2004; Kleim & Jones, 2008). In focal dystonia, constructivist, musician-led retraining builds on these same principles, aligning methods with the player’s context while keeping adjustments responsive and realistic (Détári & Altenmüller, 2025). In short, autonomy—often born of necessity—becomes a source of empowerment when it is paired with clear information, shared goals, and feedback that musicians can use in everyday practice.

Conclusion

Empowerment in MFD retraining is achieved when musicians are supported to lead their own plans, use simple and safe methods, and evaluate progress with measures that matter to them. Self-developed retraining, when coached and bounded by clear safety rules, is a practical route that fits the diverse realities of musical life. It respects artistic identity, reduces reliance on chance access to specialists, and offers a stable basis for return to meaningful performance.

7.7 LIMITATIONS OF THE PHD

The following section sets out the limitations for each of the 3 studies before discussing the overall limitations of the whole PhD, including methodological constraints, time constraints, and data availability.

Study 1

This study provides significant insight into issues of MFD awareness and PRHI discourse. However, the following limitations also need to be clearly acknowledged.

I. The generalisability of the findings is limited due to its limited geographical and cultural context (UK music conservatoires), and the relatively small sample size. Therefore, further studies with wider geographical and cultural reach are required in the future to increase the breadth of understanding.

II. The relatively small sample size (n=66 in each of the two groups) also increases the risk of sampling error due to participant variability. Non-probability and purposive sampling strategies also lower the generalisability of findings.

III. Randomisation was applied to both groups to produce the final sample, however, there is a high probability that respondents had similar characteristic or traits that may not reflect the whole population.

IV. Social desirability and recall bias are of significant concern as the study uses self-reported survey data. Also, due to the researcher's own personal experiences with focal dystonia, bias may unconsciously affect question framing and data interpretation.

V. Demographic factors including age, professional experience, specific instrumental group, or previous exposure to musicians' focal dystonia in personal or professional contexts, were discounted from this study. Therefore,

factors that could potentially influence attitudes, and also affect teachers' and students' knowledge, perceptions, and attitudes, were not considered.

VI. The study revealed important differences in MFD knowledge and attitudes between teachers and students. However, future research should investigate the driving factors of these variations in more detail. Future studies should implement qualitative research methods to thoroughly investigate these factors.

VII. Self-reported measures increase the chances of registering inconsistencies caused by differing interpretations of survey questions. Interview data was not collected which would permit a richer data set and more contextualised responses.

VIII. The cross-sectional nature of the study does not permit changes in opinions to be tracked over time.

IX. The study does not explore individual institutional policies concerning health education and therefore cannot measure survey responses against them.

Study 2

This mixed-methods research produced important information concerning the retraining utilisation of musicians rehabilitating from MFD. However, several important study restrictions must be acknowledged to increase the validity of the research.

I. This mixed-methods study offers an in-depth appraisal of how dystonic musicians experience the rehabilitation journey utilising retaining. The limitations of the reach are significant, reflecting the hypothesis generating nature of the enquiry.

II. The survey used non-probability online recruitment which produces self-selection and non-response biases and may over-represent individuals with higher digital access, health-seeking behaviour, or stronger opinions about retraining. The

research sample consisted mainly of English-speaking participants and therefore does not necessarily reflect differences in diagnosis and care pathways across different geographical locations, cultural backgrounds and healthcare systems.

III. The study had a moderate survey size of n=70. Subgroup analyses by retraining modality and instrumental group produced often small and uneven cell sizes which limits statistical power and the stability of estimates.

IV. The study uses a cross-sectional retrospective design which depends on participants recalling their time to diagnosis, subsequent time to retraining initiation, and pre/post-performance capacity. The study design makes it more likely for participants to recall events differently (recall bias) and for their responses to change over time, which excludes the establishment of cause-and-effect relationships.

V. The outcome measures, including adapted Music Performance Capacity ratings and perceived effectiveness/quality/support, were self-reported which makes them susceptible to social desirability, expectancy or justification bias, especially when participants had reported having financial or emotional stakes in particular approaches.

VI. Participants reported using multiple retraining methods with many combining different approaches. Therefore, attributing perceived improvements to any single modality is limited. Carryover effects including concurrent practice effects, concurrent medical treatments, practice reduction, changes in workload, or psychosocial support are all possible influencing factors.

VII. The six retraining categories show heterogeneity. However, the effects of each modality become less noticeable because of within-category heterogeneity and between-category overlap.

VIII. The measurement constraints included using the adapted Tubiana and Chamagne scale as a subjective self-rating scale. The lack of objective markers for triangulation restricts the ability to make claims about functional recovery.

IX. The research used instrumental group comparisons for exploratory purposes in its instrument-specific analyses. The observed patterns should be interpreted with caution due to the often-small cell size and potential influence of a particular teacher/studio. Contextual differences (e.g., repertoire demands) could also bias the observed patterns and therefore findings should be viewed as hypothesis-generating.

X. The research scope of qualitative data included a small interview sample of n=9 participants. The thematic analysis method provided additional depth to the study, but thematic saturation was applied to the sample rather than across different instruments and modalities. Researcher positionality together with limited member checking creates an increased risk of interpretive bias.

Study 3

The research design employed a qualitative approach to study the personal retraining processes experienced by musicians with focal dystonia. The research focused on examining retraining methods that musicians created for themselves instead of evaluating their effectiveness or consequences. The qualitative nature of the research is reflected in the following limitations.

I. Scope and intent: The study is experiential and descriptive and does not address the objective outcomes, effectiveness, or mechanisms of self-developed retraining methods. Accounts of personal improvements presented in this study represent subjective participant accounts and should not be taken as indicators of effectiveness.

II. The research faces challenges regarding transferability due to sample selection through online platforms. This limits the study's generalisability to MFD populations across different healthcare systems and non-English-speaking settings. The findings provide context-specific insights but is restricted when drawing broad conclusions.

III. Sample composition: The study had an unbalanced distribution among different musical instruments and affected body regions and career stages. The perspectives of individuals who discontinued self-developed retraining or completely avoided it might be underrepresented in this study.

IV. The participants who maintained self-developed approaches together with their ability to share their experiences might differ from those who experienced neutral or negative results thus leading to biased thematic results toward resilience and persistence.

V. Self-reported information contains both recall bias and response-shift effects as participants recall their experiences subjectively after the fact.

VI. “Self-developed” heterogeneity: The category encompasses diverse, overlapping practices (e.g., instrument-specific exercises, meditation, brain-spotting, movement methods) making cross-case comparison tentative and precluding attribution of any perceived change to specific components.

VII. The research failed to systemically track the duration of practice and participant adherence and practice fidelity alongside the measurement of previous therapy involvement although the study did not aim to evaluate outcomes.

VIII. The study lacked independent confirmation of MFD diagnosis and severity levels and failed to systematically distribute cases based on these criteria which affects the interpretation of findings.

IX. The study relies on participant experiences to describe different methods, yet it does not validate or prove the effectiveness of these approaches for musicians with MFD. The study cannot provide evaluation regarding their clinical value.

X. The cross-sectional nature of the study does not allow for observations of transformations in participants' experiences of their retraining strategies as they are maintained or change and their recovery and adaptation patterns evolve.

XI. The researcher's position in analysis combined with limited member checks and the absence of multiple coder validation increases the risk of interpretive bias despite reflexive measures.

XII. The need to protect confidentiality restricts the collection of complete contextual information about employment status and co-morbidities.

XIII. The recruitment process through online communities created potential biases as participants may have been influenced by established beliefs and peer interactions.

The study is descriptive and experimental and as such does not attempt to assess retraining outcomes. As such, it positions itself as a marker of importance for further investigation into the self-developed retraining of dystonic musicians.

The PhD generalisability is limited, initially due to reliance upon UK-based data from online non-probability samples, relatively small participant numbers and limited demographic representation. The three studies that comprise the research depend on retrospective self-reporting, which inherently includes recall bias and the tendency towards both response-shift bias and social desirability bias. The cross-sectional design prevents causal inference and changes tracking over time. The mixed-methods approach to the PhD faces challenges due to category heterogeneity, overlapping categories in the case of Study 2, and small cell sizes, which increase the risk of both Type I and Type II errors. The qualitative studies prioritise transferability over generalisability, with restricted contextual information concerning parameters including co-morbidities and employment status. Additionally, analytical limitations exist due to the nature of single-researcher coding, limited member checking, and researcher positionality. The PhD's findings are therefore somewhat restricted to being hypothesis-generating and practice-informing.

7.8 FUTURE DIRECTIONS

From a standpoint of awareness and prevention, the MFD research field is at an important moment. Advances in treatments continue to improve chances of recovery,

including the important work of a growing body of highly skilled retraining specialists. However, achieving complete recovery from the condition remains extremely challenging, re-enforcing the need for greater awareness and understanding of the condition amongst stakeholders.

From an educational standpoint, the dissemination of MFD and neurological playing health (NPH) information and the stimulation of discourse concerning risk-reduction and healthy practice, is crucial. Within musical Higher Education, further assessment of instrumental teachers' and students' existing PRHI knowledge can inform the development of expanded programmes of PRHI education, guiding the inclusion of MFD information and the concept of NPH. From an institutional perspective, the role of the instrumental teacher in guiding and signposting students requires further consideration. Bridging the gap effectively between the academic delivery of PRHI education, and its application within the performance faculty at conservatoires, needs collaboration between both. The combination of practical insight with theoretical knowledge is fundamental in effectively reaching and impacting students' perceptions of performance health. Longitudinal studies are needed to examine the potential effects of such initiatives, both amongst students and teachers.

Further studies are also needed to understand how we can improve the diagnostic experiences of musicians with MFD. As discussed extensively in this research, limited awareness of MFD significantly affects the ability of symptomatic musicians to seek appropriate medical help. The development of signposting frameworks to appropriate points of care is essential, as is the improvement of general clinicians' capacity to direct patients to appropriate specialists. Reducing the time between symptom onset and diagnosis must be a priority if we are to improve the chances of successful treatment outcomes.

The psychological and psychosocial factors of MFD, and their effects upon onset of the condition, are well understood within the literature. However, how these factors are addressed during rehabilitation, remains less clear. Participants in this research confirm that signposting to psychological support or assessment following a diagnosis is currently not common practice. This PhD advocates for including psychological triage and support as a part of a wider diagnostic protocol, to stimulate a more holistic and supportive approach to the diagnostic process. As musicians also report experiencing psychological and emotional transformation during their retraining

processes, intervention studies to measure potential performance capacity gains attributable to targeted psychological treatments or therapies, is desirable.

Finally, the importance of creating personalised and bespoke approaches to retraining cannot be underestimated. Constructivist approaches to retraining that are patient-led, and professionally supported, may represent the best chances for complete recovery. Investigation is required into how this can be practically achieved, including moving towards a unified retraining framework that adopts a multi-disciplinary approach to treatment. Further studies that include dystonic musicians from non-clinical settings are also needed to fully understand the concerns and requirements of dystonic musicians, including finding practical solutions to financial and geographical barriers, and increasing retraining accessibility for all.

7.9 CONCLUSIONS

During the course of this PhD, it has become increasingly clear that the experiences of professional musicians as they navigate MFD, from their earliest contact with the condition to the conclusion of their retraining, are frequently protracted and problematic. Amongst healthy musicians there remains a significant lack of awareness and understanding of MFD and its associated risk factors, a reality reflected in the confusion, difficulty, and delay reported amongst those searching for an explanation of possible symptoms. Addressing the awareness problem includes the improvement and development of health discourse between key stakeholders, particularly instrumental teachers and their students. This includes the one-to-one teaching environment within Higher Education musical institutions, an important moment in the formation of young professional musicians and a key platform from which to discuss and identify potential performance-related health issues (PRHIs).

Providing instrumental teachers with appropriate training that enables them to more effectively signpost and advise their students on PRHIs, including MFD, improves the chances of addressing potential problems more promptly. It also contributes towards creating a more centralised and proactive vision of PRHI education within undergraduate programmes of study, one that moves from a modular or elective component of music education to an integrated feature of musical training.

For students, it creates a channel of communication to discuss PRHIs, to express their concerns, and to receive appropriate support and guidance from their instrumental mentors when needed. It also encourages students to speak out about their playing-related health concerns and to take prophylactic action to reduce their PRHI risk-factors through open dialogue and more heath-centred approaches to performance.

For all musicians currently experiencing symptoms of MFD, the reality of poor awareness and understanding continues to be a significant problem in seeking appropriate medical care. Navigating the diagnostic process remains a gauntlet for many, with frequent accounts of misdiagnosis leading to extensive investigations of non-neurological causes, limited treatment options, and poor understanding of the profound effect that an MFD diagnosis can have upon the psychological wellbeing of musicians. Addressing the difficulties of diagnosis requires improved knowledge sharing between medical professionals and Performance Arts Medicine specialists, clear signposting to non-pharmaceutical treatment options including retraining, and acknowledgement of the importance of supporting musicians psychologically from the point of diagnosis itself.

For musicians that choose to retrain, a significant gap remains in the availability of comprehensive, impartial sources of information that clearly set out the aims and objectives of the current range of approaches. Instead, musicians continue to make haphazard choices, often with limited awareness of the multifactorial nature of MFD. Subsequently, many musicians are pigeon-holed into a state of “sunk cost fallacy”, being financially or emotionally tied to a particular approach or retraining specialist. Cognitive dissonance may also affect subjective evaluation of retraining methods. There is a clear divide between physiological and psychological approaches to retraining reflecting a significant shift towards holistic approaches to rehabilitation.

7.9.1 Implications for the Findings of the Research

1. Within Conservatoires

Drawing together the conclusions from this chapter, the educational implications of the findings fall within the following areas. From the standpoint of performance-related health awareness, addressing PRHI/NPH induction for new students, professional development (PD) for instrumental teachers, and establishing clear institutional signposting protocols, bridges the gap between treating PRHI education as a modular or optional experience, and being a fully integrated element of performance pedagogy. The integration of NPH elements, including sensorimotor mapping, practice variability, fatigue/stress regulation, and the importance of minimising excessive repetition into weekly studio teaching, technique classes, and assessment criteria, together with the implementation of short, observable NPH goals (for example, measurable gains in sound quality following slow/tactile drills) is also key to establishing NPH as a core element of practice and wellbeing. Setting clear boundaries for signposting versus clinical advice safeguards both students and teachers and facilitates prompt and appropriate responses to suspected NPH issues. Clear institutional policies concerning next-steps and referral procedures are needed to streamline the process and minimise the impact on teachers. PRHI discourse in the one-to-one lesson should be normalised within performance curricula and regular structured check-ins (for example, termly performance-health reports) empowers teachers to make considered observations and use appropriate language when potential issues with students occur.

When considering the financial implications of implementation within conservatoires, a single agreement made within the Conservatoires UK (CUK) network, for example, would allow member institutions to jointly commission the required specialist training from the British Association for Performing Arts Medicine (BAPAM). A joint commission would also facilitate the incorporation of funds from other relevant organisations including Arts Council England, Help Musicians, and other sources of arts-health support. It would also reduce the chance of duplication, which in turn ensures parity of provision. From a research perspective, it enables the creation of shared datasets that can be used to secure extra funding or satisfy existing funders' requirements, all at a relatively low cost.

Implementation of these changes are justified on educational, ethical, and financial grounds. Students are likely to experience fewer and milder health issues, more

efficient practice, steadier sound under pressure, and better management of stress and fatigue. Institutions can expect improved progression and retention and fewer lesson cancellations. Clear boundaries and referral routes also reduce legal risk. Shared commissioning can minimise up-front costs, whilst focusing on prevention can reduce greater spending on injury and remediation. Alignment with sector guidance also strengthens credibility with funders and professional bodies.

2. Within Music Employment

Implications for music employment reflect the need for changes to occupational health standards for music organisations within the UK. As suggested in the recommendations for UK music conservatoires, the adoption of written policies for reporting PRHIs, including suspected cases of MFD, rapid triage to PAM, and the identification/capacitation of a designated PRHI “navigator” within organisations, is crucial. Evidence-based restrictions on continuous playing together with mandated “micro-breaks” are necessary, as are protected, contractually agreed channels of confidential, non-punitive disclosure for musicians with PRHI concerns. For suspected cases of MFD, such protection layers are fundamental in encouraging musicians to seek help precociously rather than avoiding or evading treatment due to fear of potential professional repercussion or discrimination.

Implementation of written recommendations concerning PRHIs and NPH procedures should require minimal changes to existing schedules and occupational health policies within workplaces therefore facilitating rapid adaptation at low cost whilst offering measurable benefits to both players and employers. Signposting to early triage and better pacing of treatment can reduce physical crises and setbacks, which in turn reduces the number of work cancellations, and produces steadier performance quality. The health benefits to affected musicians are positive including feeling supported by their employers, and musical organisations are empowered to improve due care, which can be beneficial when negotiating with insurers and regulators. For suspected focal dystonia cases, clear protections and rapid referral channels encourage early help-seeking, shown to produce the most favourable treatment outcomes within the shortest time periods. Adjusting employment roles or responsibilities whilst undergoing

treatment can protect income, and by tracking metrics including sick days, last-minute costs for contracting deputy players, and player feedback, it is possible to gauge returns on what is, a small investment. In short, adding PRHIs and NPH to union policy and workplace standards is practical, low-cost, and raises both wellbeing and artistic results

3. **Within Health Services**

The findings of the research point clearly to a shortcoming concerning care pathways for musicians affected by MFD. Improving MFD clinical literacy through continuing professional development (CPD) for neurologists, general practitioners (GPs) and occupational therapists (OTs) is therefore recommended. Information concerning symptom recognition, differential diagnoses and non-pharmacological treatment options, together with video exemplars and red-flag checklists should be made more widely available for health service professionals. The development of mapped referral routes from GP to movement disorder neurology to PAM, together with target timelines (e.g., less than 8 weeks to specialist opinion) are also favourable, as is the publication, dissemination and availability of such information on accredited PAM websites linked to clinical health services. In doing so, this can significantly improve the ability of health professionals to make informed and more timely clinical decisions.

A standardised path to care for suspected cases of MFD can also be justified in the following ways. Firstly, by reducing costs associated with inappropriate investigations and repeat consultations with GPs, orthopaedic specialists and neurologists. Secondly, by reducing ineffective or mis-timed interventions. Thirdly by improving targeting of botulinum toxin application and pharmacological treatments to reduce wastage whilst incorporating combined retraining, and finally by improving mental health signposting and reducing the burden on crisis services.

Although the incidence of MFD is low, the investment required to provide a standardised care pathway is also low. The benefits to health care systems are positive, both in potential savings and providing more personalised, “right person, right place” care. It also allows musicians to make more informed choices concerning their

condition, in turn reducing haphazard and often allegiance influenced choices that can significantly affect professional outcomes. From a research perspective, the collection of clinical data that reflects the multifactorial nature of the condition including wellbeing, self-efficacy and return-to-work rates can also greatly help to accelerate the learning process and refine guidance for future sufferers.

This research does not set out to address the question of “which retraining approach is more effective?” or to address questions of aetiology or phenotypic heterogeneity. Instead, it draws specific attention to the reality of navigating MFD from the musicians’ standpoint. As the focus of research moves towards prevention, it is vital that we continue to develop more integrated networks of musical educators, physicians, psychologists and retraining specialists to address both the short and long-term implications of MFD, and healthy neurology in performance.

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Appendices

Appendix A: Invitation Letter and Consent Form – Teachers/Students - Study 1

TRINITY LABAN CONSERVATOIRE
OF MUSIC & DANCE

Dear Esteemed Colleague,

My name is David Gardner; I am a professional cellist currently undertaking my Ph.D. at Trinity Laban Conservatoire of Music and Dance in London.

As part of my research into focal dystonia awareness (a movement disorder that disproportionally affects musicians and their careers), I am investigating what instrumental music students and teachers currently know about, and think about the condition, and how we approach movement health and other performance health issues within instrumental lessons.

It is not important if you are an expert on the subject, or have never even heard of focal dystonia before, your contribution is equally important. This will be the first study of its kind and will help to develop strategies for awareness and prevention of focal dystonia in the future.

I would like to invite you to complete a short survey.
(It takes approximately 6 - 8 minutes to complete)

Here are the links. If you are interested in participating, please choose the link that applies to your current position.

Student Version
Teacher Version

Participant inclusion checklist:

- *I am an instrumental music teacher in a Higher Education institution of music performance.*
- *I am over 18 years of age.*
- *I have NOT been medically diagnosed with focal dystonia.*

I would like to keep all research participants up to date on the study as it progresses and if you have any questions or would like to know more, please don't hesitate to contact me at the e-mail address below.

At the end of the survey, there are a number of links to organisations that offer services for musicians' health in case you have any questions or concerns about your playing health or would like to know more about focal dystonia.

Thank you for your time!

David Gardner
MA. BMus Hons.
[redacted]

This survey has been cleared by the research ethics committee at Trinity Laban Conservatoire of Music and dance for use worldwide.

Social Media Invitation - Students - Study 1

Dear Sir/Madam,

I am currently undertaking my PhD research and was wondering if you could publish a research participation request on your social media pages?

I have included the post below in green.

With thanks in advance!

David Gardner
MA BMus(Hons)

Internet Post

Hi there! My name is David Gardner. I am a professional cellist and PhD candidate at Trinity Laban Conservatoire. My research is looking into how we discuss performance-related health issues with our principal study teachers, and what we know about focal dystonia (a medical condition that can sometimes affect musicians).

If you are an instrumental music students currently studying at a conservatoire, university or other Higher Education, I would like to invite you to take a short survey (it takes 5 minutes).

It does not matter what you currently know about focal dystonia, even if you've never heard of the condition before your participation will greatly contribute to our understanding of this condition and help in the development of prevention strategies for musicians.

To take the survey, please follow the link.

Movement Health in Musicians (Student version)
surveymonkey.com

Thank you for your time and help!

Information and Consent

Movement Health in Musicians *(Student version)*

Participant Information

Researcher Information
This study is being undertaken by myself, David Gardner, as part of my doctoral degree research at Trinity Laban Conservatoire of Music & Dance.

For more information or if you have any questions or concerns please contact my supervisor, Dr.Emma Redding, or myself at the following e-mail addresses:
[redacted]

Has the research been the subject of ethical review?
Yes, this research has been granted ethical approval by Trinity Laban Conservatoire of Music and Dance, London.

What happens next if I decide to take part?
You will be required to accept each of the terms of the consent form on the following page before commencing the survey. If you agree to the terms of the study you will still be free to withdraw at any time.

What are the possible risks of taking part?
This survey poses questions that will ask you to think about Focal Dystonia, a medical condition that may be uncomfortable for some. It is a sensitive topic that may provoke feelings of anxiety or distress. For this reason, you have the right to opt-out of completing the survey at any stage without giving any reason.

Will I be paid to take part?
No, you will not be paid to take part in the research.

Will my participation in this project be kept confidential?

All the information that is collected will be kept strictly confidential. Answers to this survey will be kept anonymous and you will not be able to identify yourself or be identified by others, including the researcher unless you opt to include your email address at the end of the survey. Any data will be stored on the Trinity Laban Conservatoire of Music and Dance centrally managed network in password-protected folders. Please consult the survey monkey privacy policy https://www.surveymonkey.com/mp/legal/privacy/

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Movement Health in Musicians *(Student version)*

Consent

Please read the following statements carefully.

- I confirm that I have read the participant information sheet for this study.

- I understand that my participation in this study is voluntary.

- I understand that I am free to withdraw from this study at any time without giving any reasons for my withdrawal.

- I consent to the data collected, once anonymised (so that it cannot be identified to any individual) to be used for this Ph.D. research and other research purposes including conferences and publications.

- I give my consent to participate in this study under the conditions outlined above.

Do you agree to the above terms? By clicking Yes, you consent that you are willing to answer the questions in this survey.

- ◯ Yes
- ◯ No

Do you consent to your personal data being processed as described above? You must click Yes in order to take the survey.

- ◯ Yes
- ◯ No

Appendix B: Invitation Letter (Both Phases) and Consent Forms - Study 2

TRINITY LABAN CONSERVATOIRE
OF MUSIC & DANCE

1. Understanding Musicians' Focal Dystonia

Thank you for taking an interest in this research, your contribution is greatly appreciated!

This survey has been designed as part of my Ph.D. research into prevention strategies in musicians' focal dystonia (MFD). It has been made for musicians who have undertaken or are currently undertaking some form of movement retraining as part of their treatment for MFD. Movement retraining for MFD includes techniques such as splinting, muscle rebalancing, biofeedback, neuroplastic retraining, sensorimotor retraining (e.g splinting) cognitive/emotionally focused retraining, neuromodulation, and may or may not include training with a therapist/specialist.

I would like to know more about your personal experiences with movement retraining, to try to understand what is working (or not!) for you, and the effects it has upon your playing.

Research continues to show the many benefits of movement retraining for musicians with MFD. Understanding these benefits, and how musicians with MFD experience them, is central to developing tools for prevention.

The information gathered from you during this questionnaire will help to provide a better understanding of MFD from the musician's point of view and hopefully point towards ways in which we can work together towards its prevention.

Completion of the questionnaire will take approximately 8 minutes.

Thank you for your time!

2. Participant Information

Researcher Information
This study is being undertaken by myself, David Gardner, as part of my doctoral degree research at Trinity Laban Conservatoire of Music & Dance.

For more information or if you have any questions or concerns please contact my supervisor, Dr.Emma Redding, or myself at the following e-mail addresses:
[redacted]

Has the research been the subject of ethical review?
This research has been granted ethical approval by Trinity Laban Conservatoire of Music and Dance, London.

What happens next if I decide to take part?
You will be required to accept each of the terms of the consent form on the following page before commencing the survey. If you agree to the terms of the study you will still be free to withdraw at any time.

What are the benefits of taking part?
Your participation will help to increase awareness and knowledge of movement retraining amongst musicians with focal dystonia. You will also be contributing towards the development of strategies for prevention and increased awareness of focal dystonia within university music departments and conservatories.

What are the possible risks of taking part?
This survey poses questions that will ask you to think about your personal experiences with Focal Dystonia and your ups and downs with retraining. It is a sensitive topic that may provoke feelings of discomfort or distress. For this reason, you have the right to opt out of completing the survey at any stage without giving any reason.

Will I be paid to take part?
No, you will not be paid to take part in the research.

Will my participation in this project be kept confidential?

All the information that is collected will be kept strictly confidential. Answers to this survey will be kept anonymous and you will not be able to identify yourself or be identified by others, including the researcher. Any data will be stored on the Trinity Laban Conservatoire of Music and Dance centrally managed network in password-protected folders. Please consult the survey monkey privacy policy https://www.surveymonkey.com/mp/legal/pri

3. Participant Information B

What if I decide to withdraw from the research after completing the questionnaire?

Under the General Data Protection Regulation (GDPR), you have a general right of access to your data, a right to rectification, erasure, restriction, objection, or portability. You also have a right to withdraw. For further information see, https://www.trinitylaban.ac.uk/about-us/governance/policies-and-freedom-of-information/data-policies-and-subject-rights/.

On what basis will the researcher process my data?

Under the General Data Protection Regulation (GDPR), Trinity Laban Conservatoire of Music and Dance has to identify a legal basis for processing personal data and, where appropriate, an additional condition for processing special category data.

The research will only be undertaken where ethical approval has been obtained, where there is clear public interest, and where appropriate safeguards have been put in place to protect data.

In line with ethical expectations and in order to comply with common law duty of confidentiality, we will seek your consent to participate where appropriate. This consent will not, however, be our legal basis for processing your data under the GDPR.

Any personal data collected by SurveyMonkey may be transferred to various countries, including the United States and other locations SurveyMonkey has offices.

Data will be held within the European Economic Area in full compliance with data protection legislation.

4. Consent

Please read the following statements carefully.

- I confirm that I have read the participant information sheet for this study.

- I understand that my participation in this study is voluntary.

- I understand that I am free to withdraw from this study at any time without giving any reasons for my withdrawal.

- I consent to the data collected, once anonymised (so that it cannot be identified to any individual) to be used for this Ph.D. research and other research purposes including conferences and publications.

- I give my consent to participate in this study under the conditions outlined above.

Do you agree to the above terms? By clicking Yes, you consent that you are willing to answer the questions in this survey.

- ◯ Yes
- ◯ No

5. Data Consent

Do you consent to your personal data being processed as described above? You must click Yes in order to take the survey.

- ◯ Yes
- ◯ No

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SurveyMonkey
See how easy it is to create surveys and forms.

Interview Participation Information and Online Consent Form

Interviews for Research

Understanding Musicians' Experiences of Movement Retraining for Focal Dystonia

Participant Information and On-Line consent to take part in research.

Researcher : PhD Candidate, David Edward Gardner M.A/BMus.
Supervisor : Professor Emma Redding Ph.D.

Trinity Laban Conservatoire of Music & Dance, King Charles Court, Old Royal Naval College, Greenwich, London, SE10 9JF , London , UK

Contact : E-mail [redacted]

Researcher Information

This study is being undertaken by myself, David Gardner, as part of my doctoral degree research at Trinity Laban Conservatoire of Music & Dance

Has the research been the subject of ethical review?

This research has been granted ethical approval by Trinity Laban College of Music and Drama, London.

What happens next if I decide to take part?

You will be required to accept each of the terms of the consent form on the following page before commencing the interview process. If you agree to the terms of the study you will still be free to withdraw at any time.

What are the benefits of taking part?

Your participation will help to increase and deepen awareness and knowledge of movement retraining amongst musicians with focal dystonia. You will also be contributing towards the development of strategies for prevention and increased awareness of focal dystonia within university music departments and conservatories.

What are the possible risks of taking part?

The questions posed in this interview will ask you to think about your personal experiences with Focal Dystonia and your personal retraining experiences. It is a

sensitive topic that may provoke feelings of discomfort or distress. For this reason, you have the right to stop the interview process at any point or refuse to answer any question at any stage without giving any reason.

Will I be paid to take part?

No, you will not be paid to take part in the research.

Will my participation in this project be kept confidential?

All interviews will be kept strictly confidential. Interviews will be kept anonymous and you will not be able to identify yourself or be identified by others, including the researcher. Interview recordings will be securely stored on the Google Meet platform GoogleMeet Privacy Terms with restricted link access being allowed on request exclusively to participants and myself, David Edward Gardner. No other access to interview transcripts will be permitted.

What if I decide to withdraw from the research after taking part in this interview research?

Under the General Data Protection Regulation (GDPR), you have a general right of access to your data, a right to rectification, erasure, restriction, objection, or portability. You also have a right to withdraw. For further information see, https://www.trinitylaban.ac.uk/about-us/governance/policies-and-freedom-of-information/data-policies-and-subject-rights/.

On what basis will the researcher process my data?

Under the General Data Protection Regulation (GDPR), Trinity Laban Conservatoire has to identify a legal basis for processing personal data and, where appropriate, an additional condition for processing special category data.

The research will only be undertaken where ethical approval has been obtained, where there is clear public interest, and where appropriate safeguards have been put in place to protect data.

In line with ethical expectations and in order to comply with common law duty of confidentiality, we will seek your consent to participate where appropriate. This consent will not, however, be our legal basis for processing your data under the GDPR.

Any personal data collected by SurveyMonkey may be transferred to various countries, including the United States and other locations SurveyMonkey has offices.

Data will be held within the European Economic area.

* Please confirm that you have read each of the following statements.

I voluntarily agree to participate in this research study.

I understand that even if I agree to participate now, I can withdraw at any time or refuse to answer any question without any consequences of any kind.

I understand that I can withdraw permission to use data from my interview within fourteen (14) days after the interview, in which case the material will be deleted.

I have had the purpose and nature of the study explained to me in writing and I have had the opportunity to ask questions about the study.

I understand that participation involves an recorded interview of approximately 45-60 minutes with the researcher.

I understand that I will not benefit directly from participating in this research.

I agree to my interview being audio-recorded.

I understand that all information I provide for this study will be treated confidentially.

I understand that in any report on the results of this research my identity will remain anonymous. This will be done by changing my name and disguising any details of my interview which may reveal my identity or the identity of people I speak about.

I understand that disguised extracts from my interview may be quoted in the final thesis of the researcher David Edward Gardner and in presentations, conferences and scholarly articles pertinent to the research.

I understand that if I inform the researcher that myself or someone else is at risk of harm they may have to report this to the relevant authorities - they will discuss this with me first but may be required to report with or without my permission.

I understand that signed consent forms and original audio recordings will be retained in a secure GoogleMeets file and as a locked file on the personal laptop of David Edward Gardner, accessible only by David Edward Gardner and interview participants until December 31st 2023.

I understand that a transcript of my interview in which all identifying information has been removed will be retained for 4 years from the date of recording.

I understand that under freedom of information legalisation I am entitled to access the information I have provided at any time while it is in storage as specified above.

I understand that I am free to contact any of the people involved in the research to seek further clarification and information.

Do you agree to take part in this research?
Yes
No
Name
Email Address

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Appendix C: Invitation Letter and Consent Form - Study 3

TRINITY LABAN CONSERVATOIRE
OF MUSIC & DANCE

Ph.D. Research Participation Invitation

Dear Esteemed Colleague,

I hope this letter finds you in good health. My name is David Gardner, and I am a professional cellist and Ph.D. candidate at Trinity Laban Conservatoire of Music & Dance in London, England. I am writing to invite you to participate in an interview-based research study investigating the self-developed retraining strategies utilised by musicians during their rehabilitation from focal dystonia.

Musicians diagnosed with focal dystonia often undertake their own retraining approaches to manage the condition. This typically involves a combination of both physiological and psychological approaches, such as adapting or developing specific exercises and techniques. Understanding the specifics of this type of retraining is vital for musicians. Unfortunately, many currently experience slow diagnostic processes, and this information is difficult to obtain, leading to prolonged delays that can adversely impact rehabilitation outcomes.

I believe that your participation in this study would help to significantly enhance our understanding of the retraining processes involved in rehabilitation from focal dystonia. The primary aim of the research is to inform and develop a more unified approach to managing musicians' dystonia through retraining. By sharing this research with medical practitioners and musicians, we can help newly diagnosed musicians achieve more successful rehabilitation by quickly recommending retraining methods that are both effective and tailored to the individual musician’s needs. This will pave the way to reduce lengthy, often haphazard retraining decisions and poor diagnostic experiences, thereby improving retraining outcomes for those recently affected.

By participating in this study, you will have the opportunity to contribute to the advancement of evidence-based research that enhances the field of bespoke retraining for musicians with dystonia. The estimated time commitment for participation involves an interview session of 60-90 minutes (to be conducted either online or in person).

Please be assured that your participation in this research will be strictly confidential. All data collected will be anonymised and used solely for research purposes in accordance with ethical approval clearance granted by Trinity Laban Conservatoire of Music and Dance. Your privacy and confidentiality will be protected throughout the study. If you agree to participate, we will schedule convenient times for your

interviews and practice observations. You are under no obligation to participate and may withdraw from the study at any time without any consequences.

If you have any questions or concerns about the research, or would like to participate, please don't hesitate to contact me at:
[redacted]

David Gardner *(Ph.D. Candidate/MA/BMus Hons)*

TRINITY LABAN CONSERVATOIRE
OF MUSIC & DANCE

Participation Consent Form

Title of Study:

Investigating The Impact of Self-Developed Retraining in Musicians' Dystonia Rehabilitation: An In-Depth Thematic Analysis

Principal Investigator: David Edward Gardner MA
Research Supervisors: Mr. Mark Phillips, MD, Dr. Emma Redding MBE Contact Information: David Gardner[redacted] Ph.D. Candidate, Trinity Laban Conservatoire of Music and Dance Email: [redacted]

Purpose of the Study:

The aim of this study is to investigate the self-developed retraining strategies utilised by musicians during their rehabilitation from focal dystonia. This research seeks to inform and develop a more detailed understanding of how we manage and navigate musicians' dystonia through retraining, ultimately improving rehabilitation outcomes for those affected.

Study Procedures:

If you agree to participate, you will be involved in the following activities:

1. An interview session of 60-90 minutes (conducted either online or in person).

Dates:

The dates for the interview will be flexible within the time frame of the interview. The interviews will begin in September and run until the end of November 2024.

Confidentiality:

All information collected during this study will be anonymised and used solely for research purposes in accordance with ethical approval granted by Trinity Laban Conservatoire of Music and Dance. Strict confidentiality will be maintained, and your data will be securely stored.

Voluntary Participation:

Your participation in this study is completely voluntary. You are under no obligation to participate and may withdraw from the study at any time without any consequences.

Potential Risks and Benefits:

Whilst the practice exercise protocols are designed to be safe, there is a possibility of discomfort or fatigue during the exercise sessions. However, the risk of any severe adverse effects is minimal. The potential benefits of participating in this study include contributing to the understanding of focal dystonia prevention, improved movement health awareness, and strategies to mitigate risks associated with focal dystonia onset.

Questions and Contact Information:

If you have any questions or concerns about this study, please contact me, David Gardner at [redacted]. If you have any concerns about your rights as a participant or wish to report a research-related problem, you may contact the [Institutional Review Board] at [Institutional Review Board Contact Information].

By signing below, you confirm that:

1. You have read and understood the information provided in this consent form.
2. You have had the opportunity to ask questions and have received satisfactory answers.
3. You voluntarily consent to participate in this research study.
4. You understand that you may withdraw from the study at any time without consequences.

- I confirm that I have read the participant information sheet for this study. - I understand that my participation in this study is voluntary.

- I understand that I am free to withdraw from this study at any time without giving any reasons for my withdrawal.

- I consent to the data collected being anonymised, and published in academic journals, and as part of this PhD research project

Participant's Signature: _____ Date: _____

Printed Name: _____

Principal Investigator's Signature: _____ Date: _____

Appendix D: Survey Instrument Study 1

Questionnaire

Survey – PRHI/MFD Awareness - Instrumental TEACHERS

Q1 “I discuss PRHIs with my students”.

Q2 "I discuss ways to resolve playing-related health issues autonomously in the future, with my students".

Q3 “I discuss ways to maintain a healthy playing technique autonomously in the future with my students”.

Q4 “I am confident that my students can maintain a healthy playing technique on my/their own in the future.

Q5 “I am confident that my students can resolve playing-related health issues on my/their own in the future.

Q6 “I can identify movements that negatively affect my students’ playing.

Q7 How aware are you of MFD?

Q8 How aware are you of risk factors associated with the possible onset of MFD.

Q9 “As a musician I am concerned about MFD”.

Q10 “Informing music students about MFD may do more harm than good”.

Survey – PRHI/MFD Awareness - Instrumental STUDENTS

Q1 “I discuss PRHIs with my teacher”.

Q2 "I discuss ways to resolve playing-related health issues autonomously in the future, with my teacher".

Q3 “I discuss ways to maintain a healthy playing technique autonomously in the future with my teacher”.

Q4 “I am confident that I can maintain a healthy playing technique on my/their own in the future.

Q5 “I am confident that I can resolve playing-related health issues on my/their own in the future.

Q6 “I can identify movements that negatively affect my own playing.

Q7 How aware are you of MFD?

Q8 How aware are you of risk factors associated with the possible onset of MFD.

Q9 “As a musician I am concerned about MFD”.

Q10 “Informing music students about MFD may do more harm than good”.

Appendix E: Survey Instrument Study 2

1. Background Information

To which gender do you most identify?

Female Male Gender Variant/Non-conforming Not Listed

What is your age?

18 to 24 25 to 34 35 to 44 45 to 54 55 to 64 65 to 74 75 or older

Which instrument/s do you play that is/are affected by your MFD?

Which area of your body has been affected by MFD?

Left-Hand Right-Hand Embouchure Other (please specify)

How old were you when you were diagnosed with MFD?

18-24 25-34 35-44 45-54 55-64 65-74 75 or older

For how long have you been affected by MFD?

Less than six months More than six months but less than a year. More than a year but less than two years. More than two years but less than three. More than three years but less than four. More than four years but less than five. More than five years.

2. Prior to Retraining

How much time passed between experiencing the first symptoms of focal dystonia and getting an official diagnosis?

Less than six months More than six months but less than a year. More than a year but less than two years. More than two years but less than three. More than three years but less than four. More than four years but less than five. More than five years.

How much time passed between getting an official diagnosis and beginning your retraining?

Less than six months More than six months but less than a year. More than a year but less than two years. More than two years but less than three. More than three years but less than four. More than four years but less than five. More than five years.

How much time have you spent retraining in total? Less than six months

Less than six months More than six months but less than a year. More than a year but less than two years. More than two years but less than three. More than three years but less than four. More than four years but less than five. More than five years.

3. Retraining choices

Which of the following type/s of retraining have you undertaken to help your MFD?

Have you undertaken any movement retraining for your MFD using [RETRAINING APPROACH]

Yes No

4. [RETRAINING APPROACH] Perceptions/Outcomes

For how long have you used this form of retraining for your MFD?

Less than 6 months More than 6 months but less than a year More than one year but less than two years More than two years but less than three years More than three years but less than four years More than four years but less than five years More than five years

Which of the following statements most closely represents your MFD symptoms BEFORE this retraining?

Unable to play
I can play several notes but stop because of blockage or lack of facility
I play short sequences without rapidity and with unsteady fingering
I play easy pieces but is unable to perform more technically challenging pieces
I play almost normally; difficult passages are avoided for fear of motor problems
I play normally

Which of the following statements most closely represents your MFD symptoms AFTER this retraining?

Unable to play
I can play several notes but stop because of blockage or lack of facility
I play short sequences without rapidity and with unsteady fingering
I play easy pieces but is unable to perform more technically challenging pieces
I play almost normally; difficult passages are avoided for fear of motor problems
I play normally

5. [RETRAINING APPROACH] Support and Quality

The next set of questions will ask you to what extent you felt supported during this retraining and how you perceive its effectiveness.

How would you rate the level of support from your instructor **DURING** this retraining?

Excellent Good Average Quite Poor Very Poor Not Applicable

How would you rate the level of support from your instructor **AFTER** this retraining?

Excellent Good Average Quite Poor Very Poor Not Applicable

How would you rate the quality of this retraining?

Very high-quality Low quality High quality Very low quality Neither high nor low quality

How could the quality of this retraining be improved?

6. [RETRAINING APPROACH] effectiveness

How would you rate the overall effectiveness of this retraining for your MFD?

Extremely effective Very effective Somewhat Effective Not so effective Not at all effective

Appendix F: Qualitative Phase Interview Schedule - Study 2

Subject: Background and Onset
1) Musical background
- Could you tell me about your background as a musician (primary instrument(s), roles, training, current work, typical performance/teaching load)?
2) MFD onset and early impact
- When did you first notice something was off in your playing? What did you notice, and how did it affect your playing?
3) Diagnosis pathway
- How did you seek help and eventually receive a diagnosis?
- Approximately how long after first symptoms was the diagnosis made? How did you experience that process?
4) Decision to retrain
- At what point in your journey did you decide to explore retraining?
- How long ago was that, and how long have you been using retraining approaches?
5) Initiation of retraining
- About how long after diagnosis did you begin retraining? How was that initial experience for you?
Subject: Perceptions of MFD
6) Understanding of MFD
- How would you describe your understanding of MFD now?
- What was your understanding before diagnosis, and has it changed since retraining?
7) Teaching, mentorship, and bodily awareness
- In what ways did your relationships with teachers/mentors help or hinder you?
- How would you describe your bodily awareness before MFD, and how (if at all) has it changed?
8) Identity and musicianship
- How has MFD influenced your musical identity and the way you think about your playing?
- How would you describe the connection between your bodily movements and musical self-expression after retraining?
9) Retrospective reflections
- Looking back, is there anything you would have done differently in your training or career prior to MFD?

Subject: Retraining Choices and Expectations
10) Retraining experiences
- Could you tell me about your experiences with retraining for MFD?
11) Rationale for choices
- What led you to undertake movement retraining, and why did you choose particular approaches over others?
12) Expectations and surprises
- What were you expecting from retraining?
- What occurred that was unexpected, and what didn't happen that you anticipated?
- What impact did you expect retraining to have on your playing?
13) Support and follow-up
- What kinds of support did you receive during and after retraining (e.g., guidance, feedback, follow-up care)? For how long?
- What, if anything, could have been improved?
Subject: Retraining Content and Outcomes
14) Techniques and concepts
- What techniques, exercises, or concepts did you learn and apply during retraining?
15) Application and adaptation
- Can you share examples of exercises/techniques you used and how they helped your playing?
- Were there elements that did not work for you?
- To what extent did you adapt or develop your own exercises based on what you learned?
16) Changes in playing
- What changes have you noticed in your playing as a result of retraining (positive, negative, or no change)?
17) Perceived effectiveness
- Overall, how effective do you feel your retraining has been, and why?
18) Advice to others
- Based on your experience, what advice would you offer to student or young musicians in training?
Subject: Closing
19) Final reflections and next steps
- Is there anything important we haven't covered?
- Do you have any questions about what we discussed?

- May I keep in contact to share updates on the research? If so, here is my email address should you wish to reach out with further thoughts or questions.

Appendix G - Interview Schedule Study 3

Musical background
- Could you tell me a bit about your musical background and what you play?
- Onset, diagnosis, and early coping
- When did you first feel something wasn't quite right, and what made you think it might be dystonia?
- How did you end up getting a diagnosis? Was it around that time?
- What was that whole experience like for you?
- How were you doing mentally through all of this?

Starting your self-developed retraining
- Was this when you began creating your own retraining approach?
- What pushed you to develop your own techniques rather than relying only on standard medical advice or therapy?

Designing and choosing methods
- Can you talk me through your methods a bit? What led you down this particular path?
- How did you get started developing your own retraining techniques? What steps did you take?
- How did you figure out which techniques might actually work for you?
- What did you consider when choosing methods (things like cost, time, ease, past experiences, input from others)?
- How did you decide when to stick with a method? What told you it was working?
- Were there any books, people, communities, or professionals that influenced your choices?

Practice and routine
- Could you walk me through a typical practice session using your self-developed methods?

Evolving the approach and overcoming challenges
- How have your techniques changed over time? Any concrete examples?
- What were the toughest parts of setting up and sticking to your retraining routine?

Measuring progress and timeline
- How do you track progress or know you're improving?
- How long did it take before you noticed meaningful progress?

Returning to performance and current impact
- What was it like getting back to playing in public?
- How do things feel for you now? How has the retraining affected your playing and your identity as a musician?

Reflections, teaching, and advice
- Looking back, how do you feel about your retraining and the results you've achieved?
- How has this journey changed the way you play and teach?
- What would you say to younger musicians or anyone facing something similar?

Prevention and hindsight
- If you'd known about dystonia earlier, is there anything you think you would have done differently in your training to help prevent it?

Appendix H: Study 1 - Factor Loadings from Principal Component Analysis

Survey Quest.	Comp.1	Comp.2	Comp.3	Comp.4	Comp.5	Comp.6	Comp.7
S.Q1:	0.194	0.320	0.356	0.560	0.068	-0.256	-0.045
S.Q2	0.050	0.442	0.333	0.284	0.046	-0.323	-0.247
S.Q3:	0.325	0.278	0.679	0.004	-0.017	-0.191	-0.026
S.Q4:	0.074	0.350	0.350	-0.021	-0.318	0.658	-0.018
S.Q5:	0.016	0.463	0.332	-0.015	-0.543	0.365	-0.064
S.Q6:	0.027	0.158	0.191	-0.116	-0.074	0.842	-0.181
S.Q7:	-0.279	0.532	-0.248	0.099	0.536	0.204	0.157
S.Q8:	-0.119	0.588	-0.140	0.133	0.487	0.310	-0.198
S.Q9:	0.332	-0.395	0.360	0.068	0.331	-0.044	-0.231
S.Q10:	-0.153	0.203	-0.506	0.229	-0.429	-0.034	-0.213
T.Q1:	0.546	0.201	-0.384	-0.205	-0.221	-0.160	-0.096
T.Q2:	0.737	-0.003	-0.123	-0.401	-0.105	-0.022	-0.092
T.Q3:	0.756	0.138	-0.150	-0.044	-0.004	-0.146	-0.160
T.Q4:	0.507	0.459	-0.157	0.089	-0.066	-0.010	0.249
T.Q5:	0.495	0.532	-0.305	0.201	0.185	-0.044	0.132
T.Q6:	0.619	-0.215	0.031	-0.327	0.269	0.174	0.030
T.Q7:	0.470	-0.434	0.195	0.350	0.048	0.276	0.115
T.Q8:	0.372	-0.413	-0.035	0.525	0.095	0.388	0.082
T.Q9:	-0.018	-0.183	-0.092	0.671	-0.229	-0.258	0.058
T.Q10:	-0.209	0.245	0.388	-0.424	0.142	-0.174	-0.100

KEY:

S. Student Questions

T. Teacher Questions

Comp. = Components

1. PRHI Communication
2. Awareness
3. Autonomy
4. Concerns about MFD
5. Confidence in Resolving PRHIs
6. Identifying Negative Movements
7. Mixed Concern

Component	Variance Explained (%)	Cumulative Variance (%)
Component 1:	15.40	15.40
Component 2:	13.08	28.48
Component 3:	9.69	38.17
Component 4:	9.41	47.58
Component 5:	7.41	54.99
Component 6:	6.74	61.73
Component 7:	5.48	67.21
Total	**67.21**	

1. Component 1: **PRHI Communication**: Items T.Q2 (0.737), T.Q1 (0.546), and T.Q4 (0.507) showed the highest loading indicating a significant focus on the importance of communication in educational contexts.

2. Component 2: **Awareness**

This component was presented through strong loadings from S.Q2 (0.442), S.Q5 (0.463), and T.Q5 (0.532), suggesting that both students and teachers are particularly aware of the dynamics within their educational environment.

3. Component 3: **Autonomy**

The question S.Q3 demonstrated a high loading (0.679), indicating that autonomy is an important factor affecting students' perceptions and experiences of their education.

4. Component 4: **Concerns about MFD**

Item T.Q9 had the strongest loading (0.671), highlighting teachers' concerns regarding decision-making processes that require quick judgments, potentially reflecting anxiety or the pressure associated with educational decision-making.

5. Component 5: **Confidence in Resolving PRHIs**

This component had varied loadings, with S.Q5 (-0.543) suggesting negative sentiments regarding the ability to resolve personal or professional challenges.

6. Component 6: **Identifying Negative Movements**

Item S.Q6 had a particularly high loading (0.842), indicating that teachers find it important to identify and address negative trends and movements of their students.

7. Component 7: **Mixed Concern**

This component did not present any strong loadings suggesting that concerns may be diverse and multifaceted, without clear consensus among respondents.

Appendix I: Raw Data Study 1

	Name	Type	Width	Decimals	Label	Values
1	S.Gender	Numeric	8	0	S.Gender	{1, Male}...
2	S.Instrument	Numeric	8	0	S.Instrument	{1, Violin}...
3	SQ1	Numeric	8	0	S. Q1 I discuss playing-related health issues with my teacher.	{1, Never}...
4	SQ2	Numeric	8	0	S. Q6 I can identify movements that I make that may negatively affect my playing.	{1, Never}...
5	SQ3	Numeric	8	0	S. Q2 I discuss ways to resolve PRHIs on my own, in the future, with my teacher.	{1, Never}...
6	SQ4	Numeric	8	0	S. Q4 I am confident that I can resolve playing-related health issues in the future, on my own.	{1, Strongly Disagree}...
7	SQ5	Numeric	8	0	S. Q3 I discuss ways to maintain a healthy playing technique autonomously in the future, with my teacher.	{1, Never}...
8	SQ6	Numeric	8	0	S. Q5 I am confident that I can maintain a healthy playing technique on my own in the future.	{1, Strongly Disagree}...
9	SQ7	Numeric	8	0	S. Q7 How aware are you of a medical condition called focal dystonia that may affect musicians?	{1, Not at all aware}...
10	SQ8	Numeric	8	0	S. Q8 How aware are you of risk factors associated with the possible onset of the medical condition focal dy...	{1, Not at all aware}...
11	SQ9	Numeric	8	0	S. Q9 As a musician, I am worried about focal dystonia.	{1, Strongly Disagree}...
12	SQ10	Numeric	8	0	S. Q10 Informing music students about focal dystonia may do more harm than good.	{1, Strongly Disagree}...
13	Gender	Numeric	8	0	Gender	{1, Male}...
14	Instrument	Numeric	8	0	Instrument	{1, Violin}...
15	TQ1	Numeric	8	0	Q1. I discuss playing-related health issues with my students.	{1, Never}...
16	TQ2	Numeric	8	0	Q6 I can identify movements that my students make, that may negatively affect their playing.	{1, Never}...
17	TQ3	Numeric	8	0	Q2. I discuss ways fto resolve PRHIs autonomously in the future, with my students.	{1, Never}...
18	TQ4	Numeric	8	0	Q4. I am confident that my students can resolve PRHIs in the future, on their own.	{1, Strongly Disagree}...
19	TQ5	Numeric	8	0	Q3. I discuss ways to maintain a healthy playing technique autonomously in the future, with my students.	{1, Never}...
20	TQ6	Numeric	8	0	Q5. I am confident that my students can maintain a healthy playing technique on their own, in the future.	{1, Strongly Disagree}...
21	TQ7	Numeric	8	0	Q7. How awarę are you of a medical condition called focal dystonia that may affect musicians?	{1, Not at all aware}...
22	TQ8	Numeric	8	0	Q8. How aware are you of risk factors associated with the possible onset of the medical condition focal dyst...	{1, Not at all aware}...
23	TQ9	Numeric	8	0	Q9. As a musician, I am concerned about FD	{1, Strongly Disagree}...
24	TQ10	Numeric	8	0	Q10. Informing music students about FD may do more harm than good	{1, Strongly Disagree}...

	Gender	Instrument	TQ1	TQ2	TQ3	TQ4	TQ5	TQ6	TQ7	TQ8	TQ9	TQ10
1	1	7	2	4	2	3	5	5	5	5	5	1
2	1	3	3	4	4	3	4	3	2	2	4	3
3	1	3	2	5	5	3	5	3	2	3	3	4
4	1	4	2	4	4	4	4	4	3	2	2	2
5	4	5	2	4	2	3	1	1	5	3	3	3
6	2	1	3	4	4	3	4	3	3	5	2	2
7	1	7	3	5	5	3	5	3	5	1	1	4
8	1	3	3	5	4	2	5	4	5	3	3	2
9	1	7	3	4	4	3	5	3	5	3	4	2
10	1	5	3	4	3	3	3	3	3	3	4	2
11	1	5	3	5	5	5	5	3	5	5	4	1
12	1	7	3	4	3	2	4	3	5	3	4	2
13	1	9	3	4	4	2	4	2	5	5	4	1
14	1	5	3	3	3	2	3	2	5	3	4	2
15	2	5	3	3	3	4	3	5	1	1	3	3
16	1	5	3	4	3	3	5	4	3	1	3	3
17	1	18	3	4	5	3	1	3	3	1	3	1
18	1	7	3	5	4	3	5	3	5	3	4	4
19	1	6	3	4	3	3	3	3	1	1	4	3
20	1	11	3	4	3	3	3	3	4	2	4	3
21	1	2	3	4	4	3	5	4	5	4	5	2
22	1	2	3	4	2	2	3	3	4	4	4	2
23	1	3	3	4	4	3	4	3	2	1	3	3
24	1	9	4	4	4	2	2	2	4	4	4	2
25	1	3	4	4	3	4	4	4	1	1	4	4
26	1	11	4	3	3	4	4	4	5	1	4	2

	Gender	Instrument	TQ1	TQ2	TQ3	TQ4	TQ5	TQ6	TQ7	TQ8	TQ9	TQ10
27	2	1	4	4	3	3	3	3	1	1	3	3
28	2	5	4	5	4	2	4	3	5	3	3	2
29	1	5	4	5	5	4	5	4	5	3	5	1
30	2	1	4	4	5	4	5	4	5	3	4	2
31	1	10	4	5	5	3	5	3	5	5	4	1
32	1	13	4	5	5	2	4	3	5	5	3	2
33	2	3	4	4	4	3	5	4	5	3	4	2
34	2	12	4	4	4	2	3	2	5	3	4	2
35	1	17	4	4	4	3	5	4	5	3	3	1
36	1	13	4	5	5	3	5	3	5	4	5	1
37	2	14	4	4	4	4	4	4	4	3	4	2
38	1	2	4	4	3	3	4	3	3	2	4	3
39	1	6	4	4	4	3	4	4	5	3	5	1
40	2	1	4	4	4	3	5	4	3	3	3	1
41	2	10	4	5	3	3	4	3	4	4	4	2
42	2	2	5	4	4	4	4	4	3	5	4	1
43	1	7	5	5	5	4	4	4	5	3	3	3
44	1	14	5	4	4	3	4	3	3	4	3	1
45	1	3	5	5	5	3	5	3	1	1	3	1
46	1	12	5	4	5	3	5	3	3	1	1	2
47	2	12	5	5	3	5	4	3	5	3	5	1
48	1	3	5	5	5	3	5	3	5	1	3	2
49	1	13	5	3	5	3	5	4	1	1	4	1
50	2	8	5	5	5	3	5	4	5	3	3	3
51	2	16	5	5	5	4	5	4	3	3	3	2
52	2	11	5	5	5	4	5	4	3	3	4	2

	Gender	Instrument	TQ1	TQ2	TQ3	TQ4	TQ5	TQ6	TQ7	TQ8	TQ9	TQ10
53	1	8	5	5	5	5	5	5	5	3	1	1
54	1	7	5	5	5	4	5	4	5	4	3	3
55	2	1	5	5	5	4	5	4	5	3	4	4
56	1	8	5	4	5	3	5	3	5	3	4	3
57	2	11	5	4	5	4	5	4	4	3	4	2
58	1	2	5	5	5	4	5	5	5	5	2	1
59	1	12	5	3	5	2	5	3	4	1	4	1
60	2	5	5	5	5	3	5	3	1	1	3	3
61	1	7	5	5	5	3	5	4	5	3	4	2
62	2	1	5	4	4	3	4	3	1	1	3	3
63	1	4	5	4	4	3	5	3	4	3	4	1
64	2	4	5	4	5	5	5	5	5	4	4	2
65	1	8	5	4	4	4	4	3	4	3	4	1
66	2	7	5	5	5	5	5	4	5	3	5	3

	S.Gender	S.Instrument	SQ1	SQ2	SQ3	SQ4	SQ5	SQ6	SQ7	SQ8	SQ9	SQ10
1	1	6	5	3	3	3	3	3	3	3	4	4
2	2	11	4	4	4	3	2	3	1	1	3	4
3	2	1	3	4	3	4	4	4	1	1	4	4
4	1	6	4	3	1	5	4	5	2	1	4	3
5	1	5	3	4	3	4	3	4	1	1	3	3
6	1	5	3	4	3	3	3	3	1	1	3	3
7	1	5	2	4	1	4	4	2	1	1	4	1
8	3	5	2	4	2	3	3	3	2	1	3	4
9	2	19	3	4	4	4	4	4	2	2	3	3
10	1	18	1	4	1	2	2	4	1	1	3	3
11	1	6	2	4	2	3	2	4	1	1	4	4
12	2	4	4	4	4	4	4	4	1	1	4	3
13	1	2	2	3	4	3	2	3	1	1	4	2
14	1	17	3	3	3	4	3	3	1	1	3	4
15	1	6	3	4	2	5	2	5	2	2	1	5
16	1	7	3	4	4	3	5	4	3	1	2	3
17	2	5	3	4	3	4	3	4	3	3	3	2
18	2	1	4	2	5	3	4	4	1	1	3	3
19	2	5	2	5	2	2	3	3	5	1	1	5
20	2	11	2	4	3	4	3	4	1	1	3	3
21	2	1	4	5	3	3	3	4	1	1	3	3
22	3	3	3	3	2	2	3	3	1	1	3	3
23	2	1	3	3	4	3	4	4	1	1	4	5
24	2	5	2	3	1	2	3	3	1	1	3	4
25	2	3	3	3	3	4	2	4	4	4	3	5
26	2	5	3	4	5	3	2	4	1	1	1	5

	S.Gender	S.Instrument	SQ1	SQ2	SQ3	SQ4	SQ5	SQ6	SQ7	SQ8	SQ9	SQ10
53	3	19	3	3	4	3	4	3	2	2	3	3
54	1	18	2	3	3	4	3	4	2	2	3	3
55	1	18	2	4	4	4	4	4	3	3	3	3
56	2	19	3	3	5	4	4	4	1	2	2	5
57	2	2	4	5	5	5	5	5	1	1	3	3
58	2	13	2	4	3	4	2	4	4	2	3	4
59	1	17	1	3	1	4	2	4	1	1	3	4
60	1	5	2	3	2	4	2	4	1	1	3	5
61	1	1	2	3	3	3	5	4	1	1	3	3
62	1	3	3	5	3	3	5	3	1	1	3	3
63	3	19	4	4	3	4	4	4	1	1	3	4
64	2	19	5	4	2	4	3	4	1	1	3	3
65	1	5	3	4	3	2	3	2	1	1	3	3
66	3	3	3	3	2	2	3	3	1	1	3	3

Appendix J: Raw Data – Study 2

	Name	Type	Width	Decimals	Label	Values	
						None	...
1	ID	String	8	0	ID		
2	Gender	Numeric	8	0	Gender	{1, Male}...	
3	Age	Numeric	8	0	Age	{1, Under 18}...	
4	Diagnostic_Age	Numeric	8	0	Age of Diagnosis	{1, Under 18}...	
5	Area_Affected	Numeric	8	0	Body area Affected by MFD	{1, Left Hand}...	
6	Plucked_Strings	Numeric	8	0	Plucked String Group	{0, No}...	
7	Bowed_Strings	Numeric	8	0	Bowed String Group	{0, No}...	
8	Keyboards	Numeric	8	0	Keyboard Group	None	
9	Woodwinds	Numeric	8	0	Woodwind Group	{0, No}...	
10	Brass	Numeric	8	0	Brass Group	{0, No}...	
11	Symptom_2Diag_Time	Numeric	8	0	How long did it take to diagnose focal dystonia after symptoms first appeared?	{1, Less than 6 Months}...	
12	Diag_2Retrain_Time	Numeric	8	0	How long did it take to begin retraining after your diagnosis?	{1, Less than 6 Months}...	
13	TimeTot_Spent_Retraining	Numeric	8	0	How long have you been utilising retraining methods for managing your dystonia in total?	{1, Less than 6 Months}...	
14	NFEEDBACK	Numeric	8	0	Neurofeedback Approaches	{1, YES}...	
15	How_long_use_NF	Numeric	8	0	How long have you used Neurofeedback Retraining?	{1, Less than 6 months}...	
16	NFsupportDuring	Numeric	8	0	How would you rate support DURING Neurofeedback Retraining?	{1, Very Poor}...	
17	NFsupportAfter	Numeric	8	0	How would you rate support AFTER Neurofeedback Retraining?	{1, Very Poor}...	
18	Symp_Before_NF	Numeric	8	0	Symptom level before Neurofeedback retraining	{0, Unable to Play}...	
19	Symp_After_NF	Numeric	8	0	Symptom level after Neurofeedback retraining	{0, Unable to Play}...	
20	QualityNF	Numeric	8	0	How would you rate the quality of Neurofeedback retraining	{1, Very Low Quality}...	
21	Effectiveness_NF	Numeric	8	0	How would you rate the effectiveness of Neurofeedback retraining?	{1, Not at all effective}...	
22	NEUROPLASTIC	Numeric	8	0	Neuroplastic Approaches	{1, YES}...	
23	How_long_use_NP	Numeric	8	0	How long have you used Neuroplastic Retraining?	{1, Less than 6 months}...	
24	NPSupport_during	Numeric	8	0	How would you rate support DURING Neuroplastic Retraining?	{1, Very Poor}...	
25	NPSupport_after	Numeric	8	0	How would you rate support AFTER after Neuroplastic Retraining?	{1, Very Poor}...	
26	Symp_Before_NeoP	Numeric	8	0	Symptom level before Neuroplastic retraining	{0, Unable to Play}...	
27	Symp_After_NeoP	Numeric	8	0	Symptom level after Neuroplastic retraining	{0, Unable to Play}...	
28	QualityNP	Numeric	8	0	How would you rate the quality of Neuroplastic retraining?	{1, Very Low Quality}...	

	Name	Type	Width	Decimals	Label	Values
29	Effectiveness_NeoP	Numeric	8	0	How would you rate the effectiveness of Neuroplastic retraining?	{1, Not at all effective}...
30	SENSORIMOTOR	Numeric	8	0	Sensorimotor Approaches	{1, YES}...
31	How_long_use_SenM	Numeric	8	0	How long have you used Sensorimotor retraining?	{1, Less than 6 months}...
32	Symp_Before_SenM	Numeric	8	0	Symptom level before Sensorimotor retraining	{0, Unable to Play}...
33	Symp_After_SenM	Numeric	8	0	Symptom level after Sensorimotor retraining	{0, Unable to Play}...
34	QualitySenM	Numeric	8	0	How would you rate the quality of Sensorimotor retraining?	{1, Very Low Quality}...
35	SenMsupportDuring	Numeric	8	0	How would you rate support DURING Sensorimotor Retraining?	{1, Very Poor}...
36	SenMsupportAfter	Numeric	8	0	How would you rate support AFTER Sensorimotor Retraining?	{1, Very Poor}...
37	Effectiveness_SenM	Numeric	8	0	How would you rate the effectiveness of Sensorimotor retraining?	{1, Not at all effective}...
38	PSYCHOLOGICAL	Numeric	8	0	Psychological Approaches	{1, YES}...
39	How_long_use_Psych	Numeric	8	0	How long have you used Psychological Retraining?	{1, Less than 6 months}...
40	Symp_Before_Psych	Numeric	8	0	Symptom level before Psychological retraining	{0, Unable to Play}...
41	Symp_After_Psych	Numeric	8	0	Symptom level after Psychological retraining	{0, Unable to Play}...
42	PsySupportDuring	Numeric	8	0	How would you rate support DURING Psychological Retraining?	{1, Very Poor}...
43	PsySupportAfter	Numeric	8	0	How would you rate support AFTER Psychological Retraining?	{1, Very Poor}...
44	QualityPsyc	Numeric	8	0	How would you rate the quality of Psychological retraining?	{1, Very Low Quality}...
45	Effectiveness_Psych	Numeric	8	0	How would you rate the effectiveness of Psychological retraining?	{1, Not at all effective}...
46	SELF_DEVELOPED	Numeric	8	0	Self Developed Approaches	{1, YES}...
47	How_long_use_Self_Des	Numeric	8	0	How long have you used Self Developed Retraining?	{1, Less than 6 months}...
48	Symp_Before_Self_Des	Numeric	8	0	Symptom level before Self Developed Retraining	{0, Unable to Play}...
49	Symp_After_Self_Des	Numeric	8	0	Symptom level after Self Developed retraining	{0, Unable to Play}...
50	QualitySelfDev	Numeric	8	0	How would you rate the quality of Self Developed retraining?	{1, Very Low Quality}...
51	Effectiveness_Self_Des	Numeric	8	0	How would you rate the effectiveness of Self Developed retraining?	{1, Not at all effective}...
52	SUPPLEMENTARY	Numeric	8	0	Supplementary Retraining Approaches	{1, YES}...
53	How_long_use_Other	Numeric	8	0	How long have you used Supplementary Retraining?	{1, Less than 6 months}...
54	Symp_Before_Other	Numeric	8	0	Symptom level before Supplementary retraining	{0, Unable to Play}...
55	Symp_After_Other	Numeric	8	0	Symptom level after Supplementary retraining	{0, Unable to Play}...
56	QualitySupp	Numeric	8	0	How would you rate the quality of Supplementary retraining?	{1, Very Low Quality}...
57	SUPLsupportDuring	Numeric	8	0	How would you rate support DURING Supplementary Retraining?	{1, Very Poor}...

	ID	Gender	Age	Diagnostic_Age	Area_Affected	Plucked_Strings	Bowed_Strings	Keyboards	Woodwinds	Brass	Symptm_2Diag_Tim	Diag_2Retrain_Time	TimeTot_Spent_Retraining
1	56	2	4	3	1	0	1	0	0	0	2	2	3
2	69	1	4	3	1	0	1	0	0	0	2	1	7
3	40	2	6	4	1	0	0	0	1	0	5	7	7
4	34	2	6	3	1	0	0	0	1	0	3	2	7
5	39	2	5	5	1	0	0	0	1	0	7	7	7
6	43	2	4	4	1	0	0	1	0	0	4	5	7
7	16	2	5	4	1	1	0	0	0	0	6	2	6
8	23	1	3	3	1	1	0	0	0	0	4	2	5
9	81	2	3	3	1	0	0	0	1	0	1	1	1
10	01	1	5	3	1	0	1	0	0	0	6	3	7
11	08	1	4	3	1	0	1	0	0	0	7	3	7
12	21	1	4	4	1	0	1	0	0	0	3	3	7
13	70	1	4	3	1	0	1	0	0	0	3	2	7
14	25	1	4	4	1	0	0	0	1	0	4	3	5
15	02	1	4	3	1	0	0	1	0	0	7	1	7
16	24	2	4	3	1	0	1	0	0	0	4	1	7
17	20	2	6	5	1	0	0	0	1	0	4	3	7
18	38	2	6	6	1	0	0	1	0	0	3	2	6
19	18	2	4	3	1	0	1	0	0	0	5	3	7
20	45	1	6	5	1	0	0	0	1	0	7	7	7
21	59	1	5	5	2	0	1	0	0	0	3	2	5
22	55	2	3	3	2	0	0	0	1	0	3	3	5
23	78	2	5	4	2	0	0	0	1	0	7	1	7
24	64	2	6	5	2	0	0	1	0	0	5	4	7
25	30	2	6	4	2	0	0	1	0	0	7	4	7
26	57	3	4	4	2	0	0	1	0	0	4	3	5

	Gender	Age	Diagnostic_Age	Area_Affected	Plucked_Strings	Bowed_Strings	Keyboards	Woodwinds	Brass	Sympt m_2Diag_Tim	Diag_2Retrain_Time	TimeTot_Spent_Retraining
27	2	4	3	2	0	0	1	0	0	2	3	7
28	1	7	4	2	1	0	0	0	0	3	1	7
29	2	4	3	2	1	0	0	0	0	3	2	6
30	1	6	4	2	1	0	0	0	0	7	2	7
31	2	6	3	2	1	0	0	0	0	3	1	7
32	2	6	5	2	1	0	0	0	0	5	2	3
33	1	3	3	2	1	0	0	0	0	2	2	4
34	1	5	4	2	1	0	0	0	0	5	4	7
35	2	4	3	2	1	0	0	0	0	2	2	7
36	1	5	4	2	0	0	1	0	0	6	6	7
37	2	6	5	2	0	0	1	0	0	2	1	7
38	1	7	6	2	0	1	0	0	0	7	5	7
39	1	6	3	2	0	0	0	1	0	3	7	7
40	1	6	6	2	1	0	0	0	0	6	1	7
41	2	7	4	2	1	0	0	0	0	6	5	7
42	1	5	4	2	1	0	0	0	0	2	1	4
43	2	4	4	2	0	0	1	0	0	5	3	6
44	2	4	3	2	0	0	1	0	0	7	7	7
45	1	7	4	2	1	0	0	0	0	5	2	7
46	1	3	3	2	0	0	1	0	0	3	2	3
47	2	7	5	2	1	0	0	0	0	7	7	7
48	2	6	4	2	1	0	0	0	0	6	6	7
49	1	4	3	2	0	0	1	0	0	4	3	7
50	1	4	2	2	0	0	0	1	0	2	2	7
51	2	3	2	3	0	0	0	0	1	2	2	3
52	1	6	3	3	0	0	0	0	1	2	1	3

	Gender	Age	Diagnostic_Age	Area_Affected	Plucked_Strings	Bowed_Strings	Keyboards	Woodwinds	Brass	Sympt m_2Diag_Tim	Diag_2Retrain_Time	TimeTot_Spent_Retraining
53	1	5	4	3	0	0	0	0	1	4	3	4
54	2	6	6	3	0	0	0	0	1	4	2	6
55	2	6	6	3	0	0	0	0	1	7	7	7
56	1	4	4	3	0	0	0	0	1	4	1	5
57	2	8	8	3	0	0	0	0	1	1	1	1
58	1	4	3	3	0	0	0	0	1	5	3	5
59	1	3	3	3	0	0	0	0	1	1	1	7
60	1	4	3	3	0	0	0	1	0	4	1	7
61	1	6	6	3	0	0	0	1	0	2	2	3
62	1	5	5	3	0	0	0	1	0	6	3	7
63	1	2	2	3	0	0	0	1	0	2	1	5
64	1	6	6	3	0	0	0	0	1	2	3	4
65	1	7	5	3	0	0	0	0	1	3	2	7
66	2	5	4	3	0	0	0	0	1	2	1	4
67	1	4	3	3	0	0	0	0	1	4	3	5
68	2	5	5	3	0	0	0	0	1	7	5	7
69	2	5	4	3	0	0	0	1	0	5	2	5
70	1	6	6	3	0	0	0	1	0	7	1	7

	NFEEDBACK	How_long_use_NF	NFsupportDuring	NFsupportAfter	Symp_Before_NF	Symp_After_NF	QualityNF	Effectiveness_NF	NELUROPLASTIC	How_long_use_NP	NPSupport_during	NPSupport_after	Symp_Before_NeoP	Symp_After_NeoP	QualityNP	Effectiveness_NeoP
1	2	.	.	.	.	.	.	.	2	.	.	.	.	.	.	.
2	2	.	.	.	.	.	.	.	2	.	.	.	.	.	.	.
3	2	.	.	.	.	.	.	.	2	.	.	.	.	.	.	.
4	2	.	.	.	.	.	.	.	2	.	.	.	.	.	.	.
5	2	.	.	.	.	.	.	.	2	.	.	.	.	.	.	.
6	2	.	.	.	.	.	.	.	2	.	.	.	.	.	.	.
7	2	.	.	.	.	.	.	.	2	.	.	.	.	.	.	.
8	2	.	.	.	.	.	.	.	2	.	.	.	.	.	.	.
9	2	.	.	.	.	.	.	.	1	1	4	2	5	6	5	5
10	2	.	.	.	.	.	.	.	1	2	4	3	2	3	4	4
11	2	.	.	.	.	.	.	.	1	1	3	2	2	2	4	2
12	2	.	.	.	.	.	.	.	1	7	4	3	2	6	4	5
13	2	.	.	.	.	.	.	.	1	2	3	2	3	2	4	3
14	2	.	.	.	.	.	.	.	1	1	4	4	4	5	4	3
15	2	.	.	.	.	.	.	.	1	4	3	1	2	4	4	4
16	2	.	.	.	.	.	.	.	1	7	4	4	5	5	3	3
17	2	.	.	.	.	.	.	.	1	5	3	3	4	5	3	3
18	1	2	3	2	4	4	3	3	2	.	.	.	.	.	.	.
19	1	1	3	2	1	3	3	3	1	7	5	4	2	6	5	5
20	1	1	3	2	5	6	3	2	1	2	4	2	5	6	1	5
21	2	.	.	.	.	.	.	.	2	.	.	.	.	.	.	.
22	2	.	.	.	.	.	.	.	2	.	.	.	.	.	.	.
23	2	.	.	.	.	.	.	.	2	.	.	.	.	.	.	.
24	2	.	.	.	.	.	.	.	1	5	4	2	3	3	3	2
25	2	.	.	.	.	.	.	.	2	.	.	.	.	.	.	.
26	2	.	.	.	.	.	.	.	2	.	.	.	.	.	.	.

	NFEEDBACK	How_long_use_NF	NFsupportDuring	NFsupportAfter	Symp_Before_NF	Symp_After_NF	QualityNF	Effectiveness_NF	NEUROPLASTIC	How_long_use_NP	NPSupport_during	NPSupport_after	Symp_Before_NeoP	Symp_After_NeoP	QualityNP	Effectiveness_NeoP
27	2	.	.	.	.	.	.	.	2	.	.	.	.	.	.	.
28	2	.	.	.	.	.	.	.	2	.	.	.	.	.	.	.
29	2	.	.	.	.	.	.	.	2	.	.	.	.	.	.	.
30	2	.	.	.	.	.	.	.	2	.	.	.	.	.	.	.
31	2	.	.	.	.	.	.	.	2	.	.	.	.	.	.	.
32	2	.	.	.	.	.	.	.	2	.	.	.	.	.	.	.
33	2	.	.	.	.	.	.	.	2	.	.	.	.	.	.	.
34	2	.	.	.	.	.	.	.	2	.	.	.	.	.	.	.
35	2	.	.	.	.	.	.	.	1	7	5	5	2	6	5	5
36	2	.	.	.	.	.	.	.	1	3	5	5	2	5	4	5
37	2	.	.	.	.	.	.	.	1	7	5	2	4	4	4	3
38	2	.	.	.	.	.	.	.	1	5	2	2	2	4	3	2
39	2	.	.	.	.	.	.	.	1	7	4	3	5	5	3	1
40	2	.	.	.	.	.	.	.	1	1	3	3	1	2	3	1
41	2	.	.	.	.	.	.	.	1	4	4	2	2	4	3	3
42	2	.	.	.	.	.	.	.	1	3	3	2	3	3	2	2
43	2	.	.	.	.	.	.	.	1	2	3	3	1	1	1	1
44	1	2	4	2	3	3	3	3	2	.	.	.	.	.	.	.
45	1	7	3	3	2	2	4	3	2	.	.	.	.	.	.	.
46	1	2	3	1	4	4	2	3	1	1	2	3	3	4	4	4
47	1	2	3	2	4	4	2	3	1	1	1	1	1	1	1	1
48	1	7	5	4	2	4	3	4	2	.	.	.	.	.	.	.
49	1	1	4	2	4	4	4	3	1	4	4	3	1	4	5	5
50	1	1	2	2	4	4	2	2	2	.	.	.	.	.	.	.
51	2	.	.	.	.	.	.	.	2	.	.	.	.	.	.	.
52	2	.	.	.	.	.	.	.	2	.	.	.	.	.	.	.

	NFEEDBACK	How_long_use_NF	NFsupportDuring	NFsupportAfter	Symp_Before_NF	Symp_After_NF	QualityNF	Effectiveness_NF	NEUROPLASTIC	How_long_use_NP	NPSupport_during	NPSupport_after	Symp_Before_NeoP	Symp_After_NeoP	QualityNP	Effectiveness_NeoP
53	2	.	.	.	.	.	.	.	2	.	.	.	.	.	.	.
54	2	.	.	.	.	.	.	.	2	.	.	.	.	.	.	.
55	2	.	.	.	.	.	.	.	2	.	.	.	.	.	.	.
56	2	.	.	.	.	.	.	.	2	.	.	.	.	.	.	.
57	2	.	.	.	.	.	.	.	2	.	.	.	.	.	.	.
58	2	.	.	.	.	.	.	.	2	.	.	.	.	.	.	.
59	2	.	.	.	.	.	.	.	2	.	.	.	.	.	.	.
60	2	.	.	.	.	.	.	.	2	.	.	.	.	.	.	.
61	2	.	.	.	.	.	.	.	2	.	.	.	.	.	.	.
62	2	.	.	.	.	.	.	.	2	.	.	.	.	.	.	.
63	2	.	.	.	.	.	.	.	2	.	.	.	.	.	.	.
64	2	.	.	.	.	.	.	.	1	4	4	3	3	4	5	5
65	2	.	.	.	.	.	.	.	1	4	5	3	1	2	4	3
66	2	.	.	.	.	.	.	.	1	1	4	1	2	2	3	3
67	1	1	2	2	5	5	2	2	2	.	.	.	.	.	.	.
68	1	1	2	1	4	4	2	3	2	.	.	.	.	.	.	.
69	1	1	3	2	2	3	2	2	1	3	3	3	4	4	3	3
70	1	1	3	2	1	2	3	2	1	5	3	2	2	2	3	3

	SENSORIMOTOR	How_long_use_SenM	Symp_Before_SenM	Symp_After_SenM	QualitySenM	SenMsupportDuring	SenMsupportAfter	Effectiveness_SenM	PSYCHOLOGICAL	How_long_use_Psych	Symp_Before_Psych	Symp_After_Psych	PsySupportDurng	PsySupportAfter	QualityPsyc	Effectiveness_Psych
1	2	.	.	.	.	.	.	.	2	.	.	.	.	.	.	.
2	2	.	.	.	.	.	.	.	2	.	.	.	.	.	.	.
3	1	1	5	5	4	3	3	3	2	.	.	.	.	.	.	.
4	2	.	.	.	.	.	.	.	2	.	.	.	.	.	.	.
5	2	.	.	.	.	.	.	.	2	.	.	.	.	.	.	.
6	1	2	3	3	2	4	3	3	2	.	.	.	.	.	.	.
7	1	3	1	1	1	4	4	1	2	.	.	.	.	.	.	.
8	2	.	.	.	.	.	.	.	1	1	4	5	5	4	4	5
9	2	.	.	.	.	.	.	.	2	.	.	.	.	.	.	.
10	2	.	.	.	.	.	.	.	2	.	.	.	.	.	.	.
11	2	.	.	.	.	.	.	.	2	.	.	.	.	.	.	.
12	2	.	.	.	.	.	.	.	2	.	.	.	.	.	.	.
13	2	.	.	.	.	.	.	.	2	.	.	.	.	.	.	.
14	2	.	.	.	.	.	.	.	2	.	.	.	.	.	.	.
15	2	.	.	.	.	.	.	.	2	.	.	.	.	.	.	.
16	2	.	.	.	.	.	.	.	2	.	.	.	.	.	.	.
17	2	.	.	.	.	.	.	.	2	.	.	.	.	.	.	.
18	1	2	4	5	3	4	3	4	2	.	.	.	.	.	.	.
19	2	.	.	.	.	.	.	.	2	.	.	.	.	.	.	.
20	1	2	5	6	3	5	4	2	2	.	.	.	.	.	.	.
21	2	.	.	.	.	.	.	.	1	2	4	5	4	3	3	3
22	1	1	4	5	3	4	4	3	2	.	.	.	.	.	.	.
23	1	3	4	4	3	3	2	3	2	.	.	.	.	.	.	.
24	2	.	.	.	.	.	.	.	2	.	.	.	.	.	.	.
25	1	7	5	5	3	3	2	3	2	.	.	.	.	.	.	.
26	2	.	.	.	.	.	.	.	2	.	.	.	.	.	.	.

	SENSORIMOTOR	How_long_use_SenM	Symp_Before_SenM	Symp_After_SenM	QualitySenM	SenMsupportDuring	SenMsupportAfter	Effectiveness_SenM	PSYCHOLOGICAL	How_long_use_Psych	Symp_Before_Psych	Symp_After_Psych	PsySupportDuring	PsySupportAfter	QualityPsyc	Effectiveness_Psych
27	2	.	.	.	.	.	.	.	2	.	.	.	.	.	.	.
28	1	4	2	4	3	3	3	1	2	.	.	.	.	.	.	.
29	1	4	1	1	2	3	2	1	2	.	.	.	.	.	.	.
30	1	7	3	4	4	4	3	4	2	.	.	.	.	.	.	.
31	2	.	.	.	.	.	.	.	2	.	.	.	.	.	.	.
32	2	.	.	.	.	.	.	.	1	3	5	5	4	4	3	2
33	2	.	.	.	.	.	.	.	2	.	.	.	.	.	.	.
34	2	.	.	.	.	.	.	.	1	5	2	2	5	1	4	2
35	2	.	.	.	.	.	.	.	2	.	.	.	.	.	.	.
36	1	2	2	3	3	3	3	3	2	.	.	.	.	.	.	.
37	2	.	.	.	.	.	.	.	1	1	4	4	5	4	4	3
38	2	.	.	.	.	.	.	.	1	1	3	5	4	4	4	4
39	2	.	.	.	.	.	.	.	2	.	.	.	.	.	.	.
40	2	.	.	.	.	.	.	.	2	.	.	.	.	.	.	.
41	2	.	.	.	.	.	.	.	2	.	.	.	.	.	.	.
42	2	.	.	.	.	.	.	.	2	.	.	.	.	.	.	.
43	2	.	.	.	.	.	.	.	2	.	.	.	.	.	.	.
44	2	.	.	.	.	.	.	.	2	.	.	.	.	.	.	.
45	1	7	2	2	3	3	3	3	1	6	2	2	3	2	3	3
46	1	1	3	2	2	4	4	2	1	3	2	3	3	2	3	3
47	2	.	.	.	.	.	.	.	2	.	.	.	.	.	.	.
48	1	7	2	5	5	5	4	5	2	.	.	.	.	.	.	.
49	1	1	2	4	3	3	1	3	2	.	.	.	.	.	.	.
50	1	3	4	4	3	4	3	3	1	4	4	4	4	2	4	3
51	1	1	4	5	3	4	4	3	2	.	.	.	.	.	.	.
52	1	4	4	5	5	4	4	4	1	2	4	4	3	2	3	2

	SENSORIMOTOR	How_long_use_SenM	Symp_Before_SenM	Symp_After_Sen M	QualityS enM	SenMsupportDuring	SenMsupportAfter	Effectiveness_SenM	PSYCHOLOGICAL	How_long_use_Psych	Symp_Before_Psych	Symp_After_Psych	PsySupportDurig	PsySupportAfter	QualityPsyc	Effectiveness_Psych
52	1	4	4	5	5	4	4	4	1	2	4	4	3	2	3	2
53	1	2	3	5	4	4	4	5	2	.	.	.	.	.	.	.
54	2	.	.	.	.	.	.	.	2	.	.	.	.	.	.	.
55	2	.	.	.	.	.	.	.	2	.	.	.	.	.	.	.
56	2	.	.	.	.	.	.	.	2	.	.	.	.	.	.	.
57	2	.	.	.	.	.	.	.	2	.	.	.	.	.	.	.
58	2	.	.	.	.	.	.	.	1	3	3	4	3	3	3	3
59	2	.	.	.	.	.	.	.	1	4	3	4	4	2	4	4
60	2	.	.	.	.	.	.	.	1	6	1	6	4	3	5	4
61	2	.	.	.	.	.	.	.	2	.	.	.	.	.	.	.
62	2	.	.	.	.	.	.	.	1	6	1	4	4	2	3	5
63	2	.	.	.	.	.	.	.	2	.	.	.	.	.	.	.
64	2	.	.	.	.	.	.	.	2	.	.	.	.	.	.	.
65	2	.	.	.	.	.	.	.	1	4	3	3	4	2	2	3
66	2	.	.	.	.	.	.	.	2	.	.	.	.	.	.	.
67	1	3	5	6	5	5	5	4	2	.	.	.	.	.	.	.
68	2	.	.	.	.	.	.	.	2	.	.	.	.	.	.	.
69	2	.	.	.	.	.	.	.	2	.	.	.	.	.	.	.
70	1	3	4	4	4	4	3	5	2	.	.	.	.	.	.	.

	SELF_DEVELOPED	How_long_use_Self_Dev	Symp_Before_Self_Dev	Symp_After_Self_Dev	QualitySelfDev	Effectiveness_Self_Dev	SUPPLEMENTARY	How_long_use_SUP	Symp_Before_Sup	Symp_After_Sup	QualitySup	SUPLsupportDuring	SUPLsupportAfter	Effectiveness_Other	EXPECTATIONS
1	1	2	4	4	3	1	2	.	.	.	.	.	.	.	2
2	2	.	.	.	.	.	1	2	4	4	3	4	2	3	2
3	1	7	3	5	5	5	1	1	2	2	3	4	3	4	4
4	1	7	4	5	3	3	2	.	.	.	.	.	.	.	4
5	2	.	.	.	.	.	1	3	4	6	4	5	5	3	4
6	2	.	.	.	.	.	2	.	.	.	.	.	.	.	3
7	1	3	1	5	5	5	2	.	.	.	.	.	.	.	4
8	2	.	.	.	.	.	2	.	.	.	.	.	.	.	5
9	2	.	.	.	.	.	2	.	.	.	.	.	.	.	4
10	2	.	.	.	.	.	2	.	.	.	.	.	.	.	4
11	1	6	1	4	3	3	1	2	1	2	3	3	3	3	2
12	1	7	2	6	4	4	1	7	2	3	4	4	4	4	5
13	2	.	.	.	.	.	2	.	.	.	.	.	.	.	4
14	1	5	3	6	5	5	2	.	.	.	.	.	.	.	4
15	2	.	.	.	.	.	2	.	.	.	.	.	.	.	4
16	1	7	5	5	3	3	2	.	.	.	.	.	.	.	3
17	1	4	4	5	3	3	2	.	.	.	.	.	.	.	2
18	2	.	.	.	.	.	2	.	.	.	.	.	.	.	3
19	2	.	.	.	.	.	2	.	.	.	.	.	.	.	4
20	1	3	5	6	4	3	1	4	5	6	3	4	2	3	5
21	1	2	5	6	4	4	2	.	.	.	.	.	.	.	2
22	1	5	4	5	4	4	2	.	.	.	.	.	.	.	3
23	2	.	.	.	.	.	2	.	.	.	.	.	.	.	3
24	2	.	.	.	.	.	2	.	.	.	.	.	.	.	3
25	2	.	.	.	.	.	1	7	3	4	4	4	3	3	3
26	1	3	4	4	3	3	2	.	.	.	.	.	.	.	1

	SELF_DEVELOPED	How_long_use_Self_Dev	Symp_Before_Self_Dev	Symp_After_Self_Dev	QualitySelfDev	Effectiveness_Self_Dev	SUPPLEMENTARY	How_long_use_SUP	Symp_Before_Sup	Symp_After_Sup	QualitySup	SUPLsupportDuring	SUPLsupportAfter	Effectiveness_Other	EXPECTATIONS
27	1	7	1	6	5	5	2	.	.	.	.	.	.	.	5
28	1	7	2	5	3	3	2	.	.	.	.	.	.	.	3
29	1	4	1	1	2	1	2	.	.	.	.	.	.	.	2
30	2	.	.	.	.	.	2	.	.	.	.	.	.	.	4
31	1	7	4	5	5	5	1	7	4	5	5	5	4	5	4
32	1	3	5	5	3	2	2	.	.	.	.	.	.	.	2
33	1	3	3	4	3	3	2	.	.	.	.	.	.	.	3
34	1	1	1	1	4	3	1	1	4	4	3	4	3	3	1
35	2	.	.	.	.	.	2	.	.	.	.	.	.	.	4
36	1	3	2	5	5	5	2	.	.	.	.	.	.	.	4
37	2	.	.	.	.	.	2	.	.	.	.	.	.	.	2
38	1	1	2	5	4	4	1	3	2	5	5	5	5	4	3
39	1	7	3	3	3	2	2	.	.	.	.	.	.	.	2
40	2	.	.	.	.	.	2	.	.	.	.	.	.	.	2
41	1	4	2	4	3	3	2	.	.	.	.	.	.	.	3
42	2	.	.	.	.	.	2	.	.	.	.	.	.	.	2
43	1	2	1	1	1	1	2	.	.	.	.	.	.	.	1
44	1	7	3	3	4	3	2	.	.	.	.	.	.	.	3
45	1	6	1	4	3	3	1	6	1	4	4	3	3	4	4
46	2	.	.	.	.	.	2	.	.	.	.	.	.	.	3
47	2	.	.	.	.	.	2	.	.	.	.	.	.	.	2
48	1	7	2	5	5	5	2	.	.	.	.	.	.	.	3
49	2	.	.	.	.	.	2	.	.	.	.	.	.	.	2
50	1	7	3	4	4	3	1	7	4	4	3	4	3	3	2
51	2	.	.	.	.	.	2	.	.	.	.	.	.	.	3
52	2	.	.	.	.	.	2	.	.	.	.	.	.	.	3

	SELF_DEVELOPED	How_long_use_Self_Dev	Symp_Before_Self_Dev	Symp_After_Self_Dev	QualitySelfDev	Effectiveness_Self_Dev	SUPPLEMENTARY	How_long_use_SUP	Symp_Before_Sup	Symp_After_Sup	QualitySup	SUPLsupportDuring	SUPLsupportAfter	Effectiveness_Other	EXPECTATIONS
53	2	.	.	.	.	.	1	2	2	3	3	4	4	2	3
54	2	.	.	.	.	.	2	.	.	.	.	.	.	.	3
55	1	7	5	5	4	3	2	.	.	.	.	.	.	.	2
56	2	.	.	.	.	.	1	3	2	4	5	5	5	4	3
57	1	4	3	3	3	2	2	.	.	.	.	.	.	.	2
58	1	7	3	4	4	3	2	.	.	.	.	.	.	.	3
59	1	7	3	4	3	3	2	.	.	.	.	.	.	.	3
60	1	7	1	6	5	3	2	.	.	.	.	.	.	.	3
61	2	.	.	.	.	.	1	2	2	4	5	5	4	4	3
62	2	.	.	.	.	.	2	.	.	.	.	.	.	.	2
63	1	1	1	2	3	2	2	.	.	.	.	.	.	.	2
64	2	.	.	.	.	.	2	.	.	.	.	.	.	.	5
65	2	.	.	.	.	.	2	.	.	.	.	.	.	.	3
66	2	.	.	.	.	.	1	4	2	4	5	5	2	5	4
67	2	.	.	.	.	.	2	.	.	.	.	.	.	.	4
68	2	.	.	.	.	.	1	3	3	5	3	4	4	3	3
69	2	.	.	.	.	.	1	3	2	3	4	4	3	2	3
70	1	6	4	5	4	4	1	4	2	2	3	5	3	4	2

Appendix K: Interview Transcripts – Study 2

P1 INTERVIEW TRANSCRIPT

ME OK, great. So, firstly, can you tell me a little bit about your musical background?

P1 Yeah, well, I'm a classical guitarist. I basically studied in the 70s, so I got a licentiate at the [REDACTED], which in those days was like what people you know, left college with. It was pre-degree time. It was just before degree time, in fact. So, then I left 77-78 and I basically taught and did a bit of playing, et cetera, et cetera. I then got married for the second time, had a daughter in the 80s, and then we moved to [REDACTED], which basically, I did the same thing there and well as I said, I got dystonia here on my 40th birthday, which was.. sorry, sorry, when I turned 40, I was aware that I had dystonia. It's so tiring worrying about not being able to get back to playing fully. You have to find a way to take it one step at a time without freaking out over the future:

ME So, when you were 40 and had dystonia, did you, did you know what it was at the time, or how long did it take you to find out what it was?

P1 It took three years before I found out what it was, and then probably another three years to actually come to terms that the quacks, maybe got it right that time. Got it right. Yeah. I had not a clue to be frank. I went to see doctors a few times. They had no idea, so I left it alone.

ME So, you were you were diagnosed by my neurologist?

P1 By a neurologist after seeing several G. Ps who were completely baffled. Oh, I also saw an orthopaedic surgeon as well. I finally saw a neurologist. He thought he'd seen one case before, but this was in rural [REDACTED], which was, you know, you might as well have been on the moon in terms of awareness of performance related diseases. If I got a sport related one, I would have, you know, I had the best treatment in the world. But in those days, it was unknown. The doc said he wanted to rule out Parkinson's as my dad had it, so I was really freaked. Looking back, I should have taken my [instrument] with me and shown him then. He might have picked it up sooner. And to top it off, I turned up at the clinic for an EMG (electromyography) but there.. the nurse or whoever, wasn't there, so obviously, go home. I already had a consultation booked on the Friday, so I ended up going with no EMG because it was too late to change it. The doctor basically just told me to come back when I had it. He wouldn't even answer any questions.

ME Yeah, oh right. So, can you talk a bit about your first experiences with dystonia and how did it manifest itself to begin with?

P1 Well, I was doing some duets with a flautist, and we made the video and when I got home, I showed my wife and happened to notice that my little finger had started to curl inwards, and I just put it down to repetitive strain or something. And there's even a picture on that video of me with a great big bulldog clip trying to keep this finger straight, and it just got progressively worse and worse and worse. And then it involved the next finger and to a lesser extent, the next one. So, by this time I was really scared and aware that all of the first no, the second, third and fourth fingers of my right hand were really curling in, and I couldn't, couldn't control them basically.

ME At that time, how did you carry on playing and trying to get through it?

P1 I mean, you know, I felt like all drowning men, and I clutched that any straw I could forage. So, I went to acupuncture and various manipulative things, and you know, who do in the laying of the hands and let's say in [REDACTED] "Candomblé" and everything I could think of if it is. But it just got worse and worse and worse and then then I had to stop completely. You can't just carry on as you were and expect it to go away. You have to accept the reality of it all and work it out slowly. It takes time to see progress, it's stressful and frustrating

ME And did you experience the symptoms only whilst playing?

P1 On the computer, everything repetitive or fiddly, like using a pen? I just happen to have a pair of pliers because I'm doing DIY. But well, I don't like to show how it went, because I don't like to go back to that stage, but you know that using the toothbrush. It was difficult. Using the pen was hard and I think that whole repetitive.

ME OK. So, at what point on your journey with dystonia did you decide to explore retraining of some sort?

P1 Oh, that was several years. Initially, this was pre-internet or just the birth of the internet, and then, the standard wisdom at the time was you never got better from focal dystonia. So just forget it. Yeah, and in fact, I sold all my instruments and stopped teaching because I was told I would never, ever play again. I had all the usual, you know, can't use a plectrum, go learn with your left hand. You know, the usual stuff. So then, that was '93, I first got it looked at. In 99, I saw an article in the newspaper, the [REDACTED], which I don't think exists anymore. It was like the [REDACTED], but for expats, and it was an article then called, “The Strainers in the Brain” and it was taken from the [REDACTED]. And for the first time ever, I've seen an article about focal dystonia. And this article was saying that it was related to research by [REDACTED]. I don't know if you're aware of it. It was how she'd worked with monkeys And doing brain maps. Yeah. How the dystonia wasn't a physical thing, it was, it was actually a neurological thing in the brain. And this was this was like, you know, bulbs going off. I started to look for alternatives and followed [REDACTED]'s research. Anyway, about six months later. By now, I've got the interview. So, we're at 2000. I met online, a violinist from [REDACTED] called [REDACTED] who had had dystonia in her bowing arm. We started to correspond, and slowly other people joined. And then I realised that people actually did start to get better. So that was when I started to look for alternatives, and following [REDACTED], she sent me her workbook, which is long gone now. But it had things like learning to read braille, so I signed up at the [REDACTED] and learned how to read braille, and the other one was to do dominoes in a dark room just by feel. And all of this stuff did absolutely nothing, but at least I felt like I was doing stuff, and then over the years, I just sort of refined a thing. There’s a lot of money that went into not very much really. There was never a clear endgame, so all the exercises were just on-going in my head. It’s weird, I learnt a lot, definitely, but it always felt like I was being told things generally, there wasn’t much detail.

ME Your ring finger curls?

P1 I notice that if I touched here, I would go into spasm. right? But if I touched here, I wouldn't. So slowly, I would move onto the bit where the strings, join the bridge, yeah, (demonstrating) and gradually.. the oh well, of course, but I could, I could…..Hang on. I think that's my wife telling me she's ready to go... and, oh just a sec, sorry. at the office, I'm just doing an interview, don’t wait, but. Oh, great, excellent. OK. OK. OK. All. Sorry about that, so, so eventually, I got up to here right now, I can forget how years ago, 10 years ago, but I think, Oh, that's [REDACTED], now presumably, you know of him in the [REDACTED]? he just used to do his thing , it was to do it like that. Well, I tried. It didn't work, so I would do, I would just concentrate on doing very small movements, very light, very small. And at a key moment, [Retrainer] had me playing again in the first session. [Redacted] told to let the tremor happen. It was such a relief to find [retrainer]. It was a magical experience for me and I’m so grateful for it. But as you know, with dystonia, I mean, this is 30 years ago. So, I've got 30 years… even now, I've got 30 years of failing, so I'm fairly sure I'm dystonia now, I it's gone completely. but I think my problem now is to, is to repair the damage that the 30 years has done. So, things like I noticed the other day that my right hand, the fingers are not parallel, so the strings will have been like that. Yeah, that's why I try to do it with my dystonia. But that's the way it should be because I get more immediate contact with the strings, all sorts of little things like that. So basically, I'd say it probably started to get… fifteen years ago, when we came back to [REDACTED], I seriously started to look at ways of correcting it, and it probably took 10 years before I got the results. A lot of days it’s hard to see much progress, but if something feels better, then I did something right, right?. When I have more stamina on one day, or the hand doesn’t shake for a bit longer, then yes, it’s a good thing.

ME OK, well, could you comment a little about your understanding of your own focal dystonia? How do you understand it, how you describe it to other people?

P1 Maybe how I describe it? It's an absolute bastard, and I wouldn't wish it on the dog. Well, I think, well, it's it's… It's. basically, the brain giving up, saying “it's too much this”. Well, people who get dystonia are a certain type. They’re driven, obsessive, emotional, blah blah blah, you know? And if anything's

going to go wrong, we're the ones that will go wrong with, basically. But it's the part of the brain that controls movement, and all the signals get mashed up together, so that the hands don't know what to do with fine motor movements.

ME Yeah, OK. A slightly different question? How would you describe the connection between your bodily movements and your musical self-expression after that, after you've recovered. Have you noticed a change in the way that you connect with the instrument or not?

P1 I'm more of a more hmm. Even though I'm not as good a player, technically, I reckon I'm a better player than I've ever been. But yeah, it's, it's. It's a more or less, it's a more emotional connection, it's not. it's no longer a question of the mechanics of technique. You know, this is the be-all and the end-all, and all of it is the music at the end, sort of thing. No, not just banging away, trying to play the flashiest, you know, most perfectly executed piece anymore. Yeah, well, plus it comes with, I just don't care anymore

ME How has your musical identity changed because of focal dystonia? How would you describe that?

P1 I was obsessive with classical guitar before. Now it's just music.

ME Great. OK, fantastic.

P1 So not technique, not technique anymore. It's the end result. It's the only thing I'll never be [REDACTED], and well. I don't care anyway..

ME Yeah. So, could you talk a bit more about the changes that you've noticed in your playing as a result of your movement retraining? The specific changes that you've noticed might not be just in your fingers or hands could be in other places as well.

P1 I'm more interested in tone now and then the music… dynamics if you like, to try and get the best possible, the most musical performance I can, and also, as you see, there's another thing to stop, thinking of it as a performance and more as playing. You know, this is it's actually cool playing music, you know, it's it shouldn't be. It's not a rite of passage or a proof of manhood anymore, which is what it was when I first started to play.

ME And in the beginning it was it was mainly classical music. Was it strictly classical training? Is that changed the style of music over the years?

P1 When I started, it was it was the usual chords and trying to play like [REDACTED] and all of that. But then as I got more into it and realized it was more to playing an instrument than just trying, trying, trying,, it, then became classical music and classical repertoire, classical technique God I was obsessive? Absolutely.

ME You say you're obsessive. Would you say that's just a general personality trait that you have or is it just specifically…..

P1 around what used to be. If I was going into something I'd go into in a big way always wanted to be the best. Even though I know that it's not a cat, you've got there or a dog.

ME That's my dog yeah, just sleep on the sofa.

P1 Yeah. So, I was obsessive about lots of things, so I've always tried to be the best. I've always failed he he he he he.

ME What's your view of your perfectionism?

P1 Now?, it's a waste of time, impossible, so what's the point? Basically, what's the point? Most of all, a bloke used to say, years ago in [REDACTED], I used to say that life's no hassle, just open another bottle. So, I think that's the same perfectionism. I the one.

ME Yeah. Oh, OK. Another question for you that I'd like to ask you. Looking back in your career to a time before you had dystonia, would you do anything differently in your musical training, if anything knowing what you now today?

P1 I don't think I'd even bother doing classical training. I'd be interested in doing it, but I think I'd take a more holistic approach to it. No, I'd do something which actually creates a living as well. I mean, I used to go on about people going and learning three chords and going and playing in a pub. But I realise now they're the ones who are getting paid and they're not going to get dystonia playing those three chords and they'll get the birds as well.

ME Do you attribute your dystonia to a time when you were studying strictly classical music?

P1 That's where it came about. If I wasn't doing classical, technical or training, it wouldn't have happened. But well, I doubt it would happen because the movements are so fine, you know, the motor movements are so far controlled. But I think that's where the where the onset happened. Yeah. I mean, yes, you know yourself, you don't hear too many rock guitarists getting it really. I mean, some rock keyboardists, too, but not guitarists. Not many.

ME Ok, yeah, I see what you mean. Well…at the time of the onset, do you remember if there was anything traumatic or difficult to deal with that was happening in your life?

P1 Not at that point, but before I had my first marriage broke up about 10 years before, but it was so devastating that it really screwed me up for a long time and a long time after the onset of dystonia as well, so it was an ongoing thing. So yeah, there was definitely something about that as well.

ME Yeah. So, were there any other significant things that you were dealing with, or having to deal with at the time as well?

P1 We moved country, we moved to [REDACTED], and that was pretty damn tricky as well because we stayed there for 15 years but came back. Basically, we didn't like it the first few years. It was all exciting, blah blah blah. but. then it wore off pretty damn quick, I can tell you. And that was, that was difficult as well, right? But I'm not going to get into that….That'll have to do for now I think. I'd better be getting ready to pick up the wife. Would love to talk more, but maybe another time if that's ok? I hope I've been of some help at least.

ME Yes, definitely I think that's pretty much it for now, actually. Thank you very much for your time as well. Is there anything else you'd like to add or tell me; do you have any questions?

P1 I can't think of anything…eh…no.

ME OK, I'm just going to finish recording.

P2 INTERVIEW TRANSCRIPT

ME Oh, so could you first tell me a little bit about your musical background?

P2 Sure, sure. Like you, I'm a classical pianist. I received my bachelor's. I'm sixty-two years old now. I received my bachelor's degree at [REDACTED] in 1981 and my master's from the [REDACTED] in 1984. And after I graduated from [REDACTED], I moved to [REDACTED], where I still live and gradually established myself as a teacher. I have a very busy teaching schedule now, and I've maintained a performance schedule through that, but certainly teaching was the mainstay of my life and certainly my livelihood. So, I can send them to you later if you want, but just if you want to hear my playing or my level or whatever, I have some recordings on [REDACTED] that I've uploaded recorded. Some are pre focal dystonia and I can send that. I send a link to that later for you. Anyway, in 2008 I first had my first symptoms of focal dystonia, which I noticed as a tendency for my fifth finger when I had an extended hand position. I'll demonstrate with my left hand, although it's my right hand. When I play the fifth finger, it would immediately retract to my fourth finger and there is a little bit loss of control involved in that, and after doing my own bit of internet self-diagnosis, you know, it's the thing that seemed most true to me was focal dystonia. Although other people did not think it was that I did see

[REDACTED], who's a very well-known [REDACTED] practitioner here, and [REDACTED] was also a pianist, and we had started with the same piano teacher in the past. So, we were kind of friendly colleagues beyond my seeking treatment for him, and he thought it might be a form of ulnar neuropathy and felt maybe it has something to do with my typing at the keyboard. So, I did get it at a keyboard when the keys were kind of divided into two sections where you were more typing this way rather than this way. Oh yeah, that didn't help at all, though. Then I did also see, there's a well-known physical therapist who's treated a lot of musicians and dancers with either hand or other body problems, his name is [REDACTED]. He also felt that it was not that it was not necessarily focal dystonia, so there was a lot of confusion early on as to what it could possibly be. I had the same stiffness as before. [Instrumental teacher] thought it was that. I never even heard of focal dystonia until then. Then I finally did go to [REDACTED]. As I said, I live in [REDACTED], so it's about two hours to [REDACTED] and saw a Rolfer there by the name of [REDACTED]. And [REDACTED] is a very well regarded Rolfer, she's probably in her 70s at least now, but she still has a kind of a hippie persona about her. She's a very cool, fun lady. And she was the first person who said, you know, she really thinks it was focal dystonia. And so, by then, I was still trying to play a little bit, but I wasn't actually playing concerts anymore, but I was playing like a few little things here and there, and the lack of control was rather bothersome and interfering from helping, well, helping me play well. And so around that time there, just to give you some background, there are a couple of things going on. Mm-Hmm. Maybe from a more emotional point of view, but also from a biomechanics point of view. As I'll talk further, I'm sort of torn between looking at treatment in an emotional way, as you said in the survey, with [REDACTED], or in biomechanics way with [REDACTED]. Mm hmm, so I was. The biomechanics work I was studying, the first Chopin Etude in C major, which I've never been able to play well, I've always been feeling out of interfered with that. And there's a recording that I found on [REDACTED] of [REDACTED] playing it, and it was in super slow motion, and it was very interesting because you'd really see his fingers flying up and the keyboard. Not that he was consciously reaching, but that part of his motion and maybe the freedom he had in his hand let his fingers to go up a little bit. So, I was practicing the etude, not obsessively, not like three hours a day doing this, but maybe spending like 15 20 minutes exploring that. And then I noticed after a few days on this outside of my fifth finger, it was, I could feel a little muscular soreness there that was lingering after a practice session. And so, I thought, OK, I'm just going to abandon this way of practicing. So, this is not helpful. And it was some time after that that I was noticed a little lack of control in my fifth finger. I was doing a recital with the [REDACTED] “Prologue do Bébé” the first book, and I forget which movement it was, and it may have been in the [REDACTED] that I noticed that. Yes. Have you played that?

ME I haven't. No, I mean, I should be more of a cellist. I mean, I trained as a pianist and a cellist, but I'm a cellist.

P2 Oh, oh, oh, oh, you're more of a cellist. I thought you were. Yeah.

ME So but I did that once I went to college to study piano as well, but I decided to stick with the cello.

P2 Well, in that case, it's just like a little piano trick. There's a lot of little simple route position arpeggios fingered with one three five and going up the white keys say Sieg, DFA Egbe. And then interspersed with that are the two black keys that surround the white keys, and it makes kind of an interesting sonic effect. And I'd always play those one, three five and and the recording that I'll send you on [REDACTED], that was with one three five. But before this recital, I just noticed my fifth finger was like, not a stable, so I changed it to one two four. So already at the time of this recital, I was noticing something was not working right with my fifth finger. Yeah. So, I did it and it worked fine, and the rest of the rest of the suite was was was no problem. But then this whole retraction of my fifth finger and lack of stability just became more and more entrenched. And as I went on. So, this is we're talking about 2008, right? And it was finally in 2011 that I felt that it was getting worse and I could see that then my fifth finger was really kind of welded to my fourth finger. And when I was playing, the contortions in my hand were, you know, uglier to look at looked more unnatural and it looked a lot worse. So it was at that time that I that I this was before [REDACTED] was commonly used by most people. And I went to there was a bulletin board for, I think, made by maybe the music dystonia, medical focal dystonia, dystonia medical foundation. It was directed by a French horn player named [REDACTED] and people would share advice. But the board administrator took sort of a hard line that and he was like a little on the negative side that there's absolutely no cure for it. But he really wanted actual medical research. But there was a violinist by the name of [REDACTED], who lives in [REDACTED] now, and just

coincidentally, she was at [REDACTED] just after me. I was just there for my master's for only two years and then, so we didn't actually know each other. But she had posted about working with [REDACTED], and I'd seen some of his videos on [REDACTED], which were very impressive, the changes made in players. So, I somehow managed to find [REDACTED], through this bulletin board, I mean, I found her on the poster board, but then they banned her from the bulletin board because they thought she was advertising for [REDACTED]. Okay, but before then we managed to get in touch and we exchanged emails and you know, and she really encouraged me to go to [REDACTED], where he was at the time. And he's in [REDACTED] now, as you probably know, so. So, I went to [REDACTED] in two thousand eleven and did they do a weeklong session with him, and of course, I was very, very impressed and had a really wonderful time being there and it was a great period. So, then I continue to try to self-study at home. Of course, there are a lot of things that I understood incorrectly, and I was trying to do things the wrong way. And at the time, it was before he got really famous. This was all pre-[REDACTED] and the viral video that that just kind of exploded his his exposure to his career. So, I could send him videos, and he'd send me a little response, a stack of things that I should try doing. I honestly had no idea if I was getting better or not. God knows what I was supposed to be feeling. And then over the years, I've probably seen him maybe once a year or once every two years, and I've either either in person once he moved to [REDACTED] or we've also done some [REDACTED] sessions when I haven't been able to go to [REDACTED]. And so, I've continued working with him in that, and it's just been a very intractable solution to get my my fifth finger, as he said, it needs to be resurrected in a way. His feel feeling was that in my brain's connections, in my brain's mapping was that the fifth and fourth finger became kind of welded together, almost like in a primitive animal with webbed appendages rather than articulate appendages. So, so. So that was what I've done with him over the years, and I will be seeing him in November for a [REDACTED] session. Then, in May of this year, kind of during the pandemic year, I did do a [REDACTED] workshop with [REDACTED]. She had posted on the [REDACTED] page of the musicians with focal dystonia, and we, I was very impressed with how well-spoken she was and particularly her assertion that our neocortex level the brain can process, I forget exactly what she said, but I'll just approximate and say, fifty thousand perception's per second, whereas the brain stem and the reptilian section of our brain will process up to 11 million bits of information per second so that there's a whole lot more going on that we're not even consciously aware of and that addressing that can really also help us get to the bottom of, of, finding of a treatment and a resolution to your dystonia. Mm-Hmm. So, I did this seminar, which was really very interesting. There were eight of us musicians, I think maybe seven or eight people all over the world and different instruments. A bunch of horn players in Europe, a guitarist in in [REDACTED], [REDACTED], who posts quite a bit on the musicians for focal dystonia page, and another go with this guy played, but there's a guy in [REDACTED] who is getting up at 2:00 in the morning to meet with us at the time and then maybe someone in [REDACTED] and someone in [REDACTED]. So, it was very interesting, and you know, as you might know, her big training in terms of understanding, underlining underlying conflicts of promise in our life is brain-spotting. And so, she did different types of brain-spotting exercises, exercises with each person during that time, and it was designed. I think the seminar was designed as a way for people to understand more about her work, but also for people who would work with her individually over a longer period of time. It would give them kind of a jumpstart into the work they would be doing with that. So, I've sort of been torn between looking at this as an emotional rooted problem or emotional dystonia being a physical response to an emotional event in our life and looking at as a as a kind of dispassionately, as a biomechanics issue, and to do exercises repeatedly and be aware of the perceptions I'm feeling in my body and try to get some freedom in my in my fingers. I remember joining a Body Mapping class online on the advice of my wife. I was in the gym every day, doing Body Mapping 'things' when I could. I had to do something, so it went from there. And so, I'm sort of on a waiting list to work with [REDACTED] at this time and I feel that in the long run, I still feel very even though it's been going on like a really long time that that I will eventually resolve that. And it may wind up being a combination of a complementary approach of using both what [REDACTED] teaches and what [REDACTED] teaches. And it's probably unfair to view [REDACTED] simply as purely biomechanics, because I know in his platform there are a lot of breathing exercises. He wants people to do all kinds of other exercises to to, you know, to free ourselves up so, I'm probably short-changing him by, you know, pigeonholing him into a biomechanics approach. Getting back to the emotional approach, there's one other thing I have to backtrack that was going on when the dystonia symptoms started. So, when I did, just I talk about the [REDACTED] video I'm talking about it a pure biomechanics sense of the soreness in my hand and then noticing the symptoms after that. Yeah, but there is another thing that went on at the same time I had three students who were really gifted. They were maybe ranging in age from 17 to 20 years old at the time. And there's a foundation, the [REDACTED], that I'm a part of, my former teacher has now passed away. [REDACTED] was the president of the [REDACTED]. He wrote a book called [REDACTED]. She was an American pianist who

studied with [REDACTED] in [REDACTED], who was a very famous European pianist who was a big kind of larger-than-life person at the [REDACTED] in the first half of the 20th century. And ah, but she felt that there was something missing in her playing, and she was one of these really creative geniuses who, through her own self exploration and looking at everything in the world around her, opened the door to what she felt were very new perceptions and understanding playing the piano. So, my teacher, my deceased teacher, [REDACTED] was a student of hers, and she felt that [REDACTED] really changed her life. And after [REDACTED] died, they thought they started this foundation to promote her books and to distribute her books to send to music libraries at universities all over the country. So, people would know that there was this other way of looking at things out there. In piano and piano playing circles, circles. I'm sure you've heard of the of the [REDACTED] approach, right? I would say that it's not too different from what [REDACTED] was teaching, but there were some differences. So, it was designed to let pianists know that there are some other possibilities out there. So anyway, after I graduated from [REDACTED], I came and studied. I met [REDACTED] sort of by chance, and then I realized when I finished, it finished at [REDACTED]. This was in 1984 when I finished my master's degree. I sort of going around in a lot of circles just to give a background, but I felt that there was something really missing in my my piano playing in that I was really intellectualising a lot of things rather than finding more internal solutions to mastering a piece. And I did have the experience after my master's degree recital in which I played [REDACTED] Second Sonata. That's some other. That was the big piece. But what impressed me is I played three just as a little interspersed between a [REDACTED] Sonata and the [REDACTED]. I played three of the [REDACTED] from Book six. Yes, just a variety and a little something a little easier to do. But I played them, and they were the easy pieces on my recital. But about two weeks after the recital, I supposed to taking a course at [REDACTED] and Eastern European music, and I was supposed to play these pieces and talk about them. So, the night before this, this little presentation in my class, I said, I better go and review the pieces. I thought, I'll just have to play them for maybe 20 30 minutes and just be sure they're there in my fingers. And like, they totally worked lists like like two hours later, I felt like I was relearning the pieces. And I've always felt that before. Once I knew something, I really knew it in my bones, and it was there. And so, this was the awareness that there was something as I was graduated from [REDACTED] and look at what I was going to be doing with my life and future studies and how I would seek a mentor out to continue my studies. And then I this made me realise I really need a mentor who's going to help me with getting this more inside. And when I met [REDACTED], everything she did in the lesson I observed said that this is the teacher for me, so so that worked with her for really until she passed away. And so as to this foundation she was ahead of has a concert series at [REDACTED], which is the smaller hall, used to be known as [REDACTED], and they present four pianists there per year. And so, in 2004, I played a concert there and then in it's part of that series. And then in 2010, there are these three very gifted students that she had heard because I brought them some of my lessons with her and she was just really blown away with them. And she wanted to present them as a demonstration of what the next generation of people trained using these principles of [REDACTED] were doing. And so, they played a recital. They each did like a 20-minute set and was very, very impressed that they were playing at a very high level and very difficult music. You know, [REDACTED] Preludes, [REDACTED] Sonata, [REDACTED] etudes. I mean, it was really serious stuff. So, one of them, who was a very poetic, lovely musician and developed tendonitis in both of his hands at this time, and I felt that there was a lot of responsibility on my part for not training him correctly so as not to have tendonitis. There's a lot more to it, but he is a very quick sight reader and a, and a fast learner had great ears, and he was also a high school student who was doing that cross-country and and activities, student government and top student in his class. So, he was kind of all over the place, and it didn't seem it was the right. And he looked quite good at the piano, and it didn't seem it was the right place to really micromanage his technique. And so, going that slowly and painstakingly over things to get things that polished didn't seem to me to be the right thing to do at the time because he was really playing quite well, but physically, he was just maybe a little too, his whole life he'd been a little bit more frail to getting sick for different things, or he had tinnitus for a while, he had lots of respiratory problems when he was little. So he was, you know, he was like a little bit more delicate and in a way. So, and he was also working with another teacher at the time. He was starting to get some exposure. His parents were a little on the pushy side. And this teacher kind of inserted himself into their lives and their family's lives and offered to do some coaching on the side with him. And so around that time, he developed this tendonitis in both of his hands. And it was really it was tough because the whole six months before this big concert and [REDACTED], he was able to play very little. Amazingly, he did the concert and played very, very well. He was doing a lot of like shadow practicing lightly on the keys, and he did the concert and played and managed to do very well. But it was a really stressful time for me and also at this time before the concert, several months before the concert, I brought him to see [REDACTED] again and explained that he is

having a lot of physical problems. And I said, could you look at him and see if there's something missing? And he played, and she said he's he's everything he's doing is right. There's nothing wrong with this, right? So, it was confusing because he was in pain. And, you know, and I felt like, you know, she just didn't have the answer to why he's in pain. And then sometime later, at one point, she had a biweekly class for students, and one of her other students knew that will this boy had come to play for her, and she couldn't see see him. Then she took me aside and said, you know, that time Will came. I, I wasn't diagnosing him. I thought I was just hearing him in a very general way. And I felt that she was washing her hands of any responsibility for his technical problems, which kind of left me holding the bag for the responsibility. I've since learned in the in her later years she developed dementia, and I do feel that at the time already she was not completely compos mentis, and she was hiding it well. But I feel that her denial of this, which at the time I experienced as a real betrayal, but I felt that it was also. In retrospect, I see that it was probably also some of the early signs of her dementia that at the end of her life was obviously very, very clear and very definite.

ME Whereabouts are you with your own dystonia at this stage?

P2 So, this is all happening as the focal dystonia is about to begin. In 2008, I had the first symptoms the year when this concert was going on. So, there are really two things that were going on. There was this [REDACTED] thing and the practicing this raised finger way not obsessively, but getting a little pain in there and then having this sort of more existential crisis, who I was as a pianist and as a teacher, and that was my technique really causing these students harm? The other two students who played one of them was already at college for an undergraduate. He was a phenomenal pianist and just, you know, technically he was extremely natural and efficient and was just great. And the other boy was like, this monster genius who tended to bang really loud. And if anyone should have terrible tendonitis, it was [REDACTED], and he would go through periods of inflammation, and he'd like to soak his hands in ice and then he'd play again. But he just, he seems to be impervious to any technical, any long-term technical problem, although he seems like someone like Will said, Why do I have to tendonitis? Why do I have this tendonitis and [REDACTED], you know, because we knew the way he played, why does he just get off Scot free? So anyway, so these two confluences were happening, the biomechanics and the emotional were happening at the same time, and I'm just I don't know how to sort out which it was, but it's just I think it's. You know, more than coincidental that they were both happening.

ME Absolutely, yeah. So how has focal dystonia affected the way in which you think about your playing?

P2 You know, I did try to play some as I was getting a little bit better and having some control. We did a revisiting of this 2008 concert instead of that concert was called the Next Generation. Then we did a concert that was called Generations, in 2016, just to see where these boys had grown and where their lives were taking them. And they were all going in their own directions. Very different directions. And then I was asked to also play at that concert as well. And I was going to open the concert, and I played a nocturne written for hand by [REDACTED], who's a very well-known jazz pianist. And it's a very effective and very beautiful piece, and I made a very good recording of it that was later kind of dubbed into a video that I made, which I'll send to you also. So, I opened with the [REDACTED] Nocturne that I was going to play a piece by [REDACTED], who is a very well-known pianist and composer who had been a student of [REDACTED] and a good friend of [REDACTED]. And he wrote a piece called [REDACTED], which was quite difficult. Not that it's technically super virtuosic, but from a musical standpoint, it's very difficult and very hard to memorise. And then I intended to play the [REDACTED] Gb flat impromptu, so it was a piece that I could sometimes play very well, but all the open positions got to be a real problem, right? And I did a run through maybe three weeks before the concert and and I realized that it was I could not perform this piece, the pressure of playing it. You know, before my students played in [REDACTED] for a public, you know, for a greater exposure, I could not play. There are some nights when I'm on my on my own, in my apartment that I'm able to play it. But it was certainly not ready for that. So, there's another beautiful piece [REDACTED], the Catalan composer, from the three landscapes called the Lake, El lago. That is a very beautiful piece and and it kind of was kind of up my alley in terms of the sound production and and musicality. So, I substituted the Lago for that, and the concert was very successful. It went very well. And then a couple of years later, they asked me to take take part in an ensemble concert, and I played the [REDACTED] fantasy in F Minor with a colleague of mine who was a student of [REDACTED] and a really, really fabulous pianist and musician and also a really dear friend. Yeah, yeah so anyway, it's, to play it really well it's really difficult. To play it kind of well, but not that well, it's pretty easy. But fortunately, when you're

playing with four hands, I was the primo part. And when you're playing in four hands, you know, you're in this weird angle. Mm hmm. Anyway, so I would redistribute the hands a lot like I could. I could take a lot of chords that were written with two notes in the left hand and four notes in the right hand. I'd take four notes in the left hand and two notes in the right hand, and I was able to just redistribute enough of the piece that we could give a really good performance of it and the performance actually went very, very well. Really one of the best live performances of my life, I thought. However. I felt incredibly fraught. Playing the concert because I was afraid of my dystonia activating in different parts, and somehow it didn't. And [REDACTED], who I played with [REDACTED], who is a super calm and serene person, kind of being up there with her and in performance also just, I think, helped deactivate any interference stress that would have happened. Yeah. So, I've had a few successful performances, but on the whole, I feel after that concert was over, then they wanted to do, the director of the series really loved her performance and then wanted to do a two piano thing the year of the pandemic, when everything closed down and we were supposed to do the [REDACTED] Sonata for two pianos. And once I was working on it, I realized there was no hiding behind me, just redistributing. And I absolutely could not play the piece, and I knew it would be really detrimental and make me crazy to perform it. So, I stepped out of it and that student of mine, I told you, this, like the monster banger, plays a lot of [REDACTED], and so he was going to he was going to volunteer with a partner of his to do some movements of the [REDACTED]. So it was at that moment that I said, I'm just going to stop. That was at the beginning of the first year of the pandemic, so year and a half ago. I guess it was then that I said that I'm just going to not play at all anymore and just really work on resolving my problem from the bottom up and not try to half play and manage playing. So, in my own perception as a pianist, you know then of myself as a pianist, I sort of, you know, for right now, I feel a little bit like a failure or a loser. My teaching is going very well, and my students, I'm very open about my dystonia to my students so that they understand why, when I demonstrate, I'm fucking up every little passage that needs my fifth finger, but you know, in terms of my musicianship and what I could do, I still have these great dreams for what I could do when I better. But so, my perception of myself as a pianist has certainly been compromised and that there's, you know, there's a fair amount of negativity and self-doubt in that. And I guess negativity and conflict between what I could be and what I am, and then self-doubt is now, how am I going to get out of this? I still feel like my playing is more superficial than before. If I just go for it then I forget what I shouldn't be doing, you know? I'm hopeful that that part will recover. I miss that a heck of a lot.

ME Ok. Could you talk about any changes that you may have noticed, or you have noticed in your playing as a result of retraining that you've undertaken recently. Has anything changed for the better, for the worse? how do you start to perceive that yourself?

P2 But not in terms of playing at the instrument. I feel a lot of the work I still need to do needs to be away from the instrument either, you know, some people have dystonia that just they have no symptoms of dystonia. And then when they get near their instrument, their hand starts going crazy, whereas in my case, this orientation in my right hand is present no matter where I am. So, it's like, if I hold my right hand, if I hold my left hand up to you, it's normal to my right hand up to you. You have that. And if I try to separate it, it's like it's with a lot of work where my fingers are less extended. It's not my fingers. They're a little bit more relaxed like this. It's a little bit more. There's a little space between them. But the straighter that they get and the more you know the tension it takes to open your hand or extend your hand, the more glued the fifth finger becomes to the fourth finger. So, I feel I need to really resolve that. Before I, I can seriously get to the piano again, right? Otherwise, otherwise, when I'm playing, I always feel that I'm compensating and un-compromised and I'm waiting for it to happen.

ME Is it a mixture of physical exercise and mental exercise? How do you feel? Is it sort of weighted in that?

P2 Increasingly, yes. I like to think more about the music. Mindfulness is all about visualisation, right? I get that right, then when I'm working at things on the [instrument], then I can get things working more quickly. Alongside that, I've leaned on structured approaches too—I remember joining a Body Mapping class online on the advice of my wife. I was in the gym every day, doing Body Mapping 'things' when I could. I had to do something, so it went from there.

ME

P2 I feel [REDACTED] is really helpful, but I feel that what I really need, what I've needed is like weekly lessons with someone who would be like, who would really oversee me and micromanage my

technique. Right. And I've sort of thought about there are some there's some [REDACTED] teachers who supposedly specialise in focal dystonia, but at the same time, I also have doubts about that. I also think the [REDACTED] teachers become a little bit monolithic and feel that they really have all the answers. And so, I'm a little bit sceptical of that. I do feel that in the last few months, the exercises I do are a little bit more focused, and so for me, in finding what movement activities are best designed to help your own particular dystonia, because we all have different manifestations of our dystonia, it's necessary to do a lot of exploration, and so on my own, I felt I've isolate, isolate the movement, said I really need to do more, so when I do see [REDACTED], I'll show him the movements I am doing. He was suggesting certain things to me and some of those might be right and might be on target. And some of those haven't helped me as much. But it's almost like I feel like I've I've needed a person to accompany me through this. Yeah. And finding the right person hasn't been so easy.

P2 Definitely varied. I've without doubt made some positive changes to my playing technique, but I still struggle with many things. I..I mentioned before, I feel as if I always need more contact time to work things through and get some more constant, you know, attention to the detail. It's still a work in progress, and I believe I'll get there in the end. There's no magic wand though, light at the end of the tunnel, yes, but no magic wand. Maybe there is? But I don't see it so far.

ME OK, so a different question. Looking back on your own career to a time before your experience with dystonia. Well, what would you have done differently in your musical training, if anything?

P2 I felt that technically I was really totally on the right track. Although there were sometimes when I was exploring some ideas that seemed really right to me and I'd share those with [REDACTED] and they weren't like what she wanted, and I think she was kind of more like like it had that strong personality that it was her way or the highway, right? I know if they use that expression and Britannic English. But so let me say that my way or the highway. So, she was a little bit like that. And so just in terms of pure technical orientation, she was a real believer in sitting low in the bench. So, your elbow is actually below the arms feeling that there was more ballast in your sound to make that happen. And a lot of pianists nowadays, and the prevailing viewpoint is that your elbows need to be level or slightly higher than your arm. And so, I would like to be more open to that exploration and then also in terms of the movement of the fingers, she was very big on there not being movement of the fingers. I was trained in some [REDACTED] pedagogy. Were you ever trained in any [REDACTED]?

ME I never went down that route.

P2 So, there's a lot of difference in technical approach with [REDACTED] teachers also, but they basically view these variations on Twinkle Twinkle Little Star as the planting the right seeds of technique. So, there are some teachers, you know, you play this rhythm, that's fun, and you play each note of twinkle twinkle little star to that rhythm. For starters, that's called Variation A. There are some teachers who will teach that you're really bouncing the finger on the key, and the arm is, the arm is very free, and the finger is not that, but that's the finger is not that active. There are other teachers who really feel that the finger is moving like like, I'll do with my left hand, which can you see better? Yeah, that's that. You're moving your finger like this. Dun dun dun dun dun. Together with the arm. And actually, I did fine after I was working at one [REDACTED] workshop and I was I felt I was finding the right balance between moving the finger well and moving the arm well, and it felt like that night I felt like suddenly everything I played was very easy. And I was playing, I was working, I was playing. We could have been a while. I was I had played [REDACTED]'s [REDACTED]. And when I was playing Shadow I. I I remember after doing this, I was trying, you know, it's a little bit more. Finger working together with the arm, and I just felt a much greater ease or freedom in a lot of the passages. Yeah, and I remember bringing that to the next lesson, and she really was not a big fan of this idea or might go up and down this route. And I sort of abandoned that.

ME So how did you feel about that at the time? How did you feel about that? That response.

P2 Conflicted. And but I eventually acquiesced to what she was wanting and didn't really do it that much. I think if I if I would go back, I would probably have just done that secretly on the side a little bit a little bit more and explore that a little bit more. And the whole sitting low saying my student who had the tendonitis, he felt that the sitting low was putting more strain on his forearm, its muscles in his forearm, and that that's also something I would probably tend to revisit. A couple of [REDACTED]'s

students who are already really high-level players who had studied at the [REDACTED] in [REDACTED] and went to [REDACTED] and studied with [REDACTED], [REDACTED]. They were already sitting high this that I just can't sit low. Second, understand what you're saying, but I just can't do. It just feels so wrong. So, there is there's definitely some, some controversy in that as well, and I would probably revisit that. In terms of purely musical point of view. I don't know if I do anything that different. I know one thing is that having dystonia has just made me a lot hungrier to wanting to really devote myself more to it. I think as I'm older, I'm a little more settled down in my life that, you know, I'm not like, why, you know, I'm much happier to be inside my house and being in the pandemic made me sit and you get more content with being inside my house. But I think I was a little bit more active socially. I was constantly running around doing with seeing people or, you know, getting this boyfriend or that boyfriend and like, you know, wasting a lot of energy and sexual or emotional pursuits. And I feel that that I feel like a very happy liberation, that I don't feel prisoner to that drive as much anymore. So, I have a I have a little dog who keeps me great company and is about like 10 times better than any boyfriend or partner I ever had. So, I sort of feel that that, you know, assuming that I get better, that I'll really have more time and motivate and I'll really be hungry, try to devote myself to my playing more.

ME In a similar vein I be based on your your experiences obviously touched on it quite a bit. But how much? How would that? How would you how have your teaching changed? Basically, how dystonia affected the way that you teach your students what due in part to them, that's based on your personal experience of destroying anything?

P2 I would say that in terms of musical concepts, not at all. I mean, when I'm working with the student who is at a level where you could talk about musicianship, that's there's not any really change. No, no change there. I think technically. I certainly, I take a little bit more of a standard approach to the height of the student, as you know, like I don't want them to sit really low. I want them to sit high. So, I make sure their parents have a set up at home with it is either an adjustable bench or some sort of supports so that they're sitting at an appropriate height and ideally something to rest their feet on. But a lot of families aren't willing to invest in that. So, they say they'll do it, but they never get around to doing it. But in terms of that, I, I, I certainly do that, and I do try to have a combination of, like what I was saying about the finger movement that I when I sort of had that work in conjunction with arm movement. I certainly do more of that than some people will say to do because I feel that that was something that helped me in my freedom and I want to hear my, you know, I make sure that when they're doing it, their fingers are more active, that it's not in a way that they're completely isolated from the rest of their mechanism. So, it's funny because when my students were promoted by the [REDACTED] and people were really impressed with them, a lot of other of my colleagues were students said, how did you teach these boys, you know, they want to know what I did? And I have to say that a lot of the teaching I did was not based on what I learned from [REDACTED] technically but was more my own sense of what was right at the instrument. So, I would say that it's probably made me look, having had dystonia and working on the recovery for that has probably made me look a little bit more mainstream in terms of how I technically work with my students. But I also feel that when you when we look at what's mainstream and what's out there, I don't, I don't like to see that division so much. But I, rather than looking at differences between technical approaches, I'd rather look at similarities that unite different approaches in terms of having a healthy and effective technical approach to playing the piano.

ME You mentioned that you all your students are aware of your dystonia. And how do you feel that they they have responded to that over the years? Do you think there's been any surprises in the way they reacted?

P2 No, no. Everyone's been very comfortable, very accepting and very comfortable about it. And I haven't had any experiences of people saying, Well, if you have dystonia, you obviously had technical deficiencies in your plane. And I have not had that experience, so people have been very understanding about it. Yes, I do feel that I wish they could have more respect from me as a pianist, that would be part of their student teacher relationship and their perception of me. And they haven't been able to perceive that as much from me, from my pianism because I'm not able to do that.

ME Interesting. I think that's pretty much it. I'm very grateful for your time as well. I think it's a comprehensive story. So, I'll start recording now anyway. Thank you very much for that.

INTERVIEW P3

ME OK, so firstly, can you just tell me a little bit about your musical background?

P3 Sure. I am a French horn player and playing professionally for about 40 years, so I'm here at the end of a career. I, yeah, I, I, I play for the [REDACTED] and the [REDACTED] and the [REDACTED], and I have played for 30 years with a group called [REDACTED], which is a period instrument orchestra. So those were sort of the three major orchestras that I've worked with. And I teach at three universities. I teach at the [REDACTED] and [REDACTED]. They're both here in [REDACTED]. And your driving distance from [REDACTED] just to give you a rough idea. And then I teach a course at the [REDACTED] in [REDACTED], once a month in period performance. So that's kind of my professional career.

ME Could you tell me a little bit more about your training?

P3 Yes, so I went to [REDACTED] and did a bachelor's in music there and studied with the principal horn player of the [REDACTED], [REDACTED]. He's a fine, fine teacher. And after I graduated with my bachelor's degree, I was lucky enough to land a job. So, I've basically been working ever since. So that's the only education that I really got. I did take a year off when I was twenty-five. I took a year off a sabbatical from my orchestra and went to [REDACTED] to study with [REDACTED]. There was kind of what they called a studio. It wasn't for a degree or anything, and that's right. That's where I picked up the natural horn. The period instrument was in my studies department and came back and that ended up becoming actually maybe the main part of my career after that. Yeah. And then the university teaching came. It's all sessional teaching. I'm not a full-time professor, obviously with a bachelor's degree. And so, I've been doing that for a number of years, the dystonia notwithstanding, I'm sixty-one. So, for a French horn player, I'm I'm at that point where some of my colleagues have already retired and I always figured 60 was the time. So that's so I'm kind of at the tail end of my career as a player, regardless of mainly focusing on the teaching.

ME Right. OK, can you tell me a little bit about your first experiences with focal dystonia?

P3 Right. OK, so that would be actually quite a while ago now. It would be approximately five and a half, six years ago when I noticed when I noticed for the first time something. I was playing in an orchestra, and I had a, there was a fermata on a note that was just me holding a note and it was a middle range note, not a difficult note. And I noticed in rehearsal already that the note, that I had a slight vibrato, slight tremor on the note, not intentional. And that was a bit disconcerting. And I thought, oh, I'm tired or whatever, or maybe I don't know, I wasn't feeling nervous or anything, and then the next rehearsal, same thing happened. And it kind of persisted on this note. I found when I was practicing that sometimes I would get, I just started to notice this creeping into my playing even when I wasn't in rehearsal and we actually had the show. It was in the spring, and it was a run of about 90 performances over the course of the summer here in [REDACTED]. And this problem persisted to the point where I was, I started to suspect that this might be focal dystonia. I was just fighting to keep things going like that, I remember thinking, I need a positive right now or that's it. I was so low. And I was aware of focal dystonia. So, I did some of my research and thought, I wonder. I did my research, but yeah, still feels like being part of some underground movement most of the time. And nobody is there telling you which way to go, apart from yourself. And I spoke to my GP, who had never heard it, of course, and understandably, but I knew enough to say, you know, I need a referral to a specialist. There is a musician's clinic at the university here in [REDACTED]. [REDACTED] runs it, [REDACTED]. That's right, [REDACTED], that's it, I think he has some international reputation in an organization, and I can't remember the name of it. It's got a few letters to it. But he, I know he goes to international meets and he knows [REDACTED], and he knows [REDACTED] and everyone. So, he and [REDACTED] run this clinic. And so, I started, I went to be assessed by them. So, this would have been maybe six months after I started noticing the tremor. After that assessment, I didn't speak with [redacted] again. I was just sort of left to figure it out by myself, which was really not what I was expecting. I was really disappointed not to meet again. And then midway through the season, I also noticed, sort of randomly, moments where I had just extreme bouts of fatigue that wasn't in relation to the playing I was doing and where I just thought, oh my gosh, I'm done. And then, later, I was able to play again, so I knew something was up. I did try self-medicating a couple of ways, I was already on propranolol beta blocker for my blood pressure. I've been on it since I was 30 and a low long-acting dose, and it was great for my blood pressure, was working very well. And it was the side benefit as a horn player of being on an interval. And I had no problem with that. I know it's maybe controversial, maybe less so now than it was 30 years ago, but anyway, so there was no need, and I was already on the panel, so I didn't try that. But I tried

Ativan, which is like I think Lorazepam is another name for it. I tried that, which is an anti-anxiety drug, and I did find that there was some benefit from that benzodiazepine. I think it's the kind of after benzo. So, there was definitely a lessening of the tremor when I used that. But that comes with its own, I mean, you're probably familiar with it, it comes with its own caveats. I mean, it's addictive or it's habit forming. And so, I knew that that wasn't going to be, that wasn't the answer, but it was information. So, I went to see [REDACTED], and I was assessed, and he said, you know, this is so-called dystonia and if you want to treat it, we're here for you, but I can't guarantee you that it will go away. But you've got nothing to lose by going after this, and he explained his own beliefs and how it was probably—I'm going to paraphrase him—you know, that he saw it as a chronic condition, performing under stress, with cortisol in the brain bathing the neurons in cortisol and, I remember him talking about certain cells that are affected by cortisol, whatever, basically saying that your brain has got some faulty wiring now, and that his approach was to do the rewiring, neuroplasticity by using that approach. And so, I embarked on his course, which has been fantastic because basically, like he said, first of all, you've got to put everything on the table, you need—you've been anxious for years, which I have been—so even if we don't cure the dystonia, you're going to be a healthier person because of the things we're going to have to do. Right. So, I started meditating and I started doing aerobic exercise. Where I'm at now is better psychologically but it took so long to feel the benefits. It's taken far longer than I thought it would, you know? Without a doubt, I'm much healthier. I'm much less stressed. I take better care of myself. And that was really the gist of their treatment. And it wasn't until I was maybe a year or two later and I was speaking to a friend of mine who's the principal horn in [REDACTED], [REDACTED], and [REDACTED], who I also knew from school, he's from [REDACTED] as well. He had been experiencing a different kind of dystonia, and he had discovered [REDACTED] and had actually gone over and worked with her and had gotten great results. So, he connected me with [REDACTED]. That was probably two or three years ago. And I've been working with her on Zoom ever since. And her approach has been a two-pronged, largely muscular retraining, and we have developed—we've been both looking, trying to, as difficult as it is, to figure out where the musculature is going wrong or not working or why, and at the same time trying to retrain the muscles, not the easiest thing to do when I couldn't go and, you know, she couldn't actually do hands-on work with me. Sure. But due to Covid, I mean, otherwise, I think I might have gotten it together to go to [REDACTED] and see her. But I didn't. But it's actually been very effective, and I have learned so, so much from her about my embouchure and about the musculature and the mechanics of the embouchure and yeah, and a few interviews with [REDACTED], ultimately, yeah. If you agree with him. And we've also discussed, you know, the psychological aspects and the stress aspects. I think that now, thanks to [REDACTED]'s work, I have actually made a lot of progress in terms of the mechanical changes that I needed to make. I've done some great exercises for strengthening and balancing the pressure—fantastic exercises that I now use with all of my students to try to pre-emptively help them have strong, healthy embouchure. It's pretty exciting to me, that aspect of it. It's been an incredible side benefit for me as a teacher. What I've not really successfully treated—what I notice is that although I can now control the tremor pretty effectively by really focusing on the embouchure, as soon as I'm under even the slightest amount of self-imposed pressure, the tremor is pretty hard to maintain, to get rid of, you know. Partly because, of course, Covid—everything shut down. We didn't play for a year with anybody. And so, the thought of going back to the ballet, which starts up again in December, is—I'm probably not going to go back because even when I think about it, I get stressed, and I try to play, and I get the tremor. Right. So, it's not that I've—so the dystonia is still inhibiting my career, but I think it's the psychological aspect. I was pretty diligent for a while, but I was stuck with what I had. I hit a wall and left it pretty quickly, to be honest..

ME You're going straight into something very interesting. Just going back to one point. What was happening roughly around the time you started noticing the tremor? Was there anything that happened around that time?

P3 Yes. Yeah, for sure. And we did look at that. And it came on the heels, right in the middle, of my elderly mother having some serious health issues and my siblings and I having to basically intervene, get her out of her house into—well, it was extremely stressful. And we were all very worried about her. And so, it does seem to be that there was a pretty major traumatic or stressful event happening right around the time that I started to have the tremor.

ME OK, How would you describe the connection between your technique and your musical self-expression after your retraining. Do you feel that they've somehow separated or have you managed to keep the two together? How do you feel about that?

P3 It's a very, that's a really interesting question. I don't know if I have—it's funny, I've not thought about that, but how I'm interpreting that question is that when things were going well for me—and maybe I misunderstand the question—I think when things were going well for me and I was in that good playing zone, right? Yeah, I had a musical thought and the technique supported that. Right. And I didn't really—you know, you're a player, when it's all working like that, you don't have to think about what you're doing. You just focus on the phrase you want to play or the colour you want to make or whatever. And for sure, when the technique fell apart, I had to reconstruct it. I think that it's, I think that the two are still organic for me in the sense that when I'm by myself and playing the horn and take up a concerto or study or something, I can forget myself in it and just play musically and it all works fine again. When I suddenly think, oh, maybe I should go back to the ballet after all, there's a breakdown and then I hear the tremor and then I'm just completely focused on trying to fix the technique. And I didn't speak with [redacted] again. I was just sort of left to figure it out by myself, which was really not what I was expecting. I was really disappointed not to meet again. I don't know if that really answers your question.

ME Yes, it is. Yes, absolutely. So, there's obviously a clear connection with the job and the stress and everything else going on there. Yes. You know, just checking a little bit, this went back to what you were saying about your teaching, because I'm very interested to hear about that as I also teach myself in university as well. Some of my teaching has changed quite, quite a lot. So, I just want you to go into that in a little bit more detail, how you approach that with your students. Are you open about your studying with your students as well? How have things changed for you?

P3 Yes, for sure. Yes. I've been completely open about the dystonia with my students and with my colleagues. That was part of what was one of the things that [REDACTED] in [REDACTED] said up front. He said, if our goal is to really take the pressure off your shoulders, you need to feel like you don't have any secrets. You need to feel like you're not trying to hide this from your colleagues. And I was very fortunate that had I been a freelancer, I think that would have been almost impossible. But because I was a tenured member of my orchestra in the ballet, I knew that I wasn't going to be—people weren't going to stop—they were going to stop hiring me, so I wasn't vulnerable in that way. So, I did. I just said, folks, guess what? This is what I've discovered and I'm getting some treatment for it, but I still feel like I can play right now, and you let me—you let me know if you think you're hearing something that I don't—I shouldn't be in the section. My colleagues were amazing. And right up until we stopped working in March of [REDACTED], I guess it was. Any time I would ask, I was reassured: you may feel the tremor, but we don't hear anything. So, I played 4th horn in the ballet, so that was nice. I wasn't principal and that probably helped. So, I was able to be open about it, which I think was a real blessing. I would hate to have been in a situation where I was trying to hide this or worry about that. Some of my students as well—I thought this is a teaching opportunity for me. Absolutely. Like a gift to talk about it. So, we've got master classes. I just said, let's—let me tell you what's going on and let's talk. I know you guys all feel invincible at the age of 18, but let's start talking now seriously about dealing with stress and having strategies to not let stress overtake you in your career. So, you know, we talked about exercise and meditation, and I had so many questions when I got back, but nobody answered them. I was disappointed, yeah..really disappointed with that. And I've been able to talk about those aspects—the anxiety and the stress, mental health issues—and then I think largely because of my work with [REDACTED], I was also able to create some exercises for them and talk about the mechanics of a healthy embouchure and healthy mechanics of breathing and the mechanics of how to strengthen your embouchure, which are just some fun exercises to do—no smiling exercises and, you know, an exercise where we put a balloon in between our cheek and our molars and then squeeze it out just to strengthen the buccinator muscles. And so, my students love it, right. Because it's so concrete, you know, the meditation and the exercise maybe roll their eyes a bit and some of them really get excited about it and some of them think it's hocus pocus and that's their age and everything, but the physical and the mechanical calisthenics that I've been able to develop with [REDACTED]'s help—yeah, it's just now it's just one of the things that I have incorporated into my teaching with my private students. And one by one, bit by bit, they learn a series of exercises to just develop all the necessary muscles for a healthy embouchure.

ME Have you noticed a difference in their playing, as well?

P3 Definitely. Definitely. Definitely. There's been some minor but, in a couple of students who really didn't have great embouchure—and you know, I mean they weren't planning to be performance majors, so it wasn't—you just work with what you had and you want them to learn to be good school teachers, but they've done these exercises and some of their embouchure issues, they've just improved and gone

away, and they're playing much better. So, it makes me look like a genius. And I'm just, you know, it's really kind of exciting for them to see. So. Yeah, yeah. It's been pretty remarkable.

ME Could you share a little bit more about some exercises and specific techniques that you used with [REDACTED].

P3 Sure. Sure. So, in terms of embouchure exercises, the first place we went to was to strengthen the buccinator, the cheek muscles. We started by using marshmallows between the teeth and then just trying to squeeze the marshmallow against your molars and you get quite a burn. It's a good exercise. And then we graduated to using—just like, I happen to have one on my music stand—so we just very, very lightly, like almost no air at all in the balloon, tuck it in there and then push against and try to push the balloon out and do that on both sides. That's a great exercise for strengthening these muscles. And it's fun for the students. We developed some smiling and almost like sneering exercises where, depending on which muscles you want to strengthen. For me, what I think—and there are a couple of muscles called the zygomaticus muscles, the major and minor zygomaticus, which kind of pull your lip up towards your cheekbones a bit—there's the one right there, the muscles that pull your nose right up when something smells bad. That muscle was totally strong for me. But these, when you smile, there are muscles that pull this way. And it turned out that, like, I could do that, but I could barely do that, and the tremor was happening right here. Yeah. And it became pretty obvious that this muscle was not functioning. I had no strength at all in one of the zygomaticus muscles. So even if you go online, you can find facial exercises to help strengthen those muscles where you just bring the corners in and then you gradually smile a bit and you hold it and then a bit more you hold it and so on. And then once you get them to the extreme, then you practice dropping one side—like that. I'm not very good at it right now. I think I'm out of shape, but if you learn to control and strengthen these muscles, that was very important for me. And then we moved on to the lower lip. Horn players, as we go down into the lower register, most horn players advocate dropping the jaw and slightly moving it forward. That's kind of—so if we think of, say, we talk in terms of an angle of the mouthpiece: in the high register, it might be angled that way and it could go lower and/or that way. So, there's a change in that. This is extreme, but I'm just going to show you. So, in the low register, we tend to play with the mouthpiece more straight on your face. In the high range, we tend to overbite a bit—might be another way of putting it. So usually, the way I've always done that and the way I think most players do it is to thrust the jaw and thrust it forward to put the lower lip forward. And what [REDACTED]—what we discovered working—is that really a lot of the tremor, a lot of, she feels, I think anyway, a lot of embouchure dystonias really have their basis in jaw tension. So even though my jaw wasn't like—it was a problem, I suddenly realized, yeah, I'm like—so we worked at just relaxing the jaw a bit, you know, just physically massaging the jaw muscles. We tried—she said, imagine if you had a jujube between your molars on either side—have that kind of spacing. I love that exercise. I give my students a couple of jujubes, and I say, put these between your teeth. They do that. And I say, OK, now eat them. And now just—now that spacing that you had with those. And they say, oh yeah, my jaw feels like it just kind of drops the jaw in a relaxed way now. And [REDACTED] would like to use the phrase I like: every time you pick up the horn to play, before you play—lose your jaw. Lose it, just let it go away. And that's been one of those kinds of aha moments for me. Like that—right—just really relax the jaw. So that's again with my students, we're just making them much more aware of their jaw. And then, conversely, looking at the jaw, you still need to get that lower lip out for the lower register—you need that firmness there. But what I had conflated incorrectly was that you did that by pushing your jaw out. So [REDACTED] would help me train to move the lower lip out without using my jaw—kind of like when you pout, right? If you pout but you consciously don't thrust your jaw forward when you pout. So, we did an exercise where we inverted the mouthpiece—so I'm trying to get in front of the camera—and the small end, form an aperture around it and then slide the lower lip. Right. You get a bit of a burn there, and it's a terrific exercise and my lower lip now can move independently of my jaw. Right. And it's actually hugely effective in reducing the tremor. So that's probably the gist of the exercises. But they're fantastic. And I wish I'd had them—like every player should have these exercises—and I'll do my best to disseminate them for the rest of my life. They're just so good. And then we also talk about breathing as well. Just working at having a very relaxed breath, more abdominal breathing. Breathing is a weird thing. I don't know how many brass or wind players you've talked about breathing, but there's a lot of different thought out there. And when I was in university, you know, it was about thrust your belly out and then hold it firm while you play. Right. And that's what everyone did. And then there was the whole school that developed in the 70s and 80s where you— that was no longer it at all. It was like, make everything as relaxed as possible and fill up like a balloon, which ended up being a lot of upper chest breathing. [REDACTED] has me doing more abdominal breathing. And then compressing to put the air out—it's actually really better for my dystonia,

so I've found it more effective. She also has talked about the—like, I don't know, yoga teachers call it the pelvic floor, like the muscle at the base of your pelvis. She talks about, at the end of your inhale, before exhaling, contract that muscle. I can do it, I have to do it consciously, I haven't been able to make that part of my life. But it's interesting, I spoke to a former student of mine who's now playing professionally, who has developed a different kind of dystonia. He's developed the kind of the stuttering one where you pick up the horn and you can't release your tongue. I don't know if you've ever dealt with anyone with that, but it's another common—yeah. And he had independently discovered the idea of contracting that muscle before articulating, and it completely got rid of that dystonia for him. It was something online—there was a fellow who developed this technique for stutterers. So, it seems to be a similar mechanism to stuttering perhaps. I don't know, is stuttering a dystonia? I don't know anyway.

ME I think it's, you know, when you come down to definitions of focal dystonia, it's a tricky one, right, where we get stuck in a lot of cases because you're pigeonholed into something that doesn't quite fit, and I don't think anybody quite fits. So, it's quite difficult.

So, can you recall anything that hasn't worked for you during your training that you've tried, and it just hasn't worked?

P3 Yes. Yes, yes. One in particular, when I was reading various things—this was before I met [REDACTED]—it was something called, is it called EMDR? I figured EMDR, I can't remember. It's a technique where they will do it, right? Eye movements or tapping on either side. I sought out a specialist in that and it did absolutely nothing for me. So, and I know it's perhaps pseudoscience anyway, and I'm—as you can probably tell—I'm not a big fan of that. I gave it a try, but it wasn't for me. I was pretty diligent for a while, but I was stuck with what I had. I hit a wall and left it pretty quickly, to be honest..

ME And to what extent have you developed your or expanded or developed your own exercise and techniques for training, have you taken anything, for example, from [REDACTED] and expanded out. You try things for yourself.

P3 Right. Well, I would say that some of the things I've described for you, especially the sneering and the smiling exercises and some of the putty ones were—I believe she gave me the seed of the idea, but I went online and found more information and developed the exercises maybe a bit further. But generally, no, I don't think I've created any. I did my research, but yeah, still feels like being part of some underground movement most of the time. And nobody is there telling you which way to go, apart from yourself.

ME And you felt this two-way collaboration with her, which is.

P3 Yes, very much so. Yeah. She seemed just as excited with what I was able to discover, and it was a lovely—yeah, it was a very helpful way to work for me. Yeah, we were kind of co-discovering and, yeah, she was very appreciative of anything I could contribute for her research. So, yeah.

ME Well, based on your experiences with focal dystonia what advice would you give to young student musicians during their training? They don't necessarily have to be your students, but whatever.

P3 Yes. So, I would—this just really reinforces my belief that when you are learning to play an instrument, it needs to be a holistic approach in terms of, you know, not just learning to play your instrument, but also learning to take care of the stresses and the mental stress, the mental health, learning to focus. Learning to—yeah—to learning kinaesthetic awareness. When I was a student in university, my horn teacher had us all take some Alexander Technique lessons, and it was fantastic. I, because I was—I had no, you know, I was just a tiny little wild 18-year-old who knew nothing about my body—and just shifting my brain to thinking about what my muscles were doing, that was the beginning that probably made me more open to what [REDACTED] was having me do as well.

ME Do you think that maybe by getting more of that kind of training earlier, not that I'm saying that the dystonia wouldn't appear, but maybe you would have been more prepared for it?

P3 I think definitely more prepared, but I think even maybe it wouldn't have appeared. I think, if I had done a better job—especially, well, everything, right? I wish, I wish. At least in the brass world, the understanding of the mechanics of the embouchure is still—you know, we've come some ways, but I had none of the information, none of the analysis and information that [REDACTED] was able to share

with me. I think working with someone like her—yeah, had I done that. My embouchure was unbalanced probably from a very early age; some of these muscles probably weren't. I was—I mean, we all do this, and we all develop compensations, and we find a way to get the music out. If you look at pictures of brass players' embouchures, very few of them are the picture-perfect ones. Right. And I'm sure it's the same with string players. We all have bad habits or strange habits. We don't do everything by the book, but we get it done. But I think that's partly what comes home to roost with something like dystonia for me. I think probably years of not having a really good foundation for the technique of the embouchure, coupled with extreme stress and my own anxiety—so, you know, an anxious person should not pick up the French horn, but they don't tell you that when you're 12 years old, so suddenly you're out there on a limb.

ME I think most musicians have some degree of anxiety right. In the character.

P3 It is right. It is. And so, I think that we should be hitting that earlier on with the music schools and really, you know, really teaching our students to take care of their mental health and their physical health. Yeah, I think that's just essential.

ME All right, so, yeah, basically I said pretty much everything, just one little thing, if you were to—when you're observing the younger horn players, doesn't necessarily have to be your students, but can you observe anything in their technique or anything that they do, that now you think to yourself: hmm, a light bulb goes on, or I think I need to change this, or this isn't healthy, this could be a problem?

P3 Yes, I have one—like one that's kind of an immediate one that I see all the time. I watch their shoulders, and you can see it right away, right? The shoulders are going up towards their ears. That's one of the easiest fixes. Again, I love these changes that they make—you look like a genius. And they really, it's just—I just say, OK, now just send your shoulders down to the floor and try that again. And, you know, it's—so that's one that I see all the time on kids playing almost any instrument. Yeah, other than that, I'd have to think. If they're standing, again, you'll see them locking their body, locking their legs. Yeah, just looking for rigidity in the body, looking for any place where they're now starting to tense up.

ME Were these things always a priority?

P3 I am more aware of it. And I'm more concerned about pointing it out to the student now. It wasn't before. I really, I think the dystonia has really sharpened my attention, again, to these matters of physical tension and mental tension. So, I've brought in—you know, I bring in a Body Mapping person or an Alexander Technique person—to do a workshop with my students now that we're back in person. Because I really want them to learn about their bodies and how to take care of them.

ME And, you've partially answered this, but how would you describe your relationship with focal dystonia now?

P3 You know, like so many things, it's a mix. I'm first of all very fortunate in that because of my age and where I am in my career and where I am financially, I am OK to retire, so I don't feel bitter about the dystonia. I've played with it for the last five years, which I know some people just don't—you can't play at all. I was very lucky in that way. So, the dystonia has kind of become a little friend, a little teacher to me. I don't want to sound like a Hallmark card, you know, to say, well, it's actually been a blessing because I've learned so much because of it. It's made me a better teacher, a better person. But it's kind of true. Where I'm at now is better psychologically but it took so long to feel the benefits. It's taken far longer than I thought it would, you know? Again, I realise the privilege that I have of being able to say that because I wasn't cut down in my career at the age of 40, and I would probably feel very differently. It would be harder for me to get to that place of "what a gift it was." But, you know, it's in my nature to try to see the best in situations and I wouldn't have chosen for dystonia to be thrown at me, but the fact that it had turned out to be a really huge learning experience. So, my relationship is not one of bitterness or feeling defeated by it, but more: I was challenged by it, and as a result, I met some awesome people and learned tons of things. So, yeah, it's a mixed blessing, OK?

ME I think that's pretty much it. Pretty much everything there. So, I'm just OK. Pressed up on recording here.

P3 OK.

P4 INTERVIEW

ME OK. the questions here are going to be kind of flexible, so they're going to be semi-structured if you like, to guide the conversation, but also to allow you to tell your story. So firstly, could you tell me a little bit about your musical background?

P4 All right. I am currently, I will be 68 in two weeks, but I started when, I started playing as a child. My parents enrolled me in a school programme, and I played the trumpet when I was in what we call third grade. I didn't care for that. I wanted to play the bagpipes. So, I took some lessons. I loved the bagpipes but didn't have good wind. But anyhow, then I was, when I was about 14 or 15, I walked into what we used to call a head shop—this whole drug paraphernalia, but not the drugs themselves and psychedelic posters. And I bought a harmonica, and I started, and I taught myself to play that, and I started playing blues instead. And my sister—then I was staying with her in [REDACTED]—and she took me to the [REDACTED] contest, and I decided that I needed to learn to play. So about six months later, I got myself a banjo and basically taught myself to play the five-string banjo. And then about six months after that, I wanted to learn to play the fiddle, so I got a fiddle and a violin, and I started teaching myself to learn to play fiddle music. And then in the 70s, by the time I was in my early 20s, because I could play, people started calling me up and having me come out and play and more or less pieced together a living, doing that for the next ten years, teaching and such. And largely, you know, I am ninety-nine-point six percent self-taught, I would say. And so, I played for many years. I played mostly country—well, I guess what you call the big deal of country music. I play bluegrass music, I guess primarily country and western, old-time fiddle music and Irish music—played a lot of Irish and Scottish music. And then I—oh, something else, what did I—oh. I went into playing country rock as well and rock and roll, and I like that. But anyhow, I also, I come from a family of smokers. I smoked a lot, maybe two or three packets of cigarettes a day, which is about seven, about 50–60—smoke constantly. And I drank too much as well but any. And in 1988 I was playing. I was in the habit of playing. I eventually got a straight job, and then in 1984, I got a straight job, which was by choice. But in 1988, I was playing in a situation that was very loud in an Irish bar on St Patrick's Day and very long. And then in a situation of emotional duress, which is another long, oddball story that would take longer than the 45 minutes for this interview. And the next day, my arm—my arm playing the fiddle—no longer really worked properly and would catch as such. There was not very much known about this, and I had other issues along with it and tried to address those, but I went back to just concentrating on the banjo. About four years later—and although I did get sober in 1988, I've been sobered since then and except for about a five-year period, I quit smoking as well—but then I started playing the banjo and then in about nineteen ninety-eight, the dystonia spread to my index and middle finger.

ME Right hand?

P4 Yeah. And so, by that time I'd managed to get formally diagnosed with dystonia by [REDACTED], passed away now. To be honest, there was nothing showing on my MRI (magnetic resonance imaging) or blood tests, so I was basically told, 'it's nothing serious, it will probably go away over time'. I was given some muscle relaxants, referred for some physio and signed off. I also remember him looking blankly at me when I told him about my lip terming only when I tried to play—I was on harmonica a lot then—and I was actually sent away with diazepam to keep me calm the first time. And so, I took up some other instruments as well. I tended to do—later, tin whistle and some flute—and did a lot of work on the harmonica and Scottish pipe band drumming, actually. I played in a pipe band. But I retired about three years ago and I've been relearning to play the banjo left-handed, picking with the left hand, fingering with the right hand. And that actually just recently had kind of a breakthrough on that, as far as reconnecting, getting the fingers to work properly. It has just been very hard to retrain them to do because my left hand is unaffected and still very good. So that wasn't the problem but retraining the right hand—and I've had a breakthrough and now we're much more connected with it. So, I think that's why. I'm also on the autistic spectrum, so I think that is connected with this all.

ME Yeah, I think there is something in that as a friend of mine who's also a flautist—she had dystonia. But she's on the autistic spectrum as well. So, could you just tell me a little bit about how your

diagnosis came about? So, when did you actually decide I need to get help? Was it the first diagnosis that you received, or did you receive other things beforehand?

P4 Well, yes. I had been to various physical therapists. I was referred to various physical therapists by my GP and all of them actually had a helpful effect because the focal dystonia—at least in my case—did not occur in isolation. I played very hard. I played stressful situations. I played intensely and controlled. And the focal dystonia was not really well known at that time. A friend of mine who was a banjo player also had it, and he actually sent me to [REDACTED]. That was in about 1998. So, it was 10 years later. But in the meantime, I had done some work with [REDACTED] patterning which is kind of cool and such because I had very poor posture as well. And I think I had tendonitis, and it turns out now also I have stenosis in my neck. And I've even had a dystonic episode where I had to go to the hospital with my neck. So yes, I think there's very much a connection between that dystonia in my arm and also in my neck, right? I think there is. In fact, I think I've got a lot of what you call motor overflow—which is…

ME But your left hand feels fine?
P4 Knock on wood, but yes.

ME OK. Can you tell me at what point on your journey with focal dystonia did you decide to explore movement retraining? At what point did you decide, I'm going to go and see a specialist, not just medical treatments, but actually exploring therapies, particularly those focusing upon movement.

P4 OK. That's a good question. I think all along I realized that a lifestyle change was necessary and I kind of stopped playing the fiddle and devoted myself to a lot of therapy and working on stress reduction and such. But I think it was really in the early 2000s—because I was working in elder care and helping people with dementia and learning about neuroplasticity and kind of exploring that idea of using different nerve pathways and such, if that makes sense. Does that answer your question? Even so, [I] had to navigate the retraining and recovery process largely on my own without [any] help.

ME Yeah. I mean, could you expand a little bit more on that, on your experiences with exploring neuroplasticity. How did you approach that.?

P4 Trial and error. I didn't have anyone to train me in this, you know? And frankly there were a lot of us just in our group; multiply that several times, there's no way [retrainer] could respond to all of us. So, I kept at it on my own.

ME And how did you—how did that work out for you? How did you begin to feel?

P4 It's not a fast route. I believe that the breakthroughs that I'm having with my fingering on my right hand now are as a result of the pathways rewiring themselves. It's a kind of slow torture, but you just have to do it. You can't give up on yourself—if I feel like that I just stop, do something else and carry on.

ME Ok

P4 Yeah. Yeah, and I think that I'm very much—I'm very glad to see my—when my picking fingers went bad on me. There was also, I can still see the face of the guitar player just grimacing at me. He was very upset because I was taking centre stage and getting a lot of applause—jealousy. And it just—this horrible—and I can still see it. And that's when the picking problems started on the right hand. Exactly. So, I think there's a very strong—at least in my case—component of, you know, the limbic system getting involved. For me it's always been a trauma response. It can't just be a physical thing; there's nothing to see. Dealing with my anxieties and stress has changed things so much.

ME And so, with the first dystonia with the bow. Was that sort of an instantaneous thing as well? Was it—was the onset quick or was it gradual?

P4 It was. The next day, my arm felt like lead.

ME It just—so that you chose to play after a concert, right?

P4 Yes.

ME OK. And just going back to that particular concert itself. Was there a specific thing that happened during that concert—was that something that you recall as a triggering factor?

P4 There was a person from my past showed up that I did not want to see. And to be clear, it was in an Irish bar, but it wasn't actually a concert. It was very loud. I had chosen to play without amplification—direct amplification. I was playing into a microphone, which was not advised either. I was not—to my credit—I was trying to show off, and that's kind of. So, I hope that puts you in the picture without going into the sordid details.

ME Could you comment upon your own understanding of your focal dystonia a little more? How do you see it for yourself? What do you consider it to be for you?

P4 Well, what do I think is going on?

ME Yes,

P4 In my case, I see it this way: I played in a very controlled way where I was using muscle groups against each other to maintain control. And I'm playing very, very hard. I'm not a particularly large person, and I was trying to emulate people that are much larger—like a lot of the great players. So, I would have this physical stress going on through overuse, which I believe—we aren't designed to use the same things constantly, repetitive motions constantly. And I think that my brain just rewired and said, OK, you want to tense up, we will tense up. And so, I kind of think that you have to actually—if you look at the neural pathways, a long maze-like thing—it's almost like you have to find a different entrance to the maze. You have to just bypass that entrance and develop a whole new, whole new world. Yeah. Does that explain that?

ME Yes, absolutely. And if you look back to a time in your musical career before your experiences with focal dystonia. What would you do differently in your musical training, if anything? How would you have approached it in any different ways?

P4 One thing that I did—when I learned to play I played the fiddle in front of me and I kind of bent over, which was very handy because I could play into a little microphone and share it with other people. But I decided that was undignified and so I actually straightened up and started using a shoulder pad. I had done that about a year earlier than before the dystonia came on. So that corresponds—very often people change instruments sometimes, etc. I used a lot of pressure to hold the fiddle down with my neck, so much so that back then this side of my jaw was actually overdeveloped. And when I went to a dentist after not having been to one, he was going to send me to a cancer specialist who thought I had cancer of the jaw. It’s now gone down. It's being taken over by old age—of course you can't tell. I remember starting to look more like [REDACTED] each day, but it's resulted in some tooth problems, and I think it resulted in the jaw problems. So, I think I would have taken better physical care of myself. I might not have played quite as hard. And I definitely would have taken better care of myself and better mental care of myself.

ME That's interesting to talk about—that the psychological connection sort of keeps coming through as well. So that's a common theme. Carrying on a little bit from that, how would you describe the connection between your physical movements and your musical self-expression? How would you describe the connection with your bodily movements and that feeling of musical self-expression after being affected by focal dystonia?

P4 Totally alienated from my body. It was almost like shock. And it was like a total—it’s almost like I had been becoming my arm and after that, it's like it's almost not me anymore.

ME So, yeah, and after some retraining—you've done all the training with the therapy that you've done—how has that evolved or changed?

P4 Should—I am learning in general. I mean, it's an ongoing process, but I am learning in general to get much more in touch with my body. I don't have any crystals here, don't worry. But yeah, I'm learning to really react more that way. I mean, this has been a generalised thing. I think there's a strong

link between my autism and how I process mirror neuron imaging. Because I don't understand people's facial expressions, I don't interpret them correctly. And I don't learn things by watching people—I develop my own ways of doing things and often being under stress. My whole body tends to adopt a stress and protective pose. So, in a way, I'm kind of—you know, I don't learn things. For many years, I tried to learn to dance, and it was very obvious that I could almost kind of do it. People would say, you dance like a musician—which it turns out is not a cool image.

ME He Hehe….

P4 So I'm reconnecting, I'm learning—actually even learning how to breathe again. I had, among other things, developed a huge node on my vocal cords, which was removed last summer. And so, I'm relearning to sing—some of my range has come back.

ME So, yeah, how has focal dystonia affected the way in which you think about your playing? Your relationship with your instrument.

P4 Has it changed? Oh, I think—well, it's no longer like I can just pick it up and go. It's not like, you know, I can just play on command. Maybe that's a good short answer. Yeah. Does that answer and address it?

ME Absolutely. So, let's move on to the next little bit here. I'd like to hear about your experiences with movement retraining. So, could you tell me why you chose a particular therapy or retraining over another? Could you give me the reasons why?

P4 Well, when I started there really wasn't very much available. This was just a complete mystery in the 90s, of course. Yeah. And the first hint that I had—I was doing some training to become a nursing assistant, and I heard about contractures that people with strokes get if you don't move. And that sounded like what I have. It's like intermittent contracture—that's the best. And there really wasn't anything like that. Then I did find this really good physical therapist who, in addition to really teaching—because I had a badly rotated scapula, among other things, from pressing so hard—got me into [REDACTED] patterning in the early 2000s. So, I realized then that I needed to start retraining my brain. But I couldn't—there weren't any resources, so it's been a self-directed journey. I need things to be clear in my head, and it just felt like I was doing exercises, but I had no way of checking if they were right or wrong. I couldn't get any answers to my questions, and I lost interest quickly after that.

ME And when you actually first told somebody that you had dystonia, was that an easy decision to make, or did you keep it hidden—how did you address that?

P4 This was a very difficult thing. For one thing, no one knew. You know, it's like the attitude is "play through it, play through it." Come on, whatever it is, you can play through it. And there are people now that I've known for years and explained this over and over but still don't understand because it's invisible—it's an invisible disability. Very, very difficult. The loss of status in the musical community with this has been a very devastating thing, and I'd put it akin to a professional athlete who is no longer able to perform. And it's not something that you think about when you're a musician because you think you're just going to get better and better. I came down with this at age 35 and I was really among the very first of my generation to come down with an overuse injury.

ME How did the relationship with your colleagues change? Musical colleagues,

P4 Oh, some are still good friends on a level other than music and some others just plain dropped me, you know. But you know, when people kind of say, "Oh, I wish you could—you're almost like your old self, we want you to play like—" you know, I'm kind of not that person anymore as well. I'm not the person that I was when I played that way. And so, it's kind of—because I had to change my whole outlook. I was kind of the bluegrass version of—you know, the highway to hell kind of thing. People think of bluegrass as big happy, jolly music. But actually, it's about pain and sorrow and misery and such. People think it's happy because it's fast.

ME You mentioned that you weren't the same person when playing anymore. Could you go into a little bit more detail about that?
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P4 I guess I feel like I needed—I have taken more control over my personal life, I guess is a broad way of putting it. It's been now almost thirty-four years. And there's a lot to fit in there, but I've taken more control over my personal life and made choices.

ME Yeah, yeah. So now at this stage in your life, how do you feel in relation to your musical self?

P4 How do I feel? I feel good. I feel good. I think like every musician that gets older—I'm afraid you never lose that. Do you have the saying, you know, the old war horse smelling smoke? You know, it's like we all have this dream that, yes, the phone calls will come, they'll put the band back together—like in the [REDACTED], we're going to hit the road. And you forget that a lot of music—at least when people watch it—is about sexual energy and all this stuff, and they don't want to see old people playing this stuff. And I even—I kind of changed my way of playing some, and I did it briefly as a way of getting by in the early 2000s before I changed careers, and I discovered I didn't really enjoy watching young people jumping up and down while I played anymore. And it's kind of over. But I'm rambling on, you know, and I forgot the original question.

ME No, you don't need to keep to the original question.

P4 What was the original question?

ME Actually, that was exactly what I wanted to hear because I want to get to understand your feelings about things.
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P4 I guess now I do a lot more listening, and I wish I had the ability—here is something else I would, you know, if I were to approach that now I understand it so much better. You know, I wish I could play that now. And to that end, I am enjoying doing that on the banjo, even though I don't perform. I never really enjoyed performing—had terrible stage fright, which I finally got over. But I'm not a person—I'm such a chatterbox, but I'm introverted. I don't like to leave the house. And there's another dichotomy: you have people that really like to stay by themselves and do this thing over and over. You say, "Oh, good, now you're good at it. Let's go out in public and do this now. Do this for everybody." I think that's a real dichotomy that a lot of musicians face. Yeah. And you know, you're putting your soul out there on the line and facing rejection all the time, you know? So, I play for myself, and I enjoy that. It actually took a number of years to really extricate me from all my various performing obligations—people would expect me to come to this and that. And also, I'm working on—I don't have it, it's about three weeks from completion in its most present iteration—but I'm actually going to relearn to play the fiddle. I've developed—some people can play it against their chest, but my fingers are rather short. I have short fingers. So, I've developed a harness that the fiddle clamps into and I'm working on getting the right angle on it now. Maybe when I get it done and get a video I'll send it to you, right?

ME Yeah. So that could be the changes or the angle of the thing so that with the bow, does that help this?

P4 It will change. It will—I believe it will help. I believe it will help that. And it will keep me from having to clamp down with my neck to hold the fiddle, which I think was also a big contributing factor.

ME So you talked about overcoming stage fright at some point in your career as well. Did the dystonia change after that as well? Do you think?

P4 You know, I don't think that had a measurable—measurable effect.

ME Yeah, so I mean, would you associate stage fright with dystonia or do you think maybe not. But how do you feel about that?
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P4 I think that any level of excitement like that actually does affect your motor movements. So, there may be an interplay going on there. You might be in a heightened emotional state. And I do know that—oh, it was actually when I had to quit smoking again. About 2010 or so, instead of smoking at the bus stop, I took up drumming and joined a Scottish pipe band—started learning pipe band drumming, which is incredibly disciplined. We have a way of just taking something whimsical and draining all the fun out of it. I mean, there is nothing more regimented than that drumming. Yeah. And I was called upon to play in a contest and a neurologist actually gave me some—he said, "Well, what we do for this," he

gave me some Xanax—"just take some before you go out," and it actually helped some because I had the fingers clapping. But that is a dangerous—yeah, getting into Xanax. And so, yeah. OK.

ME So just go down to this final section. Could you tell me a few more details about the exercises or techniques or concepts that you learnt? Firstly, with the retraining of the bow arm of your fiddle?

P4 OK. I haven't really embarked too much on that yet, except that I can see that the idea of using the muscle against the muscle is not a good one. The successful retraining that I've done is more getting my fingers to work again. It was really very difficult—I couldn't move these fingers at all when I was starting to fret. Now I can make four-note forms and I'm feeling like they are connected, and I have control over them. Still, I need things to be clear in my head, and earlier it just felt like I was doing exercises, but I had no way of checking if they were right or wrong.

ME What kind of exercises—how has your process been? Is there anything that's really stuck out as something that's crucial to making it work?

P4 I think the biggest—OK, and this is where it's a little bit like: is it the body? Is it the mind? Is there a separation? I don't believe there's a separation. I developed some carpel tunnel among other things. Finally, I thought, oh good, they could—so they sent me to a really good hand therapist, and I told them about this. I'd always sensed that the dystonia was up here in this muscle—up here—and that's where it hurts, that's where it starts. And they said, no, it's in these muscles, the extensors here—that's where it is. And the physical process of stretching these out has made a big difference. Yeah. And working on this—working to relax. So, there's a physical element as well. And then I managed to bash my finger here—it's not very pretty—with a hammer. Believe it or not, that pain has sensitised the fingers some, because I kind of didn't have the connection to the fingers.

ME Right on the ground—so the tips of the fingers, right?

P4 Well, yeah, actually it's like some of the proprioception was just—it's kind of like the brain said, we don't want to feel this part of the body.

ME So specifically for the proprioception—problems with proprioception—did you do anything?

P4 Yeah. Actually, a lot of it is mental rather than physically doing things. It is mental. I think about connecting with my fingers. I really put myself in a different frame of mind and think of moving them and think of moving them. You know—yeah, I know that sounds kind of weird.

ME Not at all. I would agree with you. Would you say that mental practices have become sort of a regular part of your playing routine.

P4 Yes, yes. I think also I was maybe more prone to this partly because of my autism, where I like to go over and over and over things. And I think, though, there's this other element—I've read that some people have postulated that maybe we are over-plastic—our brains are over-plastic. And I think there may be a level—it's a hard thing to bring up in any of the forums. But I think there may be a level. I really think—I don't know, this is not something to brag about—but when he was starting out, [REDACTED], who's a famous fiddler now, lived here in this area, and his mother took him to all the people that played, and I gave him banjo lessons and saw him rise up to become this world class star. I think there are people that simply are more gifted physically to play. They have longer fingers, they have— I mean, we all play the same instruments, asked to do the same things, but we're all different dimensions, and people that have better connections to their motor cortex and such— they just have them. And I think there is a level where you can be pretty good—better than average—but trying to get above that level leads you down pathways that a more gifted person wouldn't have to take. They wouldn't have to go through the same kinds of repetition to train their— you know, you say practice, practice, practice. But it's one thing to practice new music; it's another thing to practice things that would be very easy for a really gifted person. In the end, I couldn't get any answers to my questions, and I lost interest quickly after that—until I found a way to make the work meaningful to me again.

ME So you mentioned repetition in your practice—have you made it a conscious decision to change that or have you seen that?

P4 I—well, no, I still love the repetition. And actually, that's why, even though I was more known as a fiddle player and was better known in the world, something I really enjoyed about the banjo as well is the repetition because it is so repetitive. But one thing I have changed is I no longer feel more is better. After a certain period of time, I say, OK, this is good, this is what you need and put it down. It's a kind of slow torture, but you just have to do it; you pace it and keep going.

ME OK. So, I'll ask you the final question. Based on your personal experiences of focal dystonia, what advice would you give to young student musicians during their training?

P4 Oh. OK. One: I think body mechanics are much, much more important than was emphasised when I was learning to play. They know so much more about it now. And I would say learning not to play through pain—because I played through pain a lot—and really to not look at it quite as much as an expression of your value in the world. Also, for me it's always been a trauma response at some level; it can't just be a physical thing when there's nothing to see. Dealing with anxieties and stress will change things so much.

ME That's fascinating. Could you expand on that last point a little bit?

P4 Well, I really didn't feel—I didn't feel like I had a right to be in the world. This is something that's been changed through therapy. My worth as a person was determined by my ability to play—my self-concept. If I played well, I was a good person. And I think musicians tend to fall into that. Yeah, and they neglect the other parts of their life.

ME Yeah, so the other part is the balance between the musical self and the rest of life. So, you feel that you've managed to get a good balance there for yourself.

P4 I think I have. I think I have. It might not be everybody's performance, but it's much less fraught.

ME Well. Thank you very much.

P4 I really hope it's been helpful.

ME It's been very helpful. Very helpful. Very useful and interesting. So that's great. I'm just going to stop start recording here..

P5 INTERVIEW

ME So, just to begin, could you tell me a little a little bit about your musical background here?

P5 Sure, when I was 11, I started taking classical guitar lessons in group class whilst in [REDACTED]. Through the school, the music teacher was also a guitarist, and he was teaching extra classes after school. A lot of kids were doing it. Classical guitar is very established in [REDACTED]; it's not considered, you know, a ghetto instrument or like a second-tier instrument, as it is sometimes like here in [REDACTED]. So, I did that. I was pretty good. Like, it was pretty obvious that I had facility with the instrument, but never at a super high level. I mean, I never went to a conservatory or anything like that, but I always played it, and it was enjoyable, and I played. I guess I took those group classes for about four years or so, and they were not intense or anything. We would play. You know, I was able to play, though, and between the ages of like 15 or 16 until through college and on 21, I really didn't play guitar at all because I was in [REDACTED]. I moved from [REDACTED] to [REDACTED], and I didn't bring a guitar to boarding school, except my last year I did, but I didn't really play it much. And then after college, where I didn't have a guitar except for the last three months, I started taking flamenco lessons when I was twenty-two. I took that for nine months and that kind of got me back into playing, and then I actually went to [REDACTED] for a year or so. I didn't take guitar lessons there, but I bought a guitar my first weekend there, and I continued this pattern of studying on my own, then taking lessons. I came back to [REDACTED], and I started taking— I think I took folk guitar, like fingerpicking folk [REDACTED] guitar, and then I took jazz, then classical, then Brazilian. When I was thirty-three, in 2002, I started taking Brazilian guitar, which is my main focus now.

ME I live in [REDACTED], so I've been in [REDACTED] for 15–16 years now. You live in [REDACTED]? Yeah. I'm travelling at the moment, so I'm in the [REDACTED].

P5 [REDACTED], where do you live in [REDACTED]?

ME In [REDACTED].

P5 In [REDACTED]—do you know the [REDACTED] community? Like [REDACTED] and, well, you know, yeah. Well, [REDACTED] is a guitarist and, you know, [REDACTED].

ME Know very well. I know of him.

P5 Yeah, well, those are— I mean, [REDACTED] is one of my favourite guitarists ever. I mean, musicians, really. He's fantastic. Yeah, I have [REDACTED], like all the guys in [REDACTED] and the [REDACTED] school.

ME Yeah, I do. Yeah. And this is more [REDACTED], right?

P5 But why do you live in [REDACTED], I mean—

ME Why do I live in [REDACTED]? It's a long story. I basically took a sabbatical from my job in the [REDACTED] in 2005, and I went to help start the state orchestra in [REDACTED], and one thing led to another, and I've stayed.

P5 That's amazing. Where is the state orchestra?

ME It was in [REDACTED], and my wife is the concert mistress in the orchestra in [REDACTED] National Theatre. I was playing and we met and all the rest of it.

P5 All right. So, I don't have to explain a lot about Brazilian music.

ME No, no, no.

P5 Basically, I study—well, I haven't been into Brazilian music— I took [REDACTED] in college. And so, in 2002, I started taking— if I knew someone who was teaching Brazilian guitar, which is its own thing, I went. I got into [REDACTED] very obsessively and then the bossa nova stuff. And then I got into choro really soon. That's kind of been my main focus. So, I was getting pretty good on guitar for about, I would say, five or six years. I was really progressing. I had never really played with other people, except when I was a kid and I was playing in church accompanying the mass. But I never really performed. After about five years of still taking, it as a hobby, I noticed, wow, I'm not bad. So, I really wanted to get better. My teacher here, my Brazilian guitar teacher—sorry, this is very long, but it ties into how this happened. In 2002, I didn't have any hand issues. In 2007, I probably didn't have any issues or maybe 2006. But at a certain point I started taking, as well as Brazilian guitar lessons, classical guitar lessons with somebody who teaches at [REDACTED]. Because my Brazilian guitar teacher in [REDACTED]—I mean, his technique was kind of dirty. He understands how to teach Brazilian guitar—great for learning all the rhythms on the right hand. But I didn't like his sound, and I wanted to improve my sound. So, I took lessons with somebody named [REDACTED], who teaches at [REDACTED], went there herself—very, very good but super demanding teacher, someone who teaches in that top-down style that I think is on its way out. I got it from her—"I'm going to tell you what to do and you're under my control." With her, I improved a lot. My technique—I had never approached concert repertoire before I started with her. I wasn't great, but I made a huge step: [REDACTED], Bach, the first lute suite—quite difficult—and other challenging pieces. But she was really hard—if I didn't do what she said, I'd feel bad about it. That was the turning point when guitar became something else. It wasn't just fun and games; it was something I was measuring myself against. Now I could fail, and this was new. Also, she would do student concerts; by this time, I was thirty-five or thirty-six. Of course, I had performance anxiety—normal, but I had it pretty bad. So, I worked on it. The combination of a much higher standard, these student concerts with difficult repertoire in front of people, her judgment, and a practice I had never used before—metronome, Segovia scales, the three most difficult ones—changed how I related to the instrument. And early on, when things first started to go wrong, I didn't know what to do at the time. I

would have tried anything by that point, laying of hands, or whatever. I just needed something to hang on to.

ME I'm a cellist, but I have quite a few colleagues that are guitar players.

P5 Right? So, all of a sudden the guitar became something I would stress about. I remember studying La Catedral by [REDACTED], which has three movements. I studied it in the wrong way because I'm kind of obsessive—playing it 30 times a day or something. And actually, [REDACTED] was like, no, that's crazy. Don't do that. But I did it anyway, because that's me. I didn't think— you always think practice, practice, practice is the way. No: there is a wrong way of practicing, and that's what I was doing. I started noticing my right hand doing crazy things. There was one particular arpeggio in the third movement of La Catedral that uses these three fingers. It doesn't use this. And I would notice that when I was just using these, this finger would go in. For several years I noticed that finger was not doing what I wanted, but I was still playing pretty well, so I just looked past it. Then it got worse and worse. Fast-forward to around 2010: I stopped taking lessons with [REDACTED] as well as with my Brazilian teacher. I continued studying alone for a while. Then I went back. Throughout this, I asked [REDACTED], “Do you think I have what [REDACTED] has—that focal dystonia thing—because look at my fingers.” She said, “Oh, nobody gets focal dystonia. Are you kidding me? Hardly anybody gets it. Get it out of your head.” So, I was like, OK. Eventually, in 2013, I was thinking of doing a certification for guitar. One of the things they wanted to see on video was that your hand was relaxed, and I couldn't relax it. It got worse. I tried to correct it with Pumping Nylon and [REDACTED] 120 right-hand exercises, which made it worse. By the fall of 2013, I saw [REDACTED] at a concert and asked for a lesson. Within two minutes he said, “You have a mild case of focal dystonia—but don't worry, there's hope.” He showed me his approach. That was December 2013, and I took about four sessions where he described his method.

ME Yeah, to some degree; I'd love to hear your point of view—how you interpret it?

P5 He comes from the view that focal dystonia is a misfiring of information. The way you learned to do things—now you can't use it. So, you find an alternative way: bigger movements down to finer ones but not coming from your fingers; it's coming from your back, supposedly. He can play, so there's proof that for him this works, and he says it has worked for others. I did it for about a year. I basically didn't get worse. I sort of got a little better using his method—engaging the back. But after a year, I still couldn't play certain classical things—like Recuerdos de la Alhambra. I could do a lot of Brazilian stuff, some classical too, but arpeggios were bad; chords and samba patterns were OK. Around then, I pretty quickly realised how long it would take and what I was in for. There is no quick-quick way out, but you have to go for it if you want to improve.

ME And could I just ask you, were the sessions in person?

P5 Yeah. I'd go to his place. He said, “I can show you what you need in four lessons.” It was different movement drills—keeping tension then letting go, all “from here.” Same with free strokes, rest strokes, thumb mechanics—always “from here.” I will add, I tried various things, including the Leisner Method and Fabra's techniques. That first year I didn't get worse, got a bit better, but not enough for the classical materials I wanted.

ME What didn’t work for you with him?

P5 For classical guitar, you need very fine movements. If you want to play, say, Recuerdos de la Alhambra—how do you do that with his method? I even asked if he plays everything. He said yes. I asked specifically about Recuerdos; he said he never liked that piece. I thought, OK, come on. He’s gravitated toward composing and contemporary repertoire; he legitimately plays a lot—he sounded great on parts of the Bach Chaconne when I brought it. Still, I wasn’t satisfied; I wanted more than that technique offered me, and I still saw FD then as a neurological misfiring, like he frames it. Later, my experience pushed me to see the emotional component as central.

ME No, no quotes. Promise. Well, could you tell me a little bit—moving on to [REDACTED] as well? How did that come about?

P5 Someone who'd done [REDACTED] and hit a wall told me to try [REDACTED], who had FD in both hands and developed a fear-based/desensitisation angle. He didn't respond to me, so I contacted [REDACTED], who also has FD and lives in [REDACTED]. Complicated, because he's the ex-husband of a close friend, but she encouraged me. He told me his journey: he'd tried [REDACTED], the splint approaches, psychology, and the only one that helped him play again was working with [REDACTED]. So, I worked with [REDACTED], pretty much using [REDACTED]'s method: play freely, desensitise, belief-based reframing—convince yourself there's nothing wrong with your hand. I had some results, then went backwards. To be fair, [Retrainer] is just marvellous to work with. I always feel the improvement after a session; you just feel so supported through the process—there's nothing negative about the process at all. But life also hit hard then: I was diagnosed with thyroid cancer (I'm OK now), had severe tinnitus for months after an exposure, couldn't sleep, and my mom was diagnosed with [REDACTED]. 2014–2016 was brutal with travel and caregiving. I think that destabilised everything.

ME So that affected your confidence with him.

P5 Yeah. Later, during the pandemic, there were some things said that felt conspiratorial, and I lost trust. Before that, though, I gave those approaches real time. Honestly, there were stretches when I didn't know what to do at the time. I would have tried anything by that point—laying of hands, or whatever. I just needed something to hang on to.

ME What about the emotional reaction to the guitar itself?

P5 The first day I was told "mild focal dystonia," I looked at my guitar on the stand and felt betrayed, devastated. But I also felt hopeful because I'd been told I could get over it. I'd put so much time into getting better; it felt against everything I believed—work hard, improve—and now, practice had made me worse. Still, that belief carried me for a year: I could still play maybe 80% of what I played before. Not Recuerdos—but most Brazilian material. Over time, it became clearer to me that, for me, it's fear. Total proof was when I couldn't even rest my hand on the strings—just leaving it there—during early 2020. That's not a fine-motor pattern; that's a system on red alert. So, I used desensitisation: I watched streamed operas nightly and sat with the guitar, trying to rest my hand on the strings for as long as I could. For about two and a half months, nothing. Then over two weeks, it finally stuck. It's one step forward two back mostly, but there are periods when things change and stick like that. Those days make it good, and I just keep going with it, even when I really don't want to.

ME Do you see FD more as neurological or emotional?

P5 For me personally, it's overwhelmingly emotional. Others may have more neurological drivers, but my history points to reaction and fear loops.

ME How is your playing at the moment?

P5 When I play accompaniment in a choro group online, I'll sometimes use something to keep my fingers together, a thumb pick, and do a lot with the thumb—not ideal for FD, but it gets it out. About a year ago, I also started violin for a musical outlet. I took some lessons with [REDACTED]—[REDACTED]'s son—who clarified a lot about [REDACTED]'s technique that I'd transcribed for years. I finally understood what to do—but I couldn't execute it, and that was so frustrating. I also tried mandolin; when I got decent, FD showed up in my pick grip. So, very limited on classical guitar; more possible in Brazilian textures with adaptation.

ME Based on your experiences with focal dystonia, is there anything you would do differently in your training, and what advice would you give to young student musicians?

P5 Don't make your instrument the measure of who you are. Keep it fun. If your practice is the worst part of your day, change it—it won't help to grind through things you hate. If you love [REDACTED] scales, do them; if you hate them, pick a musical fragment from a piece you love that's a bit challenging and practice that—musical, bite-sized, repeatable. Don't make the piece the reward—make the practice itself enjoyable. And always treat the instrument as your friend. Don't compete with the next person; you're on your own path. The interesting stuff comes when you tap into what's uniquely yours—emotional depth, athleticism, sound, time feel—whatever it is. Regarding FD prevention: some get it after a lifetime of heavy practice; others when practice intensity and pressure spike, as with me. You

can likely reduce risk by avoiding obsessive, punitive, identity-tied practice. I've tried to nudge friends who practice four hours a day with a metronome and measure their worth against the guitar toward a more compassionate, conscious approach.

ME Do you consider him to be at risk?

P5 I think he's at risk, yes—because his identity is tied to the instrument and he's highly competitive. Hopefully he won't develop FD. But I don't know anyone with FD who was a slacker—you have to work very hard, often too hard, to get there. If you're just noodling your sambas and having fun, you're probably not on that path.

ME Obviously, you're repeating things to an extent, but all in your experience. Would you say regimented classical practice affected your relationship with your instrument?

P5 Yeah. I think it was that rigid, top-down method—call it the [REDACTED] method or whatever you want to call it—that pushed me over the edge. Looking back, I tried various things, including the Leisner Method and Fabra's techniques. It taught me that there's no single quick fix and no single villain; it's a system you rebuild patiently.

ME Yeah, great. Well, thank you very much. There's a lot of information—fascinating—and I'll stop recording if that's OK.

P6 INTERVIEW

ME Great. OK. Could you start by just telling me a little bit about your musical background?

P6 So, I am a flutist, and I have an undergraduate degree in music education and a master's degree in flute performance, And also I have done some what's called equivalency in graduate work, in music therapy as well. So that was kind of between the undergrad and the master's degree. So, I performed with orchestras, top orchestras, a lot of chamber music. I've taught at small universities and just have finished that up actually this past year. I'm doing that because I've kind of taken a different turn on things and I absolutely love teaching as well. So right now, my studio is made up of fifth graders through 12th graders since I'm no longer doing university level.

ME Wow, fantastic. So, can you tell me a little bit about your experiences ,your experiences of training as a flautist as well going back as far as you'd like to?

P6 Well, actually, I started my musical training as a pianist. And I keep up with piano as well. I started that. I believe in third grade and my brother played. My older brother played the flute, so I picked up the flute between fifth and sixth grade and began private study soon after that. And I'm trying to think what else in high school, I you know, I did a lot of performing with an orchestra, a youth orchestra and then of course, the school opportunities that abounded and piano recitals. My flute, my flute teacher didn't do recitals so much so of even early on. You know, I I've always been kind of the perfectionist, Type-A personality, worrier type. And so, I think that didn't affect me so much in my initial musical studies, but it did as I got into the high school level.

ME So how would you describe your relationship with your teachers through this through the years?

P6 Oh, okay. Um, good relationship with my flute teacher that I had. I mean, I did some brief lessons with the trumpet teacher and then switched to a flute teacher, and she was not that much older than me. She was in college at the time, so she could really relate to what I was doing, and so I had a great relationship with her. I was with her, perhaps too long, from sixth grade to 12th grade. Piano, poor, poor piano teacher, you know, my passion is through my life has been pedagogy, and I laugh when I look back now and see the things, he gave me on piano, never should have given to me. So, I had struggles, you know, giving me Beethoven sonatas before you do Clemente sonatas, for instance. And then I finally did pick up with another piano teacher in high school and through college. I studied off and on as well in college. My flute teacher, I went to a music conservatory, [REDACTED]. The first two years, I had an older gentleman who played with the [REDACTED], and I don't really feel like I learned

much from him at all. And it was, you know, it almost felt like you were going backwards. I felt like, yeah, it was not a good first two years. My second two years, then I studied with a flutist that played… He was the principal flutist of [REDACTED] so, he was quite inspirational, but yet I don't feel like I really dug into some of the basics with him, it was more about just kind of getting through a lot of literature because I think he saw that lack of literature that I had experienced the first two years. The other thing in colleges is I was a music education major, and I don't know if it's like this in [REDACTED], but a lot of times, I hear it from students still today, you know, if your music education, they think, oh, well, you don't need to be a performer, but performance was just as important to me as music education. And so finally, about my senior year of college, I decided, hey, I think I want to make a go of doing more performing, so I did do that for a couple of years. I didn't take a lot of auditions. But then I decided to pursue my music therapy work because my degree. In music, Ed was instrumental and special education emphasis. So, I went forth and looked for schools that offered music therapy programmes and so I made a move actually from the [REDACTED] to [REDACTED] at that point. Okay. Yeah, great. Yeah. And then after that I decided, OK, I really want to do performance, so then I went on to get a graduate degree in flute performance, right?

ME Right. So, could you tell me a little bit about your experiences, your first experience with focal dystonia?

P6 Sure. Something I've processed through a lot. When I started having some minor symptoms, I didn't see it as dystonia as maybe many of us do, we, you know, but now of course, we can look back and we can say, Oh yeah. Nobody mentioned anything for a long time to me. I wasn't practicing right, and it was in my head. That's what I thought. A colleague of mine suggested it could be dystonia. So, I would say that I started seeing symptoms in the fall of 2015. But of course, I didn't know what they were. I was really working to try to get beefier, low register on the flute. Around that Christmas time, I was also doing some recording for our [REDACTED]. My duo partner and I had to perform at our annual conference. So, we had to get those recordings in in the fall. And then come 2016, with the university I was at, I was soloing at [REDACTED] with the wind ensemble. And I think, you know, even though the music was not that difficult, there's that thing that hangs over your head. This is [REDACTED] right? So, I think that put a lot of pressure on myself. I also put additional pressure on myself because I was in the midst of caregiving for elderly parents, right? So, it's really pushing myself to say, OK, I'm going to keep going and doing what I'm doing and teaching performing. And then about April of 2016, I was pretty certain that I had dystonia.

ME Right? So, would you say that around that time, there was quite a lot of other things going on in your life?

P6 Absolutely. Absolutely.

ME Right? Yeah, yeah. And before your diagnosis, did you have any awareness or understanding of focal dystonia?

P6 I didn't know what it was. I was even actually hesitant to go to a neurologist because. You know, I felt like the first thing they were going to do was just say, OK, you need some Botox. And I had talked to a colleague also here in [REDACTED] that has recovered now, but she experienced both hand and facial or dystonia. And so, in June of twenty sixteen, I went and had a visit with her. And I mean, she wasn't trying to diagnose by any means. But you know, she was saying it. It looks something like what I've experienced. Right? And then in August of 2016, I finally did go to a neurologist, and she wanted to just give me a shot of Botox. And she referred to [REDACTED], And you know, she said, Oh, well, he would recommend it. And I thought, No, I don't think you've read his 2009 study that said, I didn't say this to her. But you know, his latest studies had said no, it's not really that effective for the study.

ME Yeah, yeah. So, I ask you a couple of similar questions. How do you think your musical identity has been changed by focal dystonia?

P6 I'm sure. I think right now from the place I'm at currently, I can say better. I definitely I struggled a lot in the first five years with coming to grips with it because my whole identity was tied up and being a flute player and teacher. Even though I am a mom, I'm a daughter, I'm a wife. You know, all those other roles we have in life, they were there, but I just that was always my association. And sometimes I always had that frustration of I was never doing enough in my musical career. So, I think I really latched

on to my identity as a flutist and I think now. You know, it's even though you cognitively may know that you're more than just your career or your music, you know you're being a musician, it's. I think now it's sunk in that that is absolutely true. You know, there's other parts to our life. This is just one part to our life.

ME Yeah, yeah. Tell me a little bit more about your reasons for undertaking any movement retraining for your focal dystonia and how that manifested. And what was your first experience of actually addressing the problem without Botox and things like that?

P6 So, my first experience was so in again, 2016. I, just kind of backtrack. I made it through, you know, I did perform at our [REDACTED] convention, made it through. And then I think stuff just really just started to fall apart after that… my colleague that I had talked with that had experienced both. She really had recommended for me to see [REDACTED] because she had seen him. And initially, I made the choice to just try some other things first off. Massage, I've got these all written down, but I don't have them in front of me.

ME That's fine.

P6 You know, massage and some reiki and a Rolfing, and what else? you know, just a lot of a lot of other stuff. A trumpeter friend of mine told me to give sensory retuning a go. An old teacher of his had dystonia and he got himself right again with that. It has worked pretty well for me. Yeah, and then I think I finally after, you know, once I got into 2017 and said, OK, maybe I need to look at some more things like, you know, I also initially looked at hypnotherapy and worked with that and I did a lot of things. So, I did. Finally spend a week with [REDACTED] in March 2018, in March of twenty eighteen. And I see that now as the basis of the starting of recovery, he did explain some things, but I had done a lot of reading as well. But, you know, and he gave me some actual exercises and movement retraining things to start to do, and I persevered because that's just my nature. I, you know, I know people that have chosen once they've developed dystonia, they choose to become a conductor or take another path in life. And I just perseverance is a gift that I think I've been given by my parents. And so, I said, Oh no, I'm going to keep going at this. But you know, I also was in the midst of more and more parents caregiving. My dad had passed in 2012; they had moved from [REDACTED] out to [REDACTED]. Like ages 83 and 86, you know, you know, so from I mean, caregiving since 2006, and it just increasingly became more, and then my mom's health conditions really increased in the fall of 2016 as well. She was diagnosed with diabetes at like ninety-three.. So, you know, I'm like, Oh, my gosh, how am I going to do all these insulin shots? And she wasn't living with me. She was at a senior community. But, you know, I was also responsible for the financial aspects and everything, and I was just I was really a stress case for a lot of years with the parent caregiving and trying to keep up with my own things as well. So, I don't really feel, you know, in retrospect, now I can see that probably wasn't the best time for me to do retraining. I live in [REDACTED]. That means travel to get treatment for almost everything. The problem is, it's so expensive to get to [REDACTED] and spend a week in a hotel, living out. Then there's the cost of retraining on top. It's 'all in' or nothing really.

ME Right.

P6 Yeah. But I also, I think I perhaps wrote this in my notes with for you. I've also been involved with the Association of Body Mapping Education. Are you all familiar? Yeah.

ME No, not personally. I mean, I've heard of it, but yeah, of course I'm aware of Body Mapping, and I

P6 know Timani?. Yeah.
ME Yes. Yeah.

P6 Yeah, OK. So, Timani and Body Mapping are very similar, Timani tends to move in more than the directions, you know, does a little more emphasis on muscular things where you think tends to be a little bit more skeletal based. Yeah, it is. It is muscles. There's a kind of an emotional psych piece and in Body Mapping as well. And I've been I was a trainee and Body Mapping from. Two thousand fifteen, but I never had time to get my stuff together because it's a self-guided kind of study. All right. So, you can get licensed. So, after my mom passed in November of 2019, you know, I just, you know, January I really feel of twenty, which is pretty much a pandemic, but I really said, OK, you know this, this is the

time now, and I really dug heavily into my Body Mapping stuff, and I am now a licensed Body Mapping, fantastic future. So that has really helped me in a lot of ways with my retraining, we like to say we have a lot of mis maps sometimes in our body, and you know, I've got two pages listings of mipmaps. I mean, yeah, see my body.

ME I think I've I've definitely got more than two pages.

P6 Well, then it's not like, OK, it's not like they're all gone either. But it's really, it's about developing that awareness of our movement. And then I started. So, I'm near the [REDACTED], which strangely enough, you know, wonderful music program. That's one of the big names [REDACTED] works, but they have nothing for performance, health care for me, like they're now starting to do some wellness things. So, you know, I had tapped into doctors there and everything, but I just I went on to the [REDACTED]. I think that's a [REDACTED] group. And I just kind of kept digging, you know, and calling all the people that were listed for [REDACTED] and trying to get in. And one of the guys, actually, unbelievable that he actually talked to me. But you know, he is a friend of [REDACTED]. [REDACTED] talked with [REDACTED] and said, you know, confirm there's just not much going on, and I've emailed him as well. But I did end up connecting with in the October of 2020 with a. No, that was actually it was right when my mom passed away. It was the very end of October 2019. I ended up connecting with an O.T, right, who really he is, his area is facial neuromuscular retraining. Right? Which is actually for people that have experienced Bell's palsy, Hunt-Ramsey syndrome, there's some other acoustic neuroma and things like that. And that since I've been doing that, the facial neuromuscular retraining in combination with the Body Mapping and thinking about the way I approach things. A much more heightened awareness of movements. Yeah. Um, I think if that's been kind of the crux of my retraining. I made solid contacts from the [retraining] sessions. We talk sometimes and swap our tales, and that,..that helps some, but no-one has had any more contact with [retrainer]. It would probably help to go again and show [retrainer] what I'm doing, but there's no way I could afford to do it. It's difficult to know what to do next, that's the thing. I definitely needed more guidance. You've really got to focus and see the wood for the trees when you're doing the exercises. No-one's there to cheer you on and most of the time you just feel like cr**.

ME It's pretty comprehensive. It's interesting to…

P6 There's other people and things in our Body Mapping conference. In 2019, we had [REDACTED]. Yeah. Yes. So, I worked some with [REDACTED], so I have things with her. Also, another a trombonist that had embouchure dystonia, his name is [REDACTED], and I worked with him at that conference as well. So hard when things aren't getting any better. It's like a feeling of total despair sometimes, you know?

ME So when you said it began, maybe with [REDACTED], the first real big step when you went to see him and spent some time with him?

P6 I think so.

ME And that sort of launched the other things subsequently.

P6 Yeah. Yeah. But as I said, I think now I can retrospectively say I wasn't really in a place with all the stuff of the parent caregiving, and it just was not in a place to really either emotionally, psychologically or maybe even physically. To really begin retraining. I didn't really know what I was supposed to do or feel after some time. We seemed to repeat a lot, but nothing was really working.

ME was just to ask you, was that in the group format, that was that individual sessions with [REDACTED].

P6 Yeah, with [REDACTED]. I did individual sessions,

ME individual sessions for the week

P6 I went. I live five hours from [REDACTED]. Yeah. So, my husband and I went for the week, and it was it was maybe an hour and a half session.

ME Right. So, from there, that's when you began to really get into Body Mapping from that particular…?

P6 I've had Body Mapping on my plate right since the early 2000s. OK. Yeah, but I just never really. And then really became I became a trainee in 2015. And, you know, I dabbled in reading things, I think, but I was never really able to, dig in at all. Right?

ME And you mentioned Timani as well. So, is that something which is a bit in addition to the Body Mapping parallel to how would you describe that relationship?

P6 I've had some conversations with [REDACTED], who is a Timani trainee? And also, with Body Mapping colleague who is also a Timani trainee and that she gave me a Timani lesson over the summer. At one point, I worked with her so, very small. I am curious to do more with that.

ME You mentioned neuromuscular retraining as well. Yes. Could you give us just a few details about that, how that works and how it was? And how did you express that yourself? How did it work for you?

P6 Well, initially it begins with, I would say, some patient education, although I was already aware of different facial muscles through my own research and working with [REDACTED], I think sometimes [REDACTED] thought I was asking too many questions getting into too much detail. So, you know, in terms of the facial muscles, the, you know, I was pretty aware of those when I started the facial neuromuscular retraining, but that typically is the first step. Then the second step, I would say, is learning to isolate muscle movements. Facial muscles are a different breed than a lot of our other muscles in our body, so all of that, you know, it was challenging at first to isolate certain movements of the different muscle groups.

ME And that was achieved through this specific exercises or. Correct. Right. So, using sort of external devices and things like that or is it not?

P6 No, not really. You know, I. Some of the things, in fact, that [REDACTED] and [REDACTED] had given me when I started facial neuromuscular retraining was like, you know, you don't want to go that route, you know that the motto that my O.T often mentioned was soft, subtle and slow, and there was just nice a nice little mantra to remember in terms of the way you're working to isolate the muscle. And in very small, minute movements so that you can again, like Body Mapping, heighten an awareness of the movement of those muscle groups.

ME So that contrasts somewhat in the work you did with [REDACTED] for example?

P6 It did a little bit. I mean, there's things that I still basically, I think the odd thought that some of the exercises that [REDACTED] gave me were a little bit to robust, robust. Right?

ME OK. So, I'd like to talk a little about the bit about your teaching as well, post your diagnosis. How would you describe your teaching after dystonia? How has it changed? Has it changed?

P6 I've always been a teacher that does a lot of demonstration and playing with students. And that was really tough for me because I just, you know, [REDACTED] probably gave the best advice. And this was earlier on that he gave me what was probably the best advice, to leave your horn at home. And so that. So that was kind of the time to stop playing in lessons. Yes, I do. You know, I do it once in a while. I'm actually just getting back to playing with students a bit, but since I do play piano. I'm at the piano a lot more. Yeah. Yeah, I never do more than 30 minutes in one go anyway nowadays. I can do a lot more away from the [instrument], but not on it.

ME The relationship with your students may have changed somewhat as well? Has it? How has it? Do your students know about your focal dystonia? If so, how do you how do you address that with your students?

P6 I would say. Back when it first developed, I did let my older students know I didn't really let you know, maybe middle school students know as much now. Currently, I have a couple of students that have been with me since they were those younger students, and they're all like 12th graders. So, you

know, those students do know, and I will just oftentimes I'll say, well, you know, I'll often give them so much more aware. I mean, I could probably write a dissertation on how my teaching has changed, but I often refer if I'm giving them something to do to find balance of the head or the way they're standing. I'll often mention and say, OK, well, I'm doing or I'm trying this in my retraining, but with my younger students, I don't really say anything about it too much. Right? Yeah, yeah. And just it's my teaching has also transformed a colleague in the Body Mapping group. Her name is [REDACTED] and I. Through COVID, she was starting a group called Transformational Teaching because. You know, there is a history you're younger than I am, but there's a history of those teachers that you know, you do it this way, you do it this way or, you know, that's horrible. That's not good enough that that whole kind of top down, really horrible teachers like that. Yeah. I mean, I wouldn't say I had those horrible task masters, but [REDACTED] has started this whole process of what we call a transformational teacher. And so really, looking at the ways we teach students and really looking more at process over content.

ME Student centred learning maybe?

P6 Yeah. So, I think I've always kind of veered toward that anyways, but yet I sometimes it depends on the student too, I mean, I'm the kind of teacher that I'll say, OK, you know, we're going to do scales or arpeggios, technique, music theory kind of that. Then we have our etudes and then we have our solo literature. And it used to also be at duets. You know that I would do every week. And now, you know, that's out of the picture right now. Maybe to come back? But I just I I would say through the pandemic and through this whole process with [REDACTED] and just really taking a closer look at. How they are learning what is it? You know, and I've always had a motto in my teaching that I tell the kids, and I say, I want you to walk out of this door knowing something you didn't know how to do when you came in today, you know, or or answering a question that you had of something you didn't understand. So, I often would say, if that takes us the whole lesson time, that's OK because you're going to be different when you walk out, you know, versus just bang, bang, bang, get through the literature, you know, whether it's, you know, the notes and rhythms. And I want them to really be aware of how they move. And not just a thing of OK, where, but you know, where do you make the crescendo? But what do you need to do when you're playing your instrument to make that crescendo? I try to develop my student's self-awareness a lot more. And self-confidence is another big thing, but that's kind of a different thing. Yeah. I mean, I feel like, you know. Not having university, even when I was teaching at university, not many students are music majors, so I will treat students if they're intending to go into music or if they were a music major, a little bit differently than those who are just doing this because they they want music to be a part of their life, right?

ME Yeah. OK, I'm going to ask you a sort of open question. Do you think focal dystonia maybe be avoidable in some cases?

P6 Oh. If someone had the awareness from early on, perhaps, but probably, I don't know. I don't think so. I mean, [REDACTED] has said to me, you know, you could have been pre-dystonic for 30 years, just the way somebody could be a pre-diabetic. And if the conditions are right. In your life, and many forms of conditions, this may indeed develop. So, I don't know, that's a that's a good question. I kind of think I would lean towards yes. If somebody is brought up in a positive nurturing learning environment and they're well aware of, you know, and have a good balance of things. Then, yes, right, but how many? You know, and as a teacher, that's what I strive to be able to, you know, to do that for my students but is it avoidable for some people that are in intense music learning? Environment, [REDACTED], [REDACTED] are big schools here in the states. I don't know if that is avoidable.

ME Right, OK. And then if you looking back on your own training as a as a flautist, is there anything that you might have done differently now knowing what you know about focal dystonia? What advice would you give to your younger self?

P6 Well, that's a big one, because I think there's just a lot as a person, you know that I now look back at myself and say, Wow, you know, I would have done things differently. But I think that for me. I think that the answer is more in the realms of. You're your emotional and psychological self. Because your psychological and emotional self affects your physical self. And so, yeah, can I say, you know, I look back at early elementary, your report cards and say. See, teachers ratings, oh, she worries too much. You know, and you know, certain, and I don't know what. You know, the buzzword in today's society, which is valid, is trauma. You know, when I look back at certain traumas that I had, you know, no, they were not abuse or anything like that, but there were certain traumas I experienced in my

elementary years that I think also affected me psychologically. So. And I know I'm going off track, but is sure I can look back now, but yeah, you know

ME You mentioned your perfectionism. You're a perfectionist, would you say?

P6 Yeah. Oh yeah. You know, I was that summa cum laude graduate and in in university and. Well, I you know, I think I always valued that a being, you know, being the best kind of thing. And of course, when you go, I still remember when I began the music conservatory in college. I remember the Dean getting up and saying you were you were all the big fish in the little pond and now you're just a little fish in a big pond, you know? And because [REDACTED] at that point, I don't know where they are now. They were one of the better conservatories in the country to be at. And so, I think I initially felt that, you know, pressure even more once I entered a music conservatory setting. And so now I look back and I think I might have been better in a different type of university where I could have been nurtured a little bit more.

ME Right. And so just to almost finish up, where are you now with with your with your flute playing? How is it? How things are you playing regularly?

P6 I never stop playing. I stopped performing. But as I mentioned, you know, even from the exercise [REDACTED] gave me, I mean, playing might involve standing in front of the mirror, doing long tones for a long time. And again, a little bit, you know, I even see I I can't get out of it, but sometimes I'm just too still too focused, you know, checking muscles here rather than looking at the whole self. But I am back to this year and again, COVID was a kind of a convenient time to retrain, but I'm playing in a flute ensemble now. I don't think I'd be going out the door to play a solo recital at this point, and I don't know if I ever will be, but I can do, you know I did a small church gig a couple of weeks back and I really felt the tension creeping in. But, you know, I was playing with a choir, so it wasn't like I was doing a big solo thing, right? OK.

ME Yeah. And finally, how would you describe the connection between your bodily movements and your musical self-expression after you've retrained? Do you feel they're still connected, or do you feel they've been separated more, how is that? Has that changed in any way?

P6 I think it's changed more in terms of the knowledge I've acquired from Body Mapping. So, I would say it's less rigid, you know, there's more of a flow to the body movements, but also there's kind of been I've always had been neurotic about breathing. And so that's been part of my journey with ambush of dystonia is the inhale. And now I'm more about the exhale and then the inhale just happens naturally. So, I think I'm still working at it. You know, it's a course of progress. I'm not completely retrained yet by any means, but I'm thrilled to even be playing in an ensemble again. And there's certain things articulations that I still struggle with to do, you know, because my aperture will just open too much. Mm-Hmm. So, I mean, my dystonia, it was such that I was kind of pulling up on this side of my face. These muscles and here were pulling up. So, I'm getting, you know, I'm getting more balance too and really a different aperture than I had prior to just dystonia. Right? OK. Well, thank you. .

ME Thank you. Yeah, thank you very much. I'll just I'll just stop record on here first if that's okay.

P7 INTERVIEW

ME Great, so first, can you just tell me a little bit about your musical background?

P7 I started playing classical guitar somewhere around 1964-5. Also, a couple of years later, I started learning flamenco and actually performed with a flamenco group as an accompanist while I was studying classical as well. I started doing both, which was unusual at the time. Ultimately, in about the mid 70s, early 70s, I switched to sculpture, and I became a sculptor and, but I continued playing guitar at a professional level, didn't perform very often classical guitar. And then I switched from classical to flamenco at the age of 50. I got a very good teacher who I communicated well with. He had his doctorate in music as well. Even though he was a gypsy and playing flamenco guitar and was doing that four-year process of switching over, when I got dystonia, which just totally wiped me out. It got into my plucking, had only a little bit in my pinkie fretting hand, but I want to wave pretty quickly. I have never, never been able to get rid of the dystonia in my right hand. And one of my four therapists in eight years,

and I still very much have it, right. By the time I went to see [REDACTED] I couldn't put one finger in front of the other which was just horrid. I was about ready to quit already.

ME Can you tell me a little bit about your experience or your first experiences with dystonia? Could you go into more detail about how to how it occurred, Was it a gradual/sudden onset?

P7 It just started one day by my index finger was going like this under medium (IMA) you're familiar with that in music, the labelling? Anyway, so I it was index going under medium like that, and then medium would extend pretty soon. I was like this, trying to play the guitar, and that happened about a three-week period

ME What was your performance schedule like at the time? Any big concerts/events?

P7 I wasn't performing at all, but I was switching over from classical to flamenco. I was practicing about three hours a day with new movements. It was a lot of different right-hand movements, flamenco that you would have a classical. The right hand on flamenco was much more involved than a classical guitar classical guitar. You're basically just plucking like that flamenco. There's all these striking motions and wrist turning and all sorts of things, so it's a dramatically different way to play.

ME So, after your initial experiences with dystonia, how long was it before you actually began to get any treatment or find out, find out exactly what was going on? How did things progress after experiencing symptoms?

P7 Well, I went to the performing arts clinic at [REDACTED] in [REDACTED], which is a prestigious hospital, and they diagnosed me with task-specific focal dystonia, told me it was an incurable condition, and I should just go do something else with my life. So, I didn't have any treatment at all for about 12 years.

ME Right. So, you went away with that diagnosis, and that was it. Basically, I'm going to have to change what I'm doing, or did you carry on playing after that? How did you how did you deal with that period?

P7 I could play with my thumb. I fortunately, I never lost my thumb. And then on. I started working with [REDACTED] for a year or something about the 13th year, I went to [REDACTED] and used his ideas, and I got a partial recovery. My index recovered fully, and I was able to do tremolo, which is kind of unusual. I can play very fast. I can't play slower, go figure. So that has never gone away, I've never recovered. Mostly, it's the median which cramps and takes all the other fingers with it.

ME Right. So, things give you a few thoughts or comments about your own understanding of the focal dystonia and what are your thoughts about the condition now after all this all this time with the condition?

P7 Well, my thoughts are informed by the main therapy I went through, which was Movement Disorder Clinic at [REDACTED] [REDACTED], mostly as teaching hospital. I was in a test group of 22 musicians. They were studying musicians' dystonia. They had a grant to do this, and they examined us quite thoroughly and gave us a lot of Botox shots over one year period. They told us it was genetic. They told us they've identified the 44 genes that cause dystonia and everybody in the test group had it. I posted this on [REDACTED], and everybody went wild. You know, they don't want to hear it, but we all have our limitations, you know?

ME So, in terms of the genetic connection, is that still your overriding theory/belief that it is a genetic connection is part of the product for everybody who has but what is going on? How do you see that?

P7 I have no way of knowing if it's everybody, but it's not a theory. It's not Summation. You too could do the exact study that they did examine the genome in this one certain area, which I believe, by the way, they said it was handed down from [REDACTED]. They associate this group of forty-four genes, one to particular everybody has it. But what a coincidence. So, to me is, this is not a theory. It's an observation. It's obviously people who take a psychodynamic point of view with this, this disorder or behavioural point of view, they're not too happy to hear that, but you follow the sciences at work.

ME Ok, could you tell me a little bit more about your own thoughts about some of the behavioural or psychological points about focal dystonia. How do you see that yourself?? How do you feel about that?

P7 Well, people who have understood dystonia, they have been known to respond to psychodynamic training. So, psychotherapy, that's useful there. It's pointless for people with a hand dystonia. I have. It's just it's not a psychodynamic problem. It's a mechanical problem. It's possible to unlearn and reprogram your brain through things like splints or playing with your arms like [REDACTED] does, which, by the way, you know, having had the experience I understand where it's coming from. You just leave your hand limp and learn to play with your arm like that. And over time, you know you can recover. Your body will start reprogramming itself to do that.

ME Yeah. Could you tell a little more about your experiences with [REDACTED]. How you found the experience, what you took from it, etc.

P7 Well, [REDACTED] is a prominent classical guitarist, and he lost the use of plucking can entirely while he was a professor at [REDACTED]. And he couldn't play for 12 years and like me, he went to everybody on the planet trying to get cured, and he finally figured out something himself. And at this point, he's cured 100% and he's turned-out lots and lots of high-end albums. So, he's done great. One of the few recovery stories I know. I know a guy in [REDACTED] who got wiped out for 10 years and he's now pretty much recovered 100 percent, is teaching flamenco again and playing for flamenco again. My experience with [REDACTED] is that worked for me, partially. It worked for me as far as the middle of my index finger, but it didn't cure me entirely. But. I've since then really examined the way other people play [REDACTED], for instance, I see plays from Xbox, a head I studied with the guy sat right in front of them and I never noticed that the frigate plays with his elbow. You'll see it. Go look at a tape of this, a tape online of him playing and you could see as plain as day. He's not plucking these movements, hands up like that. Almost like he's got a pick in his hand, so I'm always I'm always kind of amazed at the people who didn't get dystonia. But now I know, I know why. It's a genetic predisposition and probably a mechanical problem on top of each other. I mean,

ME Could you tell me something about your relationship with your [REDACTED] as well, how do you find that experience as a one-to-one teacher/student relationship?

P7

ME

P7 Well, I was 15 years old. I spent almost all of three days with him. I took a class with him. We had two hours in the morning and three hours in the afternoon, so I guess the total about 15 contact hours with him. He's a fluent English speaker, and he just went through basically everything of how to play the guitar. You know, all the things that he had come up with. And you know, he's self-taught. There was nobody to teach him, really. There were some guitarists around, but they played instruments that weren't very loud. They have gut strings on them as opposed to nylon. And you know, he, adopted the method of [REDACTED], who is holding your fingers backwards, which, by the way, is the way the form that older masters play. And I'm sort of on to this because you look at the old paintings of [REDACTED] or [REDACTED] and you see the phenomenal guitarists, you know, in the paintings, they got their hands backwards like that. It's really fascinating. And I showed this to [REDACTED], who is the head neurologist at [REDACTED], and he looked at it and he says they knew what they were doing. Very interesting because if you play like that, you're locking out these muscles here. This is where your dystonia is. It's right here. It's these muscles underneath here that play this joint right here. That's what probably 99 percent of the people have. This muscle that runs this joint goes all the way from here, all the way to the inside of arm. You can actually put your finger on it like that. Put your hand on the inside of your elbow. You're going to feel it. So, when they gave me the Botox, they were shooting me in four different places here. And that muscle tries to keep this this finger from doing that. Invest in it.

So, what are your thoughts about the effectiveness of your retraining?

To be honest, extremely varied. While I got some positive outcomes as I discussed, I still struggle with certain aspects. I continue though, work in progress, and I believe with continued practice and guidance, I can further refine my movements and achieve better results. It's wonderful, really. Every time I played I'd find another brain spot, work through it, and I'd be freer. [REDACTED] has been my saviour.

ME So just on that topic with Botox. How many sessions would be completed with Botox in your life? Is it quite a few or…

P7 Nine

ME nine total? And was that with the [REDACTED] as well?

P7 But yeah, he is supervising the program, this is he was supervising this to explain the genetic angle to me and what they were doing there.

ME I assume you are able to talk to him personally. I mean, I know who he is? I have a read a lot of papers of his and what he's doing. I know about his micro dosing, of Botox, which is quite interesting at the moment as well.

P7 Ask him about the monkey study. See, when I first got into this and started looking at it, nobody said, oh, they gave dystonia to monkeys and it's a mechanical problem or a psychological problem. He said the monkey. Study was bullshit, he basically said they were fabricated. He said there were no videos of any source who doesn't videotape these days everybody carries a video recorder in their pocket. He just thought it was nonsense and to them it's a genetic predisposition and it's treatable only by Botox if anything. So that's his point of view. There are a lot of people who think it can be treated with splints, which is a Segway into the other primary clinic in the world that treats this is [REDACTED]. I'm sure you run across them by now. I would think I was patient number eight hundred five or something like that, right?

ME So that was with the splinting itself, right?

P7 It's splinting, and it's a lot more than splinting. It's brain confusion. They you start out, you know, like trying to juggle balls or doing things you can't do. You know, they put a ladder on the ground like a football player would use to get his feet to go back and forth. And you know, you'd do that for a while and you do all these, these things that you can't do to get your brain in a certain state. And then you put the splints on and then you're not playing in. You're like pushing out at one two three and then maybe when and then this one went to three and then one two down. And like that, just doing these

bizarre non-patterns, you're not repeating anything, and they find that every time that this loosens up the brain to use a metaphor such you can reorganise your brain to make your fingers move the right way. It's typically done with splints, but not entirely.

ME Yeah. And how were your perceptions about that style of treatment? How did you experience it? How did you feel about it? Were you convinced by it?

P7 It got completely worse. My dystonia got worse. I came out of there; I couldn't even wave at somebody that looks like this trying to wave at somebody. I met another guy; came out of there he couldn't shake hands anymore. I couldn't scratch my head anymore. Now I can, but I would be like this. You know, I couldn't scratch my head anymore. Typing totally out the window couldn't type it all. That never came back, by the way. Little bit, but that never came by. I couldn't. I couldn't. And I still can't play in the air. So, I'm trying to play in the air right now. I'm trying to do this, and I still can't play in the air that happened in [REDACTED], so they changed me. They just changed me the wrong way, right?

ME Did they use any, any other equipment, such as any neuromodulation, any transcranial magnetic machines or anything like that? Or was it just purely retraining.

P7 No, there was no equipment involved. The head Doctor [REDACTED], he is an orthopaedic surgeon, so that's his training. And he put this course together partially on what he knows and partially using these [REDACTED] studies of retraining on piano through splinting. So, it's sort of an amalgam of those two things that he's using.

ME So, your patient experience was negative on that particular occasion. So, would you how would you compare the two experiences of retraining, [REDACTED] with the clinical trials?

P7 Well, [REDACTED], partial recovery, but I thought I could recover all the way going to this expensive clinic in [REDACTED], and I got nothing from my sixty-eight hundred dollars that it cost me. That was with travel and everything. Yeah, it just didn't work. Just didn't work, didn't work. He claimed an 80 percent success, so I guess I was the one out of five who wasted their time and money, went on for 14 months.

ME 14 months, quite a long time. So, with [REDACTED], did anything occur that was unexpected, something that really stuck out?

P7 Nothing shocking about it, I was very curious to see what he had discovered, the way he thought it was pretty basic. It's novel. I don't hear anybody else speaking like that, but rather than trying to retrain the muscles that are screwed up, in the area of your brain that is screwed up, he just bypasses it. He focuses upon a different area, different muscles. And so, it's kind of a novel and, I don't know his track record. I never heard from any anybody else, what percentage of people get cured, but I can tell you that, you know, it's it is a good way to play. He claimed that his students at [REDACTED]. He was showing all of them this and nobody was getting dystonia. That's claim he made. So that's true. That's a pretty good claim. I understand there was just a survey done of me as a professional guitarist and that seven to 12 percent reported some sort of dystonia. Now you heard about this.

ME Yes.

P7 He always told me if that one percent was mostly myth. How come I know, like 10 people that have it? So, you get one percent. In fact, my friend in [REDACTED], a hell of a flamenco player and teacher, he says after the age of 50, this is about 40 percent. The way he put it is, he says, we got these 15-year-olds running around [REDACTED], so they play like a bat out of hell. He says after 50 nobody can play anymore, so it's a big ass problem. Now this major people like [REDACTED], oh my God, what a player he is. One album done one. That's all he got.

ME How you were supported generally through all this movement retraining. What follow up care did you receive?

P7 From whom?

ME From any of the therapists/clinics involved.

P7 [REDACTED], you do monthly sessions with them, and they make adjustments. I'm currently working with [REDACTED], and I've been working with him for 10 months. He's a curious guy. He's got a lot more training in this area than most of therapists I've run into, his degree is in psychology of learning, so he's always talking about how tissue's change and these sorts of things. And he's a performer himself. He's a guitarist. So, I'm presently meeting with him about every eight to 10 days online. Is in [REDACTED] buyout? Pretty sure. It's wonderful, really. Every time I played I'd find another brain spot, work through it, and I'd be freer. [REDACTED] has been my saviour.

ME Do you think anything could be improved in the way that things were offered to you? Post training?

P7 No, well, these are ongoing training, the training with the [REDACTED] group was ongoing. It was just one month. You know, I quit after 14 months because it was clearly getting worse, and I can tell they were getting very nervous. They sort of picked that up. They didn't know what to do. I'm sure they had seen this before, that somebody was simply getting worse rather than better. They claim that the fastest they had seen was a cellist. She recovered in 10 months and was performing again. And they said the worst was a flamenco guitarist who was three years nowhere. So, I seemed to be on the latter track and that's why I quit.

ME So, based on your experiences with your focal dystonia, what advice would you give to young student musicians during their training?

P7 Well, probably what they don't want to hear, you know, I'm six foot one, I'm not going to play in the [REDACTED], I'm too short. Somebody is 150 pounds shouldn't be going out for [REDACTED]. They're wasting their time. I think if you're going to be a professional musician, you should get your DNA checked, see if you have these genes. You do. Don't p* away 10 15 years of your life memorising a body of work that you suddenly can't use to. Probably not what you want to hear or anybody else wants to hear, but there is information out there from about three or four years now they've published in this area. What do you do with it? You say, well, you're a bunch of liars. Or you found the problem that's wiping out years and years of work at 35 years of accumulated classical repertoire wiped out in a three-week period.

ME What would you have done anything different in your own training if you'd have known about focal dystonia before?

P7 There's one thing I've heard came from [REDACTED], she actually has a video on YouTube about it, and it makes sense from everybody I know who got dystonia. She was quite blunt, she said. People who play with a flat wrist, she said. This is what she said if you play with your wrist like that this, with this joint here and play from this joint, your index finger can move quite a bit. She says if you play like this, it's hard for it. It's very tight right here and you tend to start playing like this. And she says, when you're playing on a flat wrist and you playing with this point, you're playing with this muscle here. And she says, then you're done. She says, Everybody, I know everybody. I like that word that I know, she says, who played with a flat wrist, got dystonia, and the people who have a rounded wrist are still performing. Now that I told you that go back and look at everybody who's got dystonia, [REDACTED] playing with a flat wrist. That's a disaster. He was the greatest guitarist in the world in my opinion. You see, he plays with two fingers and the full position he nails. He plants this on the bridge and plays with one or two fingers. Now, he plays with two fingers, it's all he has left. He played with flat wrist all his life. She said that was fascinating because I realise that I have played two different ways. I play with flat wrist for everything except my tremolo, which I had learned originally from the flamingo player, and they pull up. They want to have that snappy sound, so your flamenco like that. I can still play tremolo like it never happened, but if I try to play, you know. with alma, my fingers that it's just a disaster. It's fascinating that that would be about the only advice I would have, rounded wrist playing from this joint. Now, something else I noticed with [REDACTED], he'd be talking, and his hands would be like this, you know, then when he went to play, he would go like this and start playing it, go like this, stretch his hand and then come back down. Fascinating fact. I saw a tape of him doing that online. Even though he taught us a lot, he was quite secretive with the with a lot of this stuff, I got a lot of his ideas actually from one of his students from when he was in his thirties or forties, which is still a good boy. [REDACTED] is a [REDACTED] guitarist and I think he just passed recently. Ninety-six or something, and he and I got stranded in [REDACTED], [REDACTED], on the same arts program. They had what they call sister

cities program, and they would send people from one city to another city, and in this case, he comes from [REDACTED], cross-cultural chat or whatever. Anyway, so he got moved to [REDACTED], [REDACTED], and I got an any national award from the arts council that required me to be in [REDACTED], [REDACTED]. So, I worked with him for nine months. I learned a lot from him, and I learned a lot about how [REDACTED] played from [REDACTED]. Anyway, so, yeah,

ME Going back a little bit, I mean, apart from your other teachers, your job, your musical formation, how would you describe your relationship generally with your teachers or teacher.
P7 Well, I studied with [REDACTED] every week for about nine months, once a week for about nine months. And. Learned a lot of South American music; he had actually studied with [REDACTED]. So, I was learning about it. I was learning [REDACTED], somebody who had actually studied with him. That was kind of interesting. And it was also interesting to see the schism between the European [REDACTED] and the South American [REDACTED]. They hated each other, different kind of music, different kind of style or anything like that. Very influential was [REDACTED], who was in [REDACTED], the flamenco teacher who got wiped out by dystonia, but he managed to recover going to [REDACTED], which is why I went there because he recovered. But I was unable to. Right.

ME There must have been the moment when you decided, OK, I'm going to tell everybody that I have dystonia. Was that a gradual thing, or was it an easy decision to make a difficult decision to postpone that sort of acceptance generally in the music profession for them?

P7 Well, talking about it's a good thing. I had never even heard of it. I was I was a musician for 35 years, never even heard of it. I didn't know it was. I heard something about [REDACTED] played with one hand because he had a cramp that was the only thing, I knew of it.

ME Right.

P7 As far as talking about it, I don't really care, not many people know what it is, but more and more, you know, there's chatter about it, people, I think guitarists are generally aware of it. And the ones who I've talked to, who don't have it, are scared to death they're going to get it. There's another classical guitarist in my town and she her eyes go wide when she sees me unable to play. They're scared to death that they're going to get it.

ME Yeah, that's an interesting point that people don't want to talk about it because they're scared about getting it themselves. But when you actually began to talk about it to people, how did they how do you feel you were received? You feel that people sort of stepped away or helped? Or how did you feel that this sort of relationship with your colleagues was at the time?

P7 Well, the two most useless things on Earth are a blind painter and a musician. You can't play. I mean, what a great way to call yourself a musician anymore. You can't play the instrument. And a painter goes blind, I know one happened to a guy in [REDACTED] who went blind. So, what's to talk about?

ME So, the sculpture, when did the sculpture enter into things? Is it always being a dual passion, or did it was the music become before the sculpture? How did that work?

P7 Oh, the sculpture came after the music. You know, the classical guitar was not that known in the 60s. Maybe in [REDACTED], a little bit more in [REDACTED]. There was nothing to do. There were no guitar majors in the universities. There were no performing outlets, nobody was interested in it. You know, if you turned up with the guitar, they were like, "will you sing too, or can you?" I know a guy, he went to hear [REDACTED] in the early 70s, and he thought it was going to be like [REDACTED] playing country Western music or something you didn't know what to expect, so there was no opportunity to do anything here. It was a novelty playing at a party or something, so I drifted away from that and into the visual arts. I was going to College [REDACTED]. There was no music school there at all, nor anywhere else, really. And I just gravitated to the visual arts and became sculptor.

ME Ok

P7 Very fortunate, because now I'm older and I have a life asset, which I wouldn't have had ended up being a musician, unable to play.

ME Now, how does music fit into your life? Are you able to enjoy playing again or how do you feel? What is your relationship personally with your music now?

P7 Well, I can't play, so there's no enjoyment. What I do is I put on splints and do monotonous scales for two hours a day, monotonous patterns for two hours a day, and this has been my life for the last several years.

ME Well, that was all very interesting information. Is there anything else that you'd like to add?

P7 No, not really. You know, I don't. This is still a bit of a mysterious disease that people get, and it's horrible. It's horrible for people. You know, I discuss the genetic bit that I had learned with [REDACTED], in a way, I think it's very simple. And he says the only thing we know for sure with musicians' dystonia is that just really good musicians get. This is after treating 800. It was a backhanded compliment after treating 800 people, he said. That's the only thing he's sure of. He says, we don't see any amateurs. We don't see anybody who can sort of play. It is only the very high-end ones that get this.

ME Great. Okay. That's fantastic. Thank you very much.

P7 Good luck. I look forward to reading what you write.

P8 INTERVIEW

ME OK, great. So, to begin with, can you tell me a little bit about your own musical background?

P8 OK, I started with piano first for many years when I was young, and I was quite a late starter with the violin. So, I started following, I think when I was, 19. OK. Yeah, in college or uni? Yeah. I had two years and then after that I left for uni, and I stopped. So, when I got back, I had tremors due to other things, health problems at the time. Yeah. So, I was twenty-two at that stage. So then fast forward to. Let me count this. Ten years later, no. Nine years later, I noticed something wrong with my third and fourth fingers were not cooperating.

ME And this is in your left hand, right?

P8 Yeah, yeah. Well, something that hadn't been a problem before that that easily played stuff suddenly. You know, I just couldn't play, and I couldn't figure out why. OK. So, I never heard a focal dystonia at that point.

ME Could you tell me a little about your first experience with focal dystonia? You told me about the tremors, was it just something that came on gradually? Was it just involving your instrument, or did it also happen away from the instrument?

P8 Tremors or the focal dystonia?

ME The focal dystonia? Were they linked together to tremors in the focal dystonia?

P8 You back. Now, I'm not sure whether the tremors were actually the beginning of it all, or whether the focal dystonia came as a result, partly of compensation. What goes on in the brain? I don't know, because I was having tremors for a long time before I figured out that caffeine was causing it. But meanwhile, you know, I think reading about neuroplasticity, things happen in the brain because you try to compensate when you do something. So is this a sub-conscious. So, when I realized there was a problem later, the focal dystonia, my teacher noticed it as well, and he was like, what's going on? No, I don't think he'd ever heard of it as well. So, he thought it was sort of overused, but that was very unlikely because I'm not the kind of person who really practices a lot, right? It's wild to think one day you're playing [REDACTED] and the next you're trying to play two or three notes without splitting them. When it sinks in that you might not get it back if the retraining doesn't work, man you go low. I felt useless.

ME How could you tell me a little about your relationship with your teacher as well? How is that?

P8 I don't know what to say. I mean, it's to me, a normal teacher/pupil relationship. At that point, he was encouraging me to… because I was being asked to teach. And he was saying, you have to start at some point, just go teach.

ME So, could you just comment a little about your own understanding of focal dystonia? How do you understand it for yourself? And before you mentioned it, before your diagnosis, you've never heard of it. How have your attitudes towards focal dystonia changed, maybe as a result of movement retraining as well? How do you how do you consider the condition yourself?

P8 I think my attitude to it, it has changed due to the reading that I've done more than the retraining. You know, in the sense of accepting that it is a medical condition, it's something that happens in the brain due to neuroplasticity gone wrong. Whereas back then I was like, I've done something wrong. I don't know what it is. And I just, you know, I decided maybe it's overuse after all, I left it alone, you know, hoping that would just go away. I didn't go to see a doctor at first. Okay, it was because first I pushed on with the recital and the exam, and then after that I just left the violin. I had panic attacks a lot. I didn't know how I was going earn any money, and I couldn't sleep properly.

ME OK, so the onset of focal dystonia, were you studying or doing final exams at a university conservatory at that time? Or was it a stressful time?

P8 I happened to be about to take you preparing for the [REDACTED]. ATCL in performance. But that should have been, you know, not a problem, not particularly challenging at that point, considering the pieces that I was playing way before that. But it was a very stressful period outside of music.

ME And do you feel that might have contributed in some way to one or not?

P8 The neurologists seem to think so. And reading the research that I've done since, there are studies that show that when a person is under stress, the parts of the brain that are to do with motor coordination actually suffer. So, you can, I suppose, forget how to do stuff that you used to know how to do.

ME Okay, so another question for you. Looking back at your time as a musician, and before your experiences with focal dystonia. If you think about your previous training now, would you have done something differently in your musical training? If so, what?

P8 I think I would practice more precisely. Little, more often you know. I would tell myself not to worry about always correcting mistakes before going on. I would just play more, not analyse too much; I think. I don't know, maybe also pay more attention to my pain. I always had painful shoulders; I could not work out why. Maybe also linked to the tremors. What I do know is that I practice differently now, very differently.

ME Could you tell me a little bit more about this?

P8 Looking back, I mean, what I've done along the way after I got focal dystonia was [REDACTED] technique. So that just makes a huge difference not for FDA itself, but for movement awareness and general awareness of tension before it becomes a problem. So, it's like I used to have very bad pain. I sit all day at work, so after half an hour, be terrible. So that's why I went for it because my cello teacher at the time recommended it. Then, you know, in six sessions, it was gone. The pain, yeah, yeah. They observe subtle things about your movement and position, and they train you to observe it as well that orthopaedic surgeons and physiotherapists can't see yeah. It's all about muscle usage. If we block the movement somewhere by not moving properly, we break down right? In anything we do... I need tangible things to try; therapy sessions don't cut it for me.

ME What has changed when you're playing an instrument because of your focal dystonia, how do you approach your practice sessions?

P8 Much less expectations. I've revised my expectations completely, but also, I've only agreed a few times ever since I had dystonia to perform in public, only very few times. And one of them was to

accompany my [REDACTED] friend. Yeah. At first, I told him, I said, you know, you might want to find a fully functioning pianist, but he insisted, so I found a way to practice. This was a [REDACTED] cello sonata. So, the accompaniment is not exactly easy, and these do require some stamina.

ME Certainly, the cello parts are generally less complex than the piano parts.

P8 Yeah. So, I knew that I would need stamina, and I knew that I would have to practice differently, you know, because I'd agree to it. So, there was a deadline, that was my motivation. And it just happened that luckily for me, I had lost my job at that time, so I had all the time in the world for about four weeks before the performance date. I started with five-minute slots of practice. I knew which parts I needed to work on, get that truly comfortable with the metronome. And then you turn the metronome up as usual. Yeah. So, five minutes. Many times, throughout the day. Yeah. And yeah, it worked. And the surprise to me after that was. The carry over residual effect that was completely unexpected was I was able to play the cello after that. Really interesting, I haven't touched for years because, you know, I couldn't even press on the string.

ME What happened when you pressed the strings?

P8 Cramping and tremors and everything all at once. Yeah.

ME You mentioned that you prepared in this way for that particular concert, and it worked. Can you put your finger maybe on why, why it worked? How did you feel? What was different about what did you feel as if it worked this time?

P8 So, the feeling was that my hand felt different. It was as if I was able to feel it again. Not like lost in space.

ME More connected somehow?

P8 Yeah, but after that, you know, I wasn't ever able to figure out exactly what it was. But this book that I'm reading now has the answers, a lot of my questions, were answered. There are three factors that need to be in place when rewiring the brain or using brain plasticity, its motivation and focus. So, you have to be completely focused on that thing, not multitask.

ME Right, ok.

P8 So, the reward triggers the release of dopamine, which then sort of helps the cycle change. It makes a lasting change.

ME May I ask you another question? So, you've undertaken some retraining for focal dystonia, is that with anybody in particular or is that all your own?

P8 Preparation for the performance with my friends was movement retraining by accident, I think. I didn’t intend it to be, but, you know, because I had committed to something, and I felt that I had to deliver in some way, yes, I did. After that, I discovered [REDACTED] online workshops, but I think what that that just didn't work for me. I tried for months. But I didn't have the time or the motivation or the focus to really continue with it, and I think it was all about the reward system for me. For the money I was expecting more. What, I don’t know really. I know that it’s not a magic bullet or anything, but I wish I’d known that in advance, you know? One on one sessions are so much better. You take in so much more and it’s about you; it’s not just stuff to listen to and try to absorb.

ME So, when you talk about a reward system, what is your reward system for yourself? How would you describe that?

P8 Well, with the performance, that's intrinsically rewarding because I like it's a light performance and the music can be everything, and I love playing with someone else. Yeah, so that was what was missing from the online training. My way of doing it is to enjoy things while they last and not panic if they fall apart. I don’t beat myself up about it.

ME Right. So, you felt that when you were on stage, your general demeanour was relaxed, enjoying things. How did you feel on stage when you play?

P8 I'm always nervous before, but when you when you actually start playing, it's OK. Unless, of course, the hand stops functioning, then it's a different story.

ME Could you expand on your hand not functioning?
Has this it becomes a vicious cycle in some way? Do you automatically assume that your hand doesn't function, or are you able to, to accept each day or each performance as a different entity with different outcomes?

P8 Well, I limit my performances so much that, you know, it doesn't really become an issue because I if I agree to play something, then I make sure I have a Plan B, which is hugely scaled down version of the piece that is much less demanding on the left hand. Right. So, compensation. Yeah. So, if my left hand gives out during, say, the cello performance on my cousin's wedding or something, then I would have just taken over with just make do with simple chords or whatever it is to keep it going. It's not ideal, but…

ME OK. Could you tell me what you were expecting from movement retraining training with [REDACTED], what you were expecting to achieve?

P8 I try to expect nothing, but I was hoping for a lot. I mean, I, you know, I always hope for this easy fix, but it became clear that it was going to be a lot of work over a long period, and I think I sort of, I felt that I wasn't making progress, so I stopped. After about six months.

ME So, I was it a feedback thing? Were you satisfied with the feedback? Is that a reward, that might have been missing.

P8 Well, I think to feel that I'd improved, to feel myself that I'd improved that that would be a reward. So, the other thing that I discovered by accident, not again, not a formal training program, was when I started using weights. So, I went through this occupational therapist before because I went to three neurosurgeons along the way, neurologists along the way. One of them was a hand surgeon who referred me to a neuro. And the hand surgeon eventually referred me to a hand occupational therapist, and she talked about biofeedback. So, I, you know, she was talking about needing to put some weight on your hand, your left arm because you need feedback from the joints to your brain. That's the theory I couldn't figure out how, you know, because I put weight on my arm sometimes and it doesn't do anything for me. It was only when last year during the lockdowns that I started exercise videos. YouTube videos with weights.

ME OK.

P8 Yeah. and I after, you know, exercising like this twice, I felt a surprising difference again, I felt like I could feel my left hand.

ME OK? Could you talk a little bit more about the weights, how you used those weights? Move your wrists for your fingers? How did that apply?

P8 I just use dumbbells, and I follow the exercise videos like bicep curls.

ME So, I make sure I have triceps/biceps.

P8 Extended to slow focused movements.

ME And you found that to have had a positive effect on your, on your piano playing, or away from the piano as well?

P8 Yeah. Yeah. Here's my problem, from the time 12 years ago that I discovered focal dystonia whilst playing violin. Then I stopped and then I took up cello a year later. So, it was going downhill, and then eventually, a few years after that, it was affecting everything. So, it's no longer really, truly focal, but it's not specific anymore. I couldn't do up buttons, I was dropping things.

ME Ok, so it became a problem in day-to-day tasks.

P8 So, you also kind of generalise. Yeah, absolutely.

ME think that comes back to asking you little more about your concept of focal dystonia because you describe it as a very physical/neurological disorder. How do you perceive the idea of it having of the emotional side to it being as a potential trigger as well? How do you see that? Do you agree or disagree with that to some degree?

P8 I do, because I can observe clearly that if I'm stressed, it's worse is significantly worse.

ME OK. Could you share a few examples of a few exercises or techniques that you use during your training to specific things like, I did this on the piano, or I did this on the cello, or this helped on the violin, anything particular that you can pick up that helped anything that didn't help.

P8 I actually made a list because you, I think, put that in, you know, so. Oh, great. OK. [REDACTED] technique was one. So, the awareness of tension when it pops up and being able to, you know, sort of be aware of that all the time in the background helps a lot because you won't be sinking further into the hole in another way. Focused, slow work with the metronome worked for me. I suspect that the focus is. The metronome is keeping your focus there instead of on the hand somehow. Yeah. Short sessions so that the, you are able to retain the focus throughout. So, for me, it was very short sessions, like five minutes at the beginning, then maybe 10 minutes. Frequent enough throughout the day, so that I think there needs to be enough time to build up and retain whatever changes through learning that you've made. Whatever gains for me are made over a long enough period of time, and then I enjoy the benefits for a few months after that before it goes downhill.

ME Right. So, when you when you say it goes downhill, what do you mean by that?

P8 Because I started my next job? Yeah. I couldn't keep up with the practice like that, and there was no other performance.

ME Makes sense. Could you tell me a little bit about your mental practice, then, because when you talk about small chunks of five-minute sessions during the day, maybe that your mental practicing, the way that you practiced away from the instrument changed somewhat as well.

P8 Between the five-minute sessions, especially at the beginning, I would go away and do something else different. I wouldn't be mentally practicing.

ME How do you mentally prepare a piece of music now?

P8 I think for me, everything has changed because before of focal dystonia. I was completely unaware of the physical, you know how my hands felt, or my back or shoulder. So that was probably a recipe for trouble anyway, even if it wasn't actually right.

ME So how would you describe the connection between your technique, the way you play and your musical self-expression? After your retraining, how did that relationship between your body and you what you wanted to express musically change, did it change for the better? Did it alter at all? Was it an issue?

P8 When it's good, you know what, when, when it's going well, then a few. If I compare with. Before I ever heard of this problem. I think it was easier, it was just easier and more natural before because I never had to split my attention between two things.

ME Yeah, yeah, that's I think what I'm driving at is this splitting of attention, something that many of us may experience during retraining, almost as if your musical soul is disconnected in some way. And some people have managed to make a connection, sometimes differently. Sometimes it's just fitted straight back in as they feel able to do. I'm interested in how you feel about that. Do you feel musically as fulfilled playing as you did prior to dystonia? Has the feeling changed in some way?

P8 So, sometimes if it's going well, then I'm able to enjoy the musical part of it. But when it's not going so well nowadays, I just stop it because I don't want to train the negative feelings. But I also know that I can't afford to stop it altogether because I found that if I do stop it for too long, my symptoms just degenerate.

ME OK? So, this degeneration of symptoms, how does it occur? If you leave it for maybe a week, you can feel the difference? Do you need to play every day? How do you feel?

P8 No, I can leave it for a week and come back and play something. If I had achieved some sort of learning or some change before that, I could sometimes still have it there. After a week, sometimes. Sometimes it's gone even the next day. But if I leave it say like, when I was playing the cello, I switched hands. I was too frustrated with trying to finger with the left hand I switched to using the left hand for the bow because I thought it would be easier. And then but I found that given the easier task, the left hand deteriorated further.

ME Right.

P8 So, I realize from there and from other instances that you need to keep at it with that hand but not stress out as much.

ME So, when you changed and played left-handed on the cello, how was your right hand? Well, did you feel any differences in the right hand?

P8 No. Nothing changed.

ME So, an open question based on your experience the focal dystonia. What advice would you give to young student musicians during their training?

P8 I think that movement awareness from the very start is very important. Focused training, self-care. As much as possible, you know, basic things like getting enough rest, nutrition and so on. All mental rest as well. Doing something else. Whatever it is, that's, you know, either in music or outside of music that as long as you are happy and in a good frame of mind and you take care of this stress components. Because from what I understand, some people are more genetically predisposed to this anyway. So, all you need is that trigger. So, you want to avoid the trigger.

ME Do you recognise any of these triggers in any of you colleagues or any of your students, if you teach?

P8 More than before, maybe I don't. I don't get a lot of musicians to observe because I don't work in music, I know, I remember observing a musician on [REDACTED] before and thinking, that's quite a lot of tension there. I don't remember who it was.

ME OK, well, look, I think that's great. That's a lot of really useful information there. I don't think being a professional musician or not doesn't make any difference. I think it's just the experience of having the condition, which is really useful. So, let's thank you very much for that.

P8 I'll talk about what works because I bumped into a violin professor who teaching in [REDACTED] is also a medical doctor herself, and she recommended that I contact [REDACTED] in [REDACTED]. But she also gave me some tips, and she said one of the things that she tells her students who have focal dystonia, the type of piece that you play is important. So, it's like you use more of the pieces that require some stretching. Some stretching, some more stable like frame type of movement rather than fiddling while allegro type of piece. [Retrainer] was always really attentive with me, right from the start we had targets to get to. We learned a lot together as well which was rewarding to experience. I learnt so much from [them].

ME So, did you take that on board as well for yourself? Did you try this for?

P8 I select the pieces that I work on.

ME And this is that based on the advice you were given?

P8 Yes, it was, and I do find that it does make a difference. Right. Although, of course, if your hand is cramping too much, then the pieces that require stretching are just impossible.

ME Yeah, depends on the day in the time Hehe he.

P8 Yeah…

ME OK, well, thank you very much, P8. I'm going to press up on the recording. OK. OK.

P9 INTERVIEW

ME OK, great. Are you happy to begin? All right. OK, here we go. So firstly, can you tell me a little about a little about your musical background? So why did you become a musician? Where did you train? For example, just a little bit about you.

P9 Yeah, it's kind of hard to summarise it. I started when I was about five years old. I was five years old and with the piano lessons. And the day came when I was about 10 years old and my sisters played, had lessons, violin lessons, and I was just accompanying them on the piano, and then they I felt like oh, I want to play this beautiful instrument too you know, and then I asked the teacher, the violin teacher, if I could have some violin lessons, and that's how it started.

ME OK, tell me a little bit about where you trained, so where did you start playing and how did you progress?

P9 OK, so, um, I began studying in [REDACTED] where I had my first violin teacher. He was formed by the [REDACTED] method, and he was kind of just intermediate level, then he strongly encouraged me to take lessons with a better teacher. Then I finally got in touch with one of the finest [REDACTED] teachers, which is always easier. And he lived he still lives in [REDACTED]. And then I got to take the bus and had the trip to from [REDACTED] to [REDACTED], to take lessons, and every month I went there to have two-hour lessons. I remember very well was always on Saturday. and I kept this kind of routine for about 10 years. Then I finally moved to [REDACTED]. When I took my bachelor's degree, I had another teacher there, which was [REDACTED], and for four years during the course, I had lessons with [REDACTED] but still was going to [REDACTED] to also take lessons. So, I graduated and entered the school of music in [REDACTED] in ninety-eight. I graduated there in 2001. And then I had opportunities to have jobs in major orchestras, I could achieve one of them with the state orchestra, [REDACTED]. I was very, very glad because, you know, I had a salary and I could play, you know, just professionally and had kind of a good life, you know, with my family, but then I was thinking that I was feeling that I was, I was not OK with my performance, I, I felt like I was going down technically and I could not develop by myself and, you know, on the music and on the violin playing the repertoire. So, I considered that I should go on for, you know, continuing education. So, I was going for a master's degree, and it finally happened on 2005, I got an assistantship at [REDACTED] with Professor [REDACTED], and in the fall of 2005, started my master's degree. It took about two years. I was then invited to move on to the doctor level, so and I still could keep the citizenship, which was very good for me. And so, in 2007, I started my doctorate, and I graduated in 2010.

ME So, could you tell me a little bit about your relationship with your professor in [REDACTED]? How was it, how did you find the experience?

P9 Well. You know, it was wonderful. Because he is a great example, he is one of the greatest, greatest I could take lessons from, but it was not easy. There were moments that I felt like I don't deserve it, you know, he was very strict on me, he was very demanding, and I felt like, OK, because he wants me to play at a very high level, the highest I could, you know, and sometimes I felt like I could not reach that level. And it was moving like, you know, up and down. So, there were moments that I felt like, oh, I'm getting it. I felt like powerful. But there were also moments that I felt like, you know, very poor, very incapable of, you know, playing the violin well.

ME OK, so can you tell me a little bit about your first experiences with focal dystonia? How did it begin for you and how did it affect your playing?

P9 Um. The first symptoms appeared when I was not practicing a lot and was more focused on my dissertation or doing research and, you know, it takes a lot of time and I regretted that I couldn't practice because I wanted to, but I couldn't because it was very time consuming, and I didn't know it was focal dystonia at that time. I just was feeling very weird about, you know, some movements and I could not control my ring finger, yes, and my pinkie. It's because I'm not in shape. I'm not practicing much. I'm stressed or I just need some good night's sleep you know, and then back to the practice room. And then everything would be up again, you know, would be fine. But it didn't happen, so I remember mostly playing in rehearsals, orchestra rehearsals, because, you know, I kind of never had problems playing the orchestra parts, you know. I thought, I'd better leave, I need to practice at home, you know, I had the opportunity to play many, many, you know, concertos and I knew how to play most of the repertoire, even though it's very large and, you know, but I felt like, how come I cannot play this? Oh, because usually I just sit and play. It felt very frustrating because although I was out of shape, I didn't really know what was going on. I just felt like, again, you know, well, I really need to practice. You need to change your perspectives when you're going through it. It's like you're now in the special club that no-one else is allowed into and yeah, nobody knows about it, or they don't want to know about it.

ME So, what was the point on your journey with focal dystonia? Did you decide to explore movement retraining in some form?

P9 Well. the symptoms were. every time getting worse and more. I have like I reached the bottom of, you know, how do you say? erm...

ME The bottom of the well, something like that?

P9 Yes, yes. I was about to quit because, you know, it was very hard to play physically, but also, you know, mentally. It was a kind of torture. Just thinking of the violin that my fingers wouldn't work, it was really devastating, but thanks to my wife, I have to say because it was thanks to her that I found a possible treatment and... I don't know, I was just about to, you know, quit, and never play again. And she said no. You cannot do it, you must try this treatment, and if this treatment doesn't work, then you can give up. And it was like a kind of last resort. Yeah, it was the [REDACTED] retraining that she found, and she said OK, so we need to go to [REDACTED]. So, let's do it.

ME So, had you ever heard of [REDACTED] before?

P9 No, actually, my wife found a video of a guitar player talking about [REDACTED] after years of retraining, and she then found the contact info of his clinic in [REDACTED]. And then, well, she sent an email and got a prompt response. So, like after may be one month, we flew there. We were in [REDACTED].

ME So can you tell me a little bit about your experiences with his movement retraining. Your wife had found [REDACTED] for you, so you kind of fell into it, right? But can you tell me a little bit about what you were expecting from your retraining before you went?

P9 Well, I can I just go back a little bit because yeah, because we tried, you know, um, I had many appointments with doctors, physicians previously, and none of them. I felt like, you know, they could really help me with my problem. Some of them just told me, yeah, you have got writer's cramp and OK, it's kind of related to focus dystonia, but for me, it's clear that it's different, you know, and he diagnosed me with writer's cramp, and he said that it's not possible to have a cure. So, he said that I should consider quitting and find another job. Another, who was one of the most respected neurologists unfortunately couldn't help me. One doctor, that was good for me, was a hand specialist, he was the first to suggest that I might have focal dystonia, but he needed to do some research because it wasn't something that he knew a lot about or had much experience with, but I couldn't wait for him to get more experiences, you know.

ME That was the time somebody had suggested to you that it was probably focal dystonia?

P9 Yes, yes, but the neurologist also said, you know, this is a focal dystonia, so that was something because I didn't know what was going on with me. I at least now knew that it wasn't something unknown.

ME So, you before you began your retraining, you had received a diagnosis of dystonia and now you are going to undertake movement retraining with [REDACTED]. So, what were you expecting from that? Were you hopeful that it was going to get better? What was your mental state before you began?

P9 Yeah, um, honestly speaking, I had no hope. I just went there because my wife convinced me to, you know, yeah, because I just couldn't play. I mean, I could play, but you know how hard it's it is, you know, to take years of training, you know, of practicing and developing, you know, all the techniques and, you know, and for no reason. I was constantly asking myself why this is happening to me? and what is happening to me? What did I do wrong? I had no answers whatsoever. I just remember the hand specialist, [REDACTED], he said something about Botox, is it? Yeah. This treatment, you know, and he said, well, I don't know if it's appropriate for you in your case. He was very, you know, careful here because he had heard them from a colleague that also had dystonia that, you know, the doctors know you must do the Botox treatment. You must, you know, inject because it's the way you know, this is what is going to solve your problem. OK, but something was telling me not to try Botox, you know, I don't know why, but I'd rather just give up then, you know, put the thing in my body. And then meanwhile, my wife found a doctor for me, and I sent him a video of me trying to play. He said that this is just classic, you know, focal dystonia, musicians left hand, you know. OK, so it's classic. OK, so let's go for it.

ME Ok this is quite a big question, how was your retraining experience? How did it match up to your expectations?

P9 Yeah, so as I said before, I was kind of hopeless, but then, getting there with my first session with [REDACTED], he talked a lot, explaining to me about the treatment and the retraining process, and that I should be very patient. It was really hard to recover from focal dystonia, and he could not guarantee that because it depends also on the people that, you know, I mean, it depends on me also. It's not like he's going to do something magical, you know, but he did. As he was speaking, he was touching my hand and saying that there is a contraction here, here and you need to release and so on, and then suddenly. I could play. A passage that was impossible for me for the first time since I had focal dystonia in my life. And then my reaction was just. Oh, my God, I can play. You know, so you play, and he said, "yes, you can see you are playing." And even now, I get emotional, you know, because the war was hopeless and he made me play again, you know, and then that sparkle was back again, you know, so. It was so important because it. It appears... it seems like, you know, such a small thing that he did, but it was everything, you know, just moving a finger down and up, and from that very tiny, you know, movement, my recovery my process began. After that I just was, you know, very confident. If I could do that, I can do more and more. You know, and this guy here, [REDACTED], he's going to help me on that way, you know? I would recommend [REDACTED] to anybody]. They always reply if I need to chat about something, that's the difference. You need somebody there that understands the musician. If it's too clinical than you're just waiting for results and not questioning or feeling anything. For me that's the whole point.

ME So, I'd like to know a little bit more about the techniques in the exercises, the concepts that you learnt during your movement retraining. Would you be able to share an example, maybe a few examples of exercises, techniques that you utilised during your training? What were the main things that you feel that have helped you during this process?

P9 OK, and there are many, many exercises, but most of them were based on perception. There's a specific term, which is, I don't know self-perception? I'm sorry, my English is...

ME Self-perception, self-awareness?

P9 Yes, and you know this self-awareness of tension and contraction. That somehow, I could perceive before... You know, and if we cannot perceive, how can we act, how can we work on the other things that we need to? We build simple exercise daily routines of about twenty/thirty minutes or so. Every now and again we meet and change if necessary. I need daily contact with the [instrument] even if I don't play too much. When I leave it for anytime I feel it straight away.

ME Did you believe that this lack of self-perception that you felt during the process was due to the focal dystonia, or do you feel that they existed before that is done?

P9 That's a good question. Some of it was due to the focal dystonia, but there were many things that I had, you know, along the way, since I started playing the violin, you know, way back. That was my first lesson, you know, that I was learning, you know, the posture, you know, and everything. For example, something that I developed when holding the violin was a feeling of the violin falling, you know, just slipping from my shoulder and my neck. I don't know, kind of unconsciously, having that, pressure, or excessive pressure. Yes, so I needed to learn, well if it slips, that's OK. You know, it happens, but no need to, you know, to hold the violin tightly. This is one of the things, you know, maybe it has nothing to do with me, but you know, [REDACTED] was every time calling my attention not to focus on my finger because I would need to move my finger and it didn't move properly. So, your neck also affects your finger, and then your back, you know, also your feet affect your fingers and your hands when they move. So, then I started to open up, you know, like the perception, my whole body just figured it out. My fingers are influenced by the feet. Yeah. They yeah, they were tense, you know, I needed to relax me my feet, you know.

ME So, when you when you reflect on your musical development. When looking back, is there anything in particular that you would have changed, or would you turn to your younger self and say, don't do that or do this?

P9 Well. There are many things, you know, that I would say to myself, to my younger self. I not I do not blame my first teacher, you know, but when I think about it, he said that you have many good qualities, but you also have many problems. We need to fix them for you to grow. you know, better and healthier, and I didn't know what that could be because I was playing and I could play and I felt OK, you know, but if my teacher said that I need it, then I need to fix things. So, I then started to realise, you know, the things I was doing wrong, and I played tense, you know. Reflecting on that period, I used to listen to recordings all day, just to have that reference of in order to do this, the sound, I was just picturing the violin player, but just imagining, you know, and it was so beautiful, so intense. My image was that it was clean, but full of effort, you know, and you had to play like that, you know, he's struggling somehow, and when I listen, it was that image that I was associating it with. I don't know if it makes sense. Yeah. Yeah. I needed to have that same intensity, you know, playing, it could not be relaxed. You could not be like soft, you know, because it was not like the way I played, it was marvellous, you know, full of art, so my body started to feel like that and behave like that. So, I think that has something to do with my development being sort of distorted. But I didn't know it at that time, you know, I know now.

ME So, thinking about the relationship between relaxation and technique. Is there a separation in your mind between the two things? If you concentrate on relaxation, being safer and more controlled whilst playing, would you feel a loss the musical intensity? Did you feel an internal conflict between the two things? Did you trade safety, for intensity in some way? How do you see that?

P9 Well, I tried to be very respectful of my teacher. I always tried to follow his ideas, his orientation, but this thing conflict was strong in me, you know. That's why it then became an issue, you know, some of my teachers said that you should play very relaxed, you know, and being relaxed I could reach the fullness of art, you know, musically and I really couldn't, you know, understand that. It was hard, you know because my body was saying, “That's too liberal”

ME So how did that conflict progress when you went to [REDACTED]? Did it change? How did you feel emotionally when you went to your next teacher in the [REDACTED]?

P9 OK. well, I had been taking violin violins then for about 13 years, so I was like, OK, that’s a good start. But I also felt that I still had a lot to learn. It was easier, you know, but then, you know, I also fell in love with the teacher [REDACTED]. When I got here, he said, OK, you have many problems we need to fix them, you know. I remember there was one lesson that he said, “you know, something that I don't like is your sound.” And that hit me like so hard, you know? So, if he doesn't like my sound, maybe he doesn’t like the rest. I will be very careful about, you know, my practice. Then he may appreciate, you know, how I sound but, you know, he started working on my sound production, you know, the quality and timbre.

ME OK

P9 So, then I realized that it's not like when he said “I don't like your sound” when he was working with me it was actually part of the whole you know, because there were other aspects of playing that I

thought I was doing fine, but he didn't like. So, one thing that was hard for me was constant criticism. He'd say "You have to work on that" but he didn't say how to work on the problems. He left it for me to figure out, you know, how to solve the problems. Hmm. Yeah.

ME OK, so connecting this experience to the retraining that you have undertaken for focal dystonia. You've identified this conflict between relaxation and musical intensity whilst playing. Do you feel that you've been able to reconnect those two parts of your playing? To some degree. Or to what degree?

P9 Yes, because maybe for the first time I could experiment, you know, with the balance between, you know, relaxation. and intensity of playing. I realised, "Oh, my God, I was so tense", you know, and I still am, but I can play now, you know, that's a good thing. But I constantly have to be aware and tell myself to be very cautious about that. "You're using still too much effort. You don't need to do that much, release". It's very weird because my whole life was easier to live after that. Before, people told me, relax, you know, release. I listened and tried to, but I couldn't. With [REDACTED], I could. You need somebody there that understands the musician. If it's too clinical then you're just waiting for results and not questioning or feeling anything. For me that's the whole point.

ME So, to what extent did you develop your own exercises and techniques for retraining? Based upon what you learned in with your training with [REDACTED], did you learn in your time with him? Is there anything that you developed for yourself, in addition to his techniques?

P9 Well, uh, I use a lot of the exercises that, [REDACTED]. gave me and taught me. But then there's also like, you know, for each patient, you know, very specific things, that could apply to me, but not to others, you know.

ME Could you give me an example of something that just applies to you?

P9 Well, I had, I have a problem. It's not only my neck, it's all connected, right? Shoulder, neck etc. So, it's very funny, but I need to do something like that (shrugging, lateral left arm movements whilst holding a violin) and something like that. If I'm not with the violin, ok, sometimes just thinking of the violin, I start feeling my neck also go hard, you know. So, I just do like that, (shrugging, lateral left arm movements whilst holding a violin) and sometimes when I play, I also need to do something like that, you know? So, it's kind of goofy and it's funny. I got instructions on how to do some of the exercises we learnt, but it doesn't help that much without being there in person.

ME Great, so as a direct result of your retraining, what has changed in the way you play?

P9 Well, I feel like everything changed you know, but especially the relationship with the violin. It feels a strange, you know. Even though I've been playing for more than three decades it feels strange, you know, it's I try to feel like the violin is part of my body, but it's not, you know, and sometimes this disconnection is a good. It's very interesting, but I learned a lot about my condition, my physical condition, and the relationship with my own body through the violin, so kind of understanding this better taught me how to understand myself. This is what I think has kind of changed because I was always going that direction, you know the violin should respond, I should control the violin. I need to control the feeling and everything, you know, the music, the technique. And then I said," Try to listen to what the violin is trying to tell me." And then it was very kind of surprisingly good that I could listen, I don't know if it makes any sense, but yes. It doesn't take much to answer an email, right? Everything was so impersonal afterwards. No-one appreciates that, right? I had so many questions but that's not working via e-mail. I needed one-to-one meetings which wasn't going to happen any time soon.

ME So not only the relationship with your violin changed, but your position in relation to your violin changed, Internally, as well as externally.

P9 Yes, [REDACTED], there's something else that's also important for me, because as I said I created images, you know, and I also created an image of myself, and this image he was a distortion. My fingers, I. created an image of my fingers going a certain way that would not respect natural physiology, you know, the shape and then the motion that each finger has, you know. It was, of course, before the focal dystonia, but. I don't know how to explain very well, but it was like if the fingers would go a certain way and these four fingers would go the same way, you know. It's not like this, in reality. (Demonstrates on violin)

ME Everything finger the same the same angle in relation to the violin?

P9 The same angle. Yes, OK. Although they are different, you know, in size and shape and everything, I was thinking, you know, all the notes, the columns and, you know. They should follow the same direction. And I was trying hard to make my fingers do the same thing, you know?

ME Have you understood maybe why that was the case?

P9 You know, because in my head this was right. This was correct. That was the way it should be, and it was beautiful.

ME Was it an aesthetic choice only, or a technical one?

P9 Both, you know. Like aesthetically and because, you know, as well as looking nice, I could also draw the most beautiful sound doing this.

ME This image of perfection, why was this image so strong?

P9 I think it began when I started listening to the recordings, you know, the long play records that I didn't have any images to watch. And then, of course, after we bought the video, you know, VHS. Yeah, so then I could watch and see, but then that image was already there, you know, and I, I thought that the played perfectly, so beautifully. And look at the fingers and I don't know, it's like they had, you know different shaped fingers. But for me, it was like that, you know. For every player that I could watch, yes...

ME Did that belief before the dystonia or only after dystonia?

P9 could you repeat that?

ME Did you challenge the belief of perfection in others performing, did you challenge that in your mind before you began your retraining for dystonia, or after?

P9 Before. Long before. Yes. And then with the dystonia, everything is put on, how can I say? a spotlight. Yeah, the spotlight and challenge, and I doubted everything, because I didn't know what was right, what was wrong. You know, and it was hard because I felt no floor under my feet. You need to change your perspectives when you're going through it. It's like you're now in the special club that no-one else is allowed into and yeah, nobody knows about it, or they don't want to know about it.

ME So, it's like a negative belief system and beliefs about your own playing. was challenged by the dystonia. How do you feel about that?

P9 Yes, right. Mostly dystonia. I really had to stop everything and think about every step and every aspect of my relationship with the violin. Because it's not like just the like "put the finger down", you know, it's the relationship with the movement, you know, "why I do it like that?" "My finger is doing this, you know. Why?" I felt that my pinkie was so weak, but it was not, my brain was telling me, you are so weak, you are too small. You have no refined movements. So then if you feel like that you cannot do anything so...

ME Great. Let me ask you a final question. Considering your experiences with dystonia. What advice would you give to young musicians during their training when they're learning instruments. based on your own experiences.

P9 I'm sorry to beginners or?

ME What advice would you give to young musicians, young musicians, when they are training based on your personal experiences of focal dystonia?

P9 It's a very open question. OK, OK. I would, I would say. For young musicians. It's a very. How can I? You know, when we began, we have all that, you know, passion. "I want to be a musician, a

violin player or a cello player", you know, but somehow along the way, we end up, you know, losing that passion, you know, and what I would say to young musicians this is very important, you know, and to be very passionate, to always have that relationship with music, with joy. You know. And it's full of challenges, you know, I mean, it's hard, you know, being in the practice room for many hours a day. But also, all those challenges, we need to face them with joy. You know, and. We think of, you know, health and everything, but I think. Sometimes it's hard to avoid. The health problems because we don't know about them in advance. We usually get aware when already have them, you know, some health problem. That's why it's so important, to prevent them. You know, and if those young students, young musicians are made aware, about, you know, what could happen, you know what, like, taking about health and the problems that might affect the musicians, it's good, you know. Yeah, because, you know, focal dystonia, it was terrible, and it is to in many parts of the world, you know, musicians develop focal dystonia, and they have no clue what is going on with them. And it's very hard, you know, and it's very regrettable that many musicians gave up because there's no need. I need daily contact with the [instrument] even if I don't play too much. When I leave it for anytime I feel it straight away. And finally, I'd add I got instructions on how to do some of the exercises we learnt, but it doesn't help that much without being there in person. It doesn't take much to answer an email, right? Everything was so impersonal afterwards. No-one appreciates that, right? I had so many questions but that's not working via e-mail. I needed one-to-one meetings which wasn't going to happen any time soon.

ME Great, thank you very much for your time, I thoroughly enjoyed talking with you.

Appendix L: Interview Transcripts – Study 3

P1 Interview

Me: Okay, so just to begin with, can you tell me a little about your background as a musician? And how did you get started in music? What instruments do you play, etc?

P1: Yeah. I didn't start learning the piano in my childhood. Actually, I began playing when I was about 13 – still a teenager. Initially, I taught myself. I'm quite an obsessive person and I really enjoy taking on challenges that are beyond my current level. I don't like starting with simple children's songs or anything like that. Since I had a bit of a musical background – I knew how to read music and some basic theory – I attempted to play some pieces by [redacted composer]. For instance, I tried my hand at pieces that you might hear pianists performing, like the [redacted piece]. Yes, that's one I worked on for quite a while.
At first, I was starting from scratch, I would say I was a complete beginner. However, I discovered various tricks, or methods, that helped me learn. I'm incredibly obsessive and very patient. I could spend up to half a year working on just one or two bars of music. So, I really dedicated myself to the practice because I wanted to prove to myself that I could play the piano.

I didn't want people to think that I was a beginner. So, I taught myself like that for at least two years, though I'm not exactly sure how long it was, as it was quite some time ago. After a while, I began to realise that I had some issues. My family suggested that I find a teacher, so I started looking for one. However, initially, I didn't think those teachers could help me much, as I sometimes discovered some technical problems that were rather puzzling. I believe these issues stemmed from that time, which is why I tried quite a few teachers from around the age of 17 to my early twenties. I changed teacher numerous times, and I don't think they were particularly beneficial because I had some problems with my right hand, specifically with my fourth and fifth fingers.

After trying several teachers, I eventually found a really good one who had knowledge of ergonomics. He taught me some very sound techniques, and I improved significantly, resolving many of my issues. I continued to progress and achieved Grade A in the [redacted], and finally, I felt like I was playing the piano properly. During that time, I was pushing to increase my skill level and tackle more challenging pieces. However, I started to experience some problems again, but this time in my left hand. If you've seen my post on [redacted platform], you'll find some videos showing my left wrist, which was much more severe than the issues with my right hand. I began to notice something was wrong with my left hand at least six years ago now.

Me: Can I ask, was that a gradual thing or was it a sudden, sudden thing for you? How did it actually progress in the beginning?

P1: I believe it was a gradual process because I thought I could play for a long time without any issues, but I didn't realise there was a problem. Then I started experiencing spasms, which is how I think it all began. This was about five or six years ago. Yes, I began to have these spasms, and my hand felt incredibly stiff, especially when I needed to play some [redacted composer] études or similar pieces. I had to stretch my wrist a lot, and even though I practised very hard, I still struggled to manage that. Early on I even tried taking a short break: "I took six weeks off at the beginning expecting to be back at work for the start of the season. You just have no notion of how long this stuff takes until you're in it."
So, I started to realise that perhaps I had some issues, as I didn't observe other people dealing with the same problem. Even while teaching my students, I instructed them to move their wrists and perform the same wrist motions, and they were perfectly fine, but I wasn't. I think there must be some underlying problems for me, though I'm not quite sure what they are. And I came to feel strongly that "You don't cure yourself by just treating symptoms."

Me: So, what were your thoughts and feelings around that time? What were your suspicions or how did you get to a diagnosis of focal dystonia at the time?

P1: Yes, I was truly frustrated because I consulted numerous doctors. Living in [redacted place], we have access to both [redacted] medicine and [redacted] doctors, and I saw practitioners from both disciplines. However, none of them could explain what was happening. "The family doctor had no idea

what was going on, so I got a referral to an orthopaedic specialist. I wasted a lot of time for nothing." Eventually, I found a doctor who was able to diagnose my problem, but she informed me that it couldn't be cured. She just abandoned me and gave up. After that, I never returned to her; instead, I started looking for ways to address the issue myself.

Me: So how did you go about identifying techniques for retraining that were effective for you? How did that begin?

P1: Yes, as you recall, I mentioned that I had a teacher who taught me some ergonomic techniques, so I had some understanding of those concepts. However, my teacher wasn't able to address the issues I had with my left hand. Because of this, I began searching for another method. In my post, I noted that I practise [redacted practice].

[Redacted practice] has been the most helpful and significant factor in my improvement. In fact, I believe I've cured the issue. Sometimes, the concepts of exercising through [redacted practice] and playing the piano are quite similar. Yes, there are some aspects that I can apply from one to the other.

After that, I sought out a teacher to guide me in [redacted practice]. I practised diligently, dedicating at least one to two hours a day, and I've maintained that routine for about a year now, since April of last year. I truly feel I can say I'm cured. I believe I am cured. Although the hand problem still bothers me a little in my daily life when playing the piano, I am continuously improving. Importantly, "I need to feel fully connected to my movements, not just going through a sequence of exercises."

Me: So, can you tell me a little bit about how, for you, your [redacted practice] translated into retraining your dystonia on the piano?

Here's the adjusted version in British English while preserving the original context:

P1: What specific elements of [redacted practice] have actually helped you with playing the piano?

Me: Exactly.

P1: For instance, are you familiar with the [redacted method]? It focuses on bone alignment, teaching you how to align your entire body to improve how you walk, sit, and manage various aspects of your life. [Redacted practice] does something similar but expresses it in a different way. Additionally, it emphasises the fascia. I mentioned that in my post as well, but I need to articulate it in English, so I'll try to speak slowly.

For example, [redacted practice] suggests that if you have a problem in your fingers or wrist, it may actually originate from your neck, shoulder, or even further away. Issues can begin anywhere in your body because there are soft tissues connecting your muscles. When you move your fingers or wrist, the fascia and all the muscles in your hand are involved, although you may not feel it. For instance, when I hold my hand straight and rotate my arm, the skin from my hand to my feet is engaged; it rotates all the way down because everything is interconnected, much like fabric or cloth.

This is how fascia operates, everything is related, and you need to practise to become aware of it. [Redacted practice] is a comprehensive method for developing motions, such as spiral and rotating movements, to unlock any adhesions in your fascia. That's basically how it works. And other exercises, like standing meditation, simply involve standing still.

If you're familiar with the [redacted method], it has a lying down component, but [redacted practice] includes a standing meditation, which is incredibly powerful. It's one of the most effective exercises, and the simplest one has been the most beneficial for me. In that spirit, "I can really connect the body, so I feel strong. One example that's good to do, balancing work like the 'single whip', moving outwards, every limb It's a common tai chi sequence. Then I sit at the piano, repeat and then I play. It lets you feel all the sensations of the hands and fingers on the keys."

Me: Yes, that sounds great.

P1: Alright, this is how we stand in a normal position. However, in [redacted practice], we lower the pelvis slightly. You can see my knee bends a little, but only slightly. I raise my head a bit and maintain this position for at least 45 minutes. There are so many details to learn because the theory states that when I stand like this, I need to align all my body parts and bones. This alignment helps keep your body in a balanced state. You must balance your entire body. If you can maintain this position, then…

Sorry, it's quite challenging to express this in English, even more so than in [redacted language]. Sometimes, [redacted culture] discusses "Chi," which is difficult to explain. I prefer not to label it as "Chi" since I aim for a more scientific understanding. Essentially, by keeping your body balanced and releasing muscle tension, if you can maintain this position for an extended period, you may notice issues, like my wrist problem, it feels like it arises from here and extends all the way down to my pinky.

You begin to become aware of where the tension originates, and with continued practice, everything can eventually be released. However, it takes time. If I experience tension around my shoulder, say, it improves significantly. If the shoulder improves, so too will the wrist.

Me: Could you walk me through a typical practice session incorporating these methods? When you're at the piano, how do you incorporate this? Do you apply [redacted practice] off the piano only, or do they translate to your playing? How does [redacted practice] become integrated into your piano practice?

You mentioned standing meditation, right? How does it work for your retraining at the piano?

P1: It's quite similar to posture training. You could say it's about posture, but the concepts can be applied to any position. When I play the piano, I have to sit, right? Let me show you.

So, I need to sit in front of the piano, and I can apply the same concept to align my body. In [redacted practice], we talk about "[redacted term]." I'm not sure how to express that; just give me a moment.

Me: No problem.

P1: So, you know what [redacted term] is, right? Yes. We typically refer to [redacted term] as being just below the belly button, which, scientifically, relates to your centre of gravity, a point of balance.

However, there isn't just one [redacted term]; there's one in your pelvis where you can identify the centre, another in your chest, and another in your head. So, there are three points that you need to balance and keep aligned to avoid falling.

We need to apply the same principles when sitting or standing. For my sitting posture at the piano, I must align these three points, and once I align them, I have to maintain that alignment.

It's challenging to articulate this clearly.

Me: No worries.

P1: There's another concept in [redacted practice]: you need to sink your shoulders and drop your elbows. If you observe someone doing [redacted practice], you might see movements resembling this.

I need to keep my elbows lowered and my shoulders relaxed. We must sink our shoulder blades and keep our elbows pointing toward the floor. I apply this same principle when playing the piano.

To begin the sitting meditation, I align all my [redacted term] points. Then, I place my hands on the piano like this while maintaining the position of relaxed shoulders and dropped elbows. I hold this stance for several minutes without moving. During that time, I can feel how my body is balanced. The piano keyboard is fixed, after all. When our posture is unbalanced, we might lean forward or backward, but the piano remains stable. By resting my hands on the keyboard, I let it assist me in finding balance. As a mindset for this, "When I'm calm then I work things out well. I always try to be in a calm state. If I can't then I do something else. I need a positive experience when I play or there's no point." And to make space for experimentation, "I like to make quiet time to think about what I'm doing or it's just too stressful to focus. When I'm in that state I can try things out without overthinking things."

Me: That's great. So, once you're set up to play, what outcomes are you looking for? When you've been working to reduce the symptoms of dystonia, what do you seek? Are you aiming for a release of tension, stiffness, or is it something else? How do you measure improvement?

P1: For example, there are some patterns I wasn't able to play before, and now I can. I've also incorporated wrist stretches. If you've seen the video I posted on [redacted platform], you'll notice that I perform circular motions with my wrist. Previously, I was stiff and often twisted outward, but now I can move with ease. I also try to stay connected with others through this process: "I share a lot of my thoughts and ideas online. I get a lot of feedback which I need to have. I'm less unsure about things then." And "I like to keep connected to people online otherwise I can get pretty fussed up on my own. I like to share my ideas as well."

Me: So, there's still room for improvement? How do you continue to enhance your abilities? Are you modifying anything, is there more learning involved, or are you discovering new ways to refine existing techniques?

P1: Actually, I stopped playing for two years. I continued teaching students, but I didn't practice on my own.

I focused solely on [redacted practice] for those two years, dedicating hours each day to it, which didn't leave time for piano practice, and I also wanted to rest. After practising [redacted practice], I improved my overall body function, enabling me to do things on the piano that I couldn't manage before. My skills got better without requiring much practice.

I truly believe I have the skill, but physical issues limited my execution of those skills. By improving those issues, I can now perform confidently.

Me: You mentioned earlier that you tend to be an obsessive person, perhaps a perfectionist. Would you say that [redacted practice] has impacted that part of your personality?

P1: Yes, I think so. Also, because I took a break for two years.

During this time, I changed a bit. I learned to stop pushing myself, as I used to feel the need to constantly compare myself to others, striving to be better than them. However, I realise there are many things I simply cannot do. The things I thought were easy but couldn't achieve made me blame myself. After being diagnosed with focal dystonia and understanding that it was about issues with my hands, I felt a sense of release. It's not merely a personal flaw; it's an external factor affecting me.

So, I stopped comparing myself to others. Now, I progress at my own pace, allowing myself time to improve. As I came to realise, "I compared myself to others and was [always] getting down about it. Then this [dystonia] just slaps you in the face. It's such a waste of time, nobody cares how you play anyway, let's be honest."

I can now do more than before, but I no longer practise as intensely as I once did. Still, there's a trade-off I'm mindful of: "When I have to think about how I move I lose the expression. Sometimes I'm playing and then realise that I have no idea what I'm trying to say, musically. That is still the worst thing for me sometimes".

Me: So, do you believe that experiencing dystonia has had a positive long-term effect on your playing?

P1: Yes, absolutely.

Me: I'd like to shift the focus a bit and discuss your views on risk reduction and prevention. Based on your experiences and retraining, what advice would you offer fellow musicians regarding reducing the risk of focal dystonia in the future? Not necessarily prevention, but how to mitigate risk factors? What guidance would you provide to healthy musicians?

P1: You mean suggestions for others? Yes. Always be aware of your entire body. Professional musicians often practise very hard, focusing solely on their instruments or just their hands and fingers,

without considering the rest of their bodies. When I practise [redacted practice], it involves the whole body, from your pinkie to your toes.

You need to be aware of your entire being when moving your fingers; focus on what's happening in your feet, skin, even your hair. This has become more of a lifestyle for me. To cultivate a healthy lifestyle, we must develop habits as professional musicians, not just focusing on practice but also ensuring a healthy way of living.

It would also be beneficial to learn exercises, such as [redacted practice] or yoga. I recommend that all musicians explore these practices. Personally, I am eager to conduct a course teaching musicians how to relax.

Also, as you've mentioned, the [redacted method] encompasses similar principles.

Me: Since conservatory-level musicians generally have more exposure to the [redacted method] than [redacted practice] or yoga, how do you see the relationship between [redacted practice] and the [redacted method]? Are there similarities, or should there be further development in this area?

P1: Yes, there are certainly parallels since both approaches emphasise body and mental balance. They both address alignment, including bone and body alignment, which is a significant similarity.

However, [redacted practice] also includes unique concepts about how we engage our fascia during movements.

Me: How important do you think awareness and education about focal dystonia are for young professional musicians entering the field? What are your thoughts on the importance of this awareness? Do you see any associated problems?

P1: It's tremendously important. Many young pianists, for instance, practise tirelessly, aiming for perfection without any awareness of their bodies or minds. They can execute techniques proficiently, yet they may face severe issues due to a lack of understanding.

If we want to increase their awareness, we may need to encourage them to slow down their process. Musicians often strive hard for competition success or to graduate, pushing themselves without recognising the hidden problems behind those achievements.

We must help them become aware of all of this and encourage them to pace themselves during competitions.

There is a particular challenge regarding the discourse on focal dystonia in musician education. While musicians often receive information about musculoskeletal issues, details about neurology, including focal dystonia, are less prevalent. What do you think about informing musicians about focal dystonia and how to lower their risk?

Me: Do you think it's beneficial to discuss this with them directly, or could that have potential negative repercussions?

P1: That's a valid point. Even if musicians don't have focal dystonia now, most have experienced stiffness or pain during practice.

Focal dystonia is indeed a related issue; managing pain and stiffness are interconnected. Adhesions in the fascia between muscles can contribute to focal dystonia and other pain-related conditions.

If we could communicate these ideas to musicians, particularly in music schools and conservatories, it could raise awareness not only of focal dystonia but of the importance of overall body management in relation to technique and playing style.

Me: That sounds like an excellent approach.

P1: Yes, definitely.

Me: As we wrap up, what future goals do you have, both musically and in your ongoing journey with focal dystonia? What are your aspirations in terms of musical development and full recovery?

P1: I'm still in recovery and have recently started practising the piano again, although only for about half an hour a day right now. I will continue practising [redacted practice] and playing piano, aiming to integrate both into a singular practice routine.

Because of [redacted practice], my teaching methods have also evolved considerably. I've developed techniques that combine [redacted practice] principles with piano instruction, like how to position oneself at the piano and how to drop the elbows while relaxing the shoulders.

In the future, I would like to create a course focused on helping musicians learn how to relax their bodies effectively.

Me: Finally, how has your experience in developing and applying these techniques affected your perspective on the relationship between physical and mental health? Has it changed for you?

P1: Regarding mental health, I feel calmer. I've always been a bit nervous when speaking to others. In the past, if I needed to converse with someone unfamiliar, I'd tremble or shake a lot, but I don't do that anymore.

This whole-body tension has diminished significantly, which I've managed to let go of.

Me: That's wonderful to hear. Is there anything else you would like to add or discuss?

P1: If there are no further questions, please let me know if there's anything else you'd like to discuss. I sometimes feel that I don't convey my thoughts very well in English, and I may have made some mistakes.

But as far as I'm concerned, your English has been perfectly understandable. If you have anything else to add, please feel free to share.

Me: Perfect. I would welcome any additional thoughts you have. Perhaps we could revisit this conversation at another time if you'd like.

P1: Yes, that sounds good. If you still have questions, let me know.

Me: Alright, I'll stop recording now.

P1: Okay.

P2 Interview

Me: So, thank you very much for talking to me. So could you just tell me a bit about your backgrounds as a musician and the instruments you play, just for my reference here.

P2: So, I'm a classical guitarist, quite simple in that sense. And I don't play any other instruments, I never have. I've played ever since I was seven and a few months old. I first developed what eventually was labelled dystonia in the summer of 2014.

I had no idea what it was at the time. I was working through some repetitive arpeggio exercises. If you're familiar with the guitar at all, that would be the [redacted instrument exercises].

Me: Specifics, but I understand the basics.

P2: Yeah, lots and lots of arpeggio, different arpeggio patterns done repetitively. At the time, I guess I could identify with being both a perfectionist and a lover of punishment. So, I was working through them very fast, repetitively for standard periods of time, probably 10 minutes per pattern or more. There's 120

of them, so it takes a while. And one day, deep into that, I think number 92 or 93, things just started thickening on me. My fingers just started moving slower and slower as if they'd gone from air to quicksand. I stopped, went away for lunch, came back and tried to go again. It felt like I had sprained a finger. My ring finger felt both very tight and painful. This went on for a few days.

I thought I had actually gotten myself an RSI, so I treated it like that, rested a while, and tried to go back to playing. Something was just off. I would miss notes, or I couldn't coordinate the legato from one note to the next. Eventually I found I couldn't hit notes in time at tempo. I wondered if I'd been practising wrong. I tried re-fingering pieces, index–middle alternation instead of involving the ring finger, and that worked for a while. But I noticed my ring finger would tuck into my palm. A couple of months ahead, I couldn't even do that because the tension in there stopped my other fingers from moving freely. At that point I started to seek help.

Initially, a physiotherapist and an orthopaedist both thought I had done something to either connective or muscle tissue and that it was an injury to overcome. But with time it was clear I wasn't injured, and it wasn't going away. I sought further help and got a diagnosis from a doctor in [redacted], and a confirmation from someone in [redacted]. “I was actually only diagnosed last year. I have had so many tests over the past few years, and I was repeatedly told I was physically fine, that it was psychological. I kind of found out first on my own, that it wasn’t.” When I finally went to a clinic for options, “The only suggestion at the clinic was Botox [botulinum toxin injections]. No one was there to do it, and I was quickly going downhill, so I left. I thought sod it; I’m on my own.”

It so happens that before I got into music, I studied psychology, and my university was very generous and gave us continuing journal database access. Since I couldn't play anymore, I decided I might as well learn about this thing. I read every single paper I could find on dystonia. Initially, that didn't go anywhere, it just taught me what was wrong with me.

I tried several approaches. What first seemed promising was a more mental and emotional approach from [redacted], letting go and allowing mistakes, trying to flow through it. It made me feel better about playing badly and slowly, but it didn't get any better. From there, I went to slow-down exercises along [redacted] in [redacted], which got me somewhat better, from quarter notes at approximately 40 bpm to approximately 60. That felt wonderful, but it obviously was not real-world progress.

Then I spoke to someone in [redacted] named [redacted], an Olympic lifting coach and musician familiar with focal dystonia. The idea was that much like lifting is neural circuit training, you could address focal dystonia by firing very hard through the right neural circuits for short speed bursts. Applying speed bursts to things that shouldn't have speed bursts, like block chords. Again, it was promising in the sense that forceful gestures can override dystonia in the moment, but it doesn't translate to playing without dystonia. I tried that for a while; it didn't go anywhere. I switched a lot of my repertoire to gesture-based pieces, lots of chords, slow music, got very into [redacted composer] for a while.

But then I came across [redacted]’s papers. A lot went off; it made sense to me. All of the protocols were things I’d understand in a clinical setting. So, I basically took that protocol and replicated it first. That achieved exactly the same kinds of results, partial recovery. It took me from completely unable to play to being able to play in some ways; some hand functions were restored. It wasn't 100%, though. I tried to make a go of that, hoping partial recovery would jog the other pieces loose; it didn’t. At that point I told myself, “If I really understand what it is I’m working at then I just carry on until it’s better. I treat it like a project more than rehabilitation.” And, frankly, “I’ll give most things a try, really. My thoughts are, there’s no cure out there for me, so I’ll stir the pot until there is.”

Then I reread the same papers and thought about the rationale behind the designs. If those steps made some changes, couldn't the same principles be applied to changes that had not yet been made? I developed a few different protocols aimed at my own idea of what was wrong and therefore what needed to be adapted and put myself through them.

Me: I mean, if you could just go through those, that'd be great. You know, as little or as much as you'd like to go into.

P2: After I took the protocols, constraint-induced movement therapy with splinting, I felt it was a bit scattershot: splinting applied across all fingers with patterns that didn’t target my specific issue. With

multiple participants you need a common set, but for me, with a ring finger that curled, some things made sense, some didn't. Having thought further, I realised what we're really teaching is activation or inhibition, neurons on or off. Had I taught the "off" state for the dystonic synergy in every scenario? No. Had I taught the "on" state for the target finger independently in every relevant scenario? Also no. So, I built tests for independent activation and saw it was unable to activate cleanly, that's where the work was needed. I hypothesised instrument-specific drills to do that work and ran them.

On the guitar-specific level, the core was splinting and playing. In [redacted]'s work, the splint didn't fully immobilise the hand; there was fingertip play. I built my own splint, early prototypes from a plastic hanger head, carved wood, cloth bands, later an aluminium splint, so the finger was genuinely immobilised. Immobilising at the instrument's natural resting position for that finger was crucial. Counter positioning into extension didn't help; the natural resting shape did.

With the ring finger splinted in that position, I hammered the brain–hand system with arpeggios using the other fingers: e.g., thumb–index–middle–index–thumb–index–middle–index, or [redacted instrument exercises] permutations, compound movements (thumb middle, index, etc.). It helps if exercises are at least 10 minutes long and use varying tempos, so I built a 10-minute metronome track that cycled roughly 40–90 bpm and used that for all exercises.

Me: And the timeline for removing the splint and getting back to unsplinted playing?

P2: Working in the dark, I took them off too soon at first. [Redacted] had participants play daily after exercises; I found that detrimental and stopped. I waited until I could start exercises with no residual pull/push into the splints, about nine-Ish weeks, then, at the end of sessions, I'd remove the splint and try to play. The finger no longer curled; it felt uncoordinated, so I explored drills without splints to reawaken coordination. Those didn't go far until I designed a second phase to train independent activation of the ring finger,22 days long. After that, I reintroduced free play very conservatively: two hours of exercises per day, followed by two minutes of unsplinted playing. It sounds tiny, but prior to training those two minutes would have caused problems. Resisting the urge to overplay was key, "When you can see the big picture, that's when all the bad days start to mean less and less." I then weaned off exercises by about 10 minutes per day while building free play over ~10 weeks from 2 minutes to 30 minutes.

Me: You mentioned perfectionism. How did that affect the way you constructed this method?

P2: I was lucky to be wearing two hats. The musician hat was off; the psychology hat was on. The point of the exercises was movement, not performance. The metronome prescribed sequences; mistakes like wrong strings or accidental double-stops were fine. Because I thought like an experimenter rather than a performer, I didn't get trapped in perfectionist loops. That said, back in performance I do still obsess over right notes at the right times, but I'm now committed to mechanical relaxation. My baseline activation is lower; I return to rest after each action, micro-rests between strokes. Implementing that took attention and consistency, but it's become a cornerstone.

Me: Influential resources or individuals beyond what you've mentioned?

P2: I lifted weights (powerlifting) and laid off for a while on advice, given a hyperflexion dystonia. In the end, it wasn't relevant; when I retrained, I was lifting again. So not particularly influential.

Me: How do you measure progress?

P2: Able to play without dystonic movements; without sensations of instability or tension; and, crucially, playing without the expectation that you must navigate around a problem. Early on, "There was no two-way contact really. You need to take a big leap of faith to believe it'll work." Over time, you replace that with evidence.

Me: Could you expand on expectation?

P2: After months or years with dystonic patterns, you expect them to appear. Even after retraining, that expectation lingers. I went back to performing right away, I even booked a concert the day after my

activation phase ended. It worked, but I had to silence the inner expectation daily for about a year. Then it faded; I came to expect the new normal, relaxed hand, coordinated movements.

Me: Do you feel you play better now than before?

P2: In keyways, yes, especially in baseline relaxation and economy. I think of it as learning not to burn out in the practice room.

Me: Risk mitigation and prevention, what advice for non-dystonic musicians?

P2: Don't spend hours straight practising. Work in short bouts,Pomodoro-ish 20/20 or up to 40 minutes, then break. How you practise is critical: repetition at speed without perceiving feedback is dangerous. Even for fast scales, be mindful; feel what you're doing. Slow practice is king because it keeps you cognitively with your fingertips. Don't treat fingers like pistons; that leads to muscling, excessive activation, and bad technique.

On whole-body use: posture is foundation. Sit or stand with balance and without tension. Before dystonia I was tight and off-balance. Now I set a stable base, let the hips and shoulders release, feet grounded, then use the largest effective muscle groups, keeping digits relaxed. "We need to know where our centre is and be balanced inside, then you can start working properly on the playing."

I've spoken with groups in [redacted], [redacted], [redacted] and [redacted]; younger musicians are pushing hard and seeing problems earlier. A more balanced approach to development, without burning out, needs to be part of conservatory life.

Me: Some argue we shouldn't talk to students about dystonia to avoid planting doubt. Thoughts?

P2: I'm categorical: it's fine, and necessary, to teach boundaries so people don't cross them. Awareness prevents problems, it doesn't cause them.

Me: Future goals, in the context of being careful about dystonia?

P2: I don't think of myself as a dystonic musician. I had a condition that removed me from playing for a bit; I rebuilt. Now I also teach, something I never wanted before. I want people to learn how to learn, to reduce barriers between themselves and their instruments, to execute with minimal effort. That's the goal, arriving there sustainably, not sprinting toward it.

Me: Finally, how has this affected your view of physical and mental health?

P2: I compartmentalise, but this taught me to gain some distance from playing. I play now as a conscious musical expression, not just an outlet for emotion. That shift has been healthy.

Me: Is there anything else you'd like to add?

P2: For non-dystonic players: strive for full relaxation, nothing firing that isn't necessary; incorporate micro-rests. For those overcoming dystonia: aim for the same end-state, no unnecessary activation. The routes differ, but the destination is shared.

P3 Interview

Me: Ok. So, thank you for being here. So, tell me a little about your background.

P3: Well, I'm a violinist, professional, and I was diagnosed with FD in 2012. It took around two years from initial symptoms for me.

Me: Two years. Yes.

P3: I remember going to doctors in the city where I lived, [redacted], and I had consultations with neurologists and a specialist hand doctor. I started to feel the symptoms when I was still living in [redacted]. That was in 2010. The correct diagnosis only came in 2012, after sending a video to [redacted], who reported it was a classic case of focal dystonia in the left hand. Waiting and hoping for the perfect appointment didn't help, "Waiting for my doctor wasn't helpful. Feeling useless doesn't help either. I just got my f* you hat on and went for it."

Me: So, you had a consultation and then went away with the wrong diagnosis, or suspecting it was focal dystonia, or did they not help at all?

P3: The first neurologist I visited diagnosed me with writer's cramp and said there was no cure, that I should give up the violin and find another profession. Hearing that felt like a symbolic death sentence. I had already been studying conducting, so I briefly considered continuing as a musician but not as a violinist.

Me: Did you discuss your diagnosis with fellow musicians or other health professionals for support?

P3: Yes. It was complicated because I didn't know what was happening. I had loss of control in my left-hand fingers. In [redacted], at work in a chamber orchestra and with chamber groups, I couldn't play simple passages. A conductor I spoke to thought it was "in my head," stress maybe. Some colleagues assumed I'd become lazy after my doctorate and just wanted an easy life in [redacted], which was painful to hear. In reality, "I started noticing, there was also an emotional connection that had to be addressed. Without getting into that, I was up against it, I think."

Me: Moving on, can you describe the strategies for retraining you developed to manage focal dystonia? Any specific examples, exercises, or techniques? Do you follow a structured routine?

P3: It's a long journey. I'll start where I saw the light at the end of the tunnel, sessions with [redacted] in [redacted], first in 2012. The most important step wasn't a "medicine" or a quick fix; it was faith in the process. Early on there's often no immediate feeling or clear feedback, sensation is distorted, and touch sensitivity can be dysfunctional. For me it was a combination of belief and tiny proofs. When something small worked, I held onto it and kept going.

Me: So, the first stage was refocusing your vision, finding faith and small signs you were on the right path?

P3: Yes, but it also meant changing my entire operating mode. As [redacted] told me, if I continued as I had always played, I wouldn't be able to play anymore. That was a huge challenge, letting go of old habits and adopting a different approach to the violin. "You have to be humble. Dystonia doesn't have room for ego."

Me: Could you give examples of that change, what you attribute to your retraining?

P3: I realised the seed of dystonia, for me, was planted in my very first violin lesson with a visiting teacher from [redacted]. She was impatient and told me I had no way with the violin, that I looked like a little monster. That word stuck. I began to see my left hand as ugly, especially the ring and little fingers, which were the first affected by dystonia. I chased an "ideal" aesthetic hand posture that ignored physiology.

Me: After seeing [redacted], did that change?

P3: Exactly. That was the key. I stopped trying to make my hand an imagined, “beautiful” hand and began welcoming my real hand, as it is. I had to accept the emotional distortion registered in the brain and work with it, not against it.

Me: What changed in your approach at the violin? How did you maintain this change?

P3: Concretely, I’d been forcing all fingers into the same curve and angle, ignoring that each finger articulates differently. I pressed the little finger straight and overextended; I sought symmetry that the physiology doesn’t support. I often played with my eyes closed to avoid seeing my “ugly” hand, which only reinforced the disconnection. After [redacted], I relearned to respect natural finger angles and reduce interosseous overactivation. We used imagery like “the hand is like a roof”, each finger has its own slope and direction. I learned to give space for the fingers to relax and to remove pressure entirely, then reintroduce it with a “dropper,” minimal-dose approach, respecting sensation.

Me: How did you approach changing from position 1 to position 2,technically and mentally?

P3: Several things. The big key was looking at my real hand without judgement and accepting it. [Redacted] encouraged “welcoming” and gentle touch, relearning pleasant tactile feedback I had lost. I discovered I was tense even without touching the string. So, I worked from zero: no pressure, then the smallest increments. This required patience and faith through inconsistent sensations, hypersensitive index finger, anaesthetised ring finger, and cyclical progress. On difficult days, “It’s hard to deal with the dead ends or things that don’t work. That’s when I’m thinking, should I just give up?” But I kept going, “When you learn to deal with your stress, then you can deal with the dystonia. The two walk hand in hand in my opinion.”

Me: How did you assess good vs bad days without reverting to self-judgement?

P3: Focus was central. I was told to de-focus from the fingers, counterintuitive for precision. I practised shifting attention: reading text, describing a painting while fingering. I also noticed strong physical stress responses, nausea, “vomiting anxiety”, especially when the fingers released. I learned to “surf” through that wave: gentle shaking, diaphragmatic release, and even dance (e.g., belly dance patterns) to free the abdomen. Managing stress and nervous system tone became as important as finger work. In fact, I later found that “Doing twenty minutes of it [mindfulness] before my slow exercise work, and there you go. I can play stuff better. It makes a big difference.” In the same spirit, “It’s no fun worrying about things you try not working out. I always make sure I begin exercise sessions in a calm state. It makes a lot of sense to me nowadays. If I’m feeling stressed out, there’s no point.”

Me: Did you follow a structured routine or a flexible one?

P3: It varied over time. I used to be pragmatic but struggled to follow a strict order (scales, etudes, caprices, repertoire) and regular metronome work. Dystonia initially made everything messier, but paradoxically it taught me discipline where needed, especially rhythmic organisation, because dystonia can pull you off rhythm. I rebuilt sensitivity in each finger alongside rhythm drills. Over time I could be both disciplined and flexible: sometimes warm up thoroughly; other times just tune and play. I also learned the value of brief daily contact,[redacted] advised, “Don’t stop playing.” Even five minutes daily mattered. Long breaks didn’t help; symptoms returned as soon as I resumed. So, I kept a daily thread, even when I didn’t want to.

Me: Setbacks or plateaus?

P3: Many. Early on I couldn’t play even simple scales without the hand collapsing. I desperately wanted to play [redacted repertoire], but I had to accept very slow, simple music first. At one point, a slow melody like the [redacted] Sonata showed zero symptoms, yet I couldn’t recognise it as “good” because it wasn’t 100%. That perfectionism is a barrier. I had to allow myself to play “badly” publicly to break the fear. Also, at times I felt utterly alone; clinics offered limited options. “When you learn to deal with your stress, then you can deal with the dystonia. The two walk hand in hand in my opinion.” And when medical systems stalled, I decided to take initiative: “Waiting for my doctor wasn't helpful. Feeling useless doesn’t help either. I just got my f* you hat on and went for it.”

Me: How effective do you perceive your retraining to be?

P3: Effectiveness is dynamic. Many days I forget dystonia exists. Whether that's "cure" or not, I can play and function well; I treat dystonia as an ally, an alert when something's off, rather than an enemy. That mindset shift has been crucial.

Me: Has retraining changed your overall playing and performance?

P3: Absolutely. In many areas I play better than before dystonia, more natural hand use, less force, more sensitivity. Some specific sequences (e.g., involving the third finger, 4–3–2–1 patterns at certain tempi) can still be punctual challenges, but overall technique is easier and healthier.

Me: Psychological or emotional effects of the process?

P3: Many. The condition isn't "psychological," but it affects psychology. I had anger, shame, and had to confront my own arrogance. Accepting those parts of myself helped me play again. And I learned that managing stress and emotional load is not optional in recovery, "When you learn to deal with your stress, then you can deal with the dystonia. The two walk hand in hand in my opinion."

Me: Support, family, peers, mentors?

P3: I've been fortunate. My partner, [redacted], supported me daily, including keeping me accountable for short, consistent practice. Professionally, connecting with peers who also experienced dystonia was vital. The isolation is one of the hardest parts, so finding community made a big difference.

Me: Key elements that make your retraining effective?

P3: Establishing a loving, welcoming relationship with the instrument and with learning itself; accepting my real hand; removing pressure to zero and dosing it back in; rhythmic organisation; mindful de-focusing and stress regulation; daily brief contact; humility. "You have to be humble. Dystonia doesn't have room for ego."

Me: Similarities with other musicians' approaches?

P3: The capacity to change, to adapt quickly, is a strong predictor. Not everyone finds it easy, and I feel for colleagues who struggle. But the common threads I see are acceptance, stress regulation, incremental exposure, and a willingness to start from simple, even "easy," music without shame. As a practical habit, "Doing twenty minutes of it [mindfulness] before my slow exercise work" consistently set me up for better sessions.

Me: Any final reflections?

P3: Just that setbacks will come, "It's hard to deal with the dead ends or things that don't work. That's when I'm thinking, should I just give up?", but calm, consistent work wins. "It's no fun worrying about things you try not working out. I always make sure I begin exercise sessions in a calm state. It makes a lot of sense to me nowadays. If I'm feeling stressed out, there's no point."

P4 Interview

Me: Thank you for doing this interview today.

P4: Thank you for having me.

Me: Great, so, the aim today is to explore your personal strategies for managing musician's dystonia and how they have impacted your condition and rehabilitation. Everything you share will be kept confidential, and you can choose to withdraw at any time without any consequences. Ok, so do you have any questions before we begin?

P4: Nope, I'm ready when you are.

Me: Ok, so, can you briefly describe your musical background, your instrument, experience etc?

P4: I'm a cellist with over 20 years of experience. Studied in [redacted] with [redacted]. I've performed mainly with regional orchestras and lots of chamber stuff, that kind of thing. I began cello at 10, piano at 6. It was love at first listen when I heard [redacted] as a kid.

Me: That inspired you to start playing the cello.

P4: And my parents introduced me to classical music early on. I remember begging for lessons after hearing it live though.

Me: Ok, so getting into your experiences with focal dystonia, when were you diagnosed, and what were the initial symptoms you noticed?

P4: I noticed something was wrong in 2021. My two fingers, ring and pinkie, on the left hand were curling during complex passages. Looking back, I think they always did, but suddenly I realised that I couldn't control it. "Every time I played; I was expecting it to fail. Musically, I was empty really, no idea what to do at the time. Like a student again with shaky fingers, I suppose." "I was actually only diagnosed last year. I have had so many tests over the past few years, and I was repeatedly told I was physically fine, that it was psychological. I kind of found out on my own that it wasn't." After a few months of back and forth from GPs and trying to get a referral to a neurologist, I was diagnosed with focal dystonia.

Me: How long did it take from noticing the symptoms to getting a formal diagnosis?

P4: It took about a year or so, I think. I was avoiding a lot of stress; I had an anxiety disorder diagnosed around that time as well.

Me: Oh right. Would you be able to elaborate a little on that? By no means do you have to if you don't wish to, ok? Just to make that clear.

P4: No, I don't mind at all, I've talked about it a lot. I had pretty bad OCD as a child which made a lot of things pretty difficult, you know? The cello was a good therapy for a while but as I got more serious with it, it got quite stressful sometimes.

Me: Did your condition affect the way you practiced at the time?

P4: Oh yes, there's no doubt about that. As I know now, perfectionism is a symptom of dystonia, right? I would get stuck sometimes repeating things and gradually feeling more and more anxious. I couldn't prepare for anything at all really at college until I saw Dr. [redacted] who really helped me get things under control.

Me: Did you get more than one opinion before receiving your diagnosis?

P4: Yes. My GP first and then I found [redacted] online. I consulted two neurologists in the end, one retired and I got passed on. The second one took a while to get back to me with a diagnosis. He knew what he was talking about, and his partner was a musician apparently, so I expect that helped. He suggested that I do therapeutic massage as well as carry on with what I'd been doing with yoga. He wanted me to try Botox and gave me some pills to try, but I really didn't like the idea of that. I don't like taking pills to be honest. I read the booklet that came with them and decided that it wasn't for me. I did some reading about them as well and I freaked myself out, so I left that alone. I still think that was probably the right thing for me. I try and look after my diet anyway, so I talked to a nutritionist friend of mine about things, and she suggested basically that leafy green veg could help so that is all I did on that score. I'm fine with that though.

Me: Interesting. Ok well if we could move it on a little? Could you tell me a little about the retraining strategies you've developed to manage your focal dystonia?

P4: Right, well this is where it gets a little fuzzy, really. My approach I suppose is best summed up as a mix of slow and deliberate. I do a lot of meditation, and I am a part-time yoga instructor as well now. I have found such a lot of comfort over the years, especially when I've been bad with OCD. It wasn't

really a conscious decision to be honest. I basically just carried on with what I was doing before the dystonia, just with more of an objective I suppose. “I was [still] really confused after deciding I needed to retrain myself. I needed a quick fix. I remember being so worried all the time. Obviously, this was counter intuitive.” Over time I realised, “When you think about it, you can’t separate the two things. When I stopped fighting symptoms and started looking after me as a whole person, I begin to feel better. If I feel better then I retrain better.”

Me: Oh right! That’s interesting. So how have meditation and yoga influenced your approach to retraining? Can you share some examples of exercises or techniques you have developed because of them?

P4: I learnt a lot of deep breathing exercises to centre myself when I was younger, way before any dystonia appeared. It really helped my OCD a lot, so I sort of naturally brought that in. I would sit with the cello and do breathing exercises. I do a lot of tense-and-release focused stuff, tensing toes then releasing, trying to really connect with the body. I remember being so upset when I picked up the cello; it was like I had a sick relative or something. I cry pretty easily and feel better when I do, so it was sort of cathartic. Then I began to try to play. It was not good at all, but I felt better when I was playing than not. I could block things out as long as I didn’t use 4 and 5.

Me: So how did you incorporate the yoga?

P4: At the beginning, I would do some yoga stretches for a while and pick up the cello straight after. Then I would get into the breathing. I still do that a lot if I can; I always play better if I’m in the zone. “Doing twenty minutes of it [mindfulness] before my slow exercise work, and there you go. I can play stuff better. It makes a big difference.”

Me: Ok, great, so how did you address the issues with your fourth and fifth fingers? Did you introduce other things as well?

P4: Yeah, so that was phase three, I suppose. I remember just trying to go straight into playing time after time. It was always horrible; if anything, it seemed to get worse. I noticed my thumb would start to hurt almost immediately, tightness in the palm. I saw a masseuse who did [redacted] style massage; she kept finding more tension on my right side than my left. My arms felt better overall. Then I got some simple repertoire from the grade 2 syllabus and began to work at that. I took out all vibrato and took my thumb off the back for a while. I tried to rotate my wrists more and not press the fingers down as much. That was a big eye opener, like a light went on. Things started to get better from there.

Me: That’s very interesting. So, can I ask you, do you follow a structured routine or flexible schedule for your retraining?

P4: It's a bit of both really. I’m pretty good with routines. My partner also helped a lot when I couldn’t work, very supportive. I adjusted my routine based on feedback from my body. Some days flexibility is key; some days I need to get calmer. “I know what I need to work at any one time nowadays. I improve as long as I have my action plan in my head.” And practically, “It’s so hard, but you have to just do it over and over. A bit of contact every day with the instrument, at least. That’s so important, for me at least, to keep motivated.”

Me: Ok, so how did you come up with these strategies. How did you connect the dots?

P4: It sorts of just happened, I think. I didn’t do much research into the whys and what-furs of dystonia. I knew what it was and that I was a typical case. There was trial and error. I talked a lot with [redacted] by e-mail and he seemed to confirm a lot of what I felt as well. I spoke to a few musicians online who had used similar exercises; it made sense. One person said he was completely cured; he’d done some Body Mapping too, which I’m now quite interested in.

Me: So, are there any specific theories that guided your approach to your retraining?

P4: The Body Mapping has opened my eyes more to how we connect with the body. I always felt disconnected when I play. I like learning how it moves. I definitely feel more connected to my body when I play now.

Me: Can you walk me through a typical retraining session or practice routine, how do these elements influence things?

P4: I always start with meditation and positive affirmations, about 20 minutes. If I don't do it I feel it. Then I try to get my hand to stay on the cello without getting tight. I don't play at first, just place and release. Sometimes I don't even get the bow out. I do some position changes,1st to 4th,keeping the fingers in a line. If it feels ok, I do all four fingers, then 4 alone, then 4+3, then 4+3+2, etc. Then scales, keeping it light. I'm always working on keeping things light, even if my vibrato isn't right for now.

Me: Could you tell me a bit about the vibrato not being right?

P4: My vibrato makes me push too hard with the thumb and then the hand doesn't cooperate. I'm still working on this; I've talked a lot with [redacted] about changing or adapting it but I'm not sure how to get past it. It's frustrating, I can't express myself the way I want. I know what helps the fingers to behave, but some days it's still really frustrating.

Me: Right, interesting. So, following on from this then, how effective do you perceive your self-developed retraining strategies to be in managing your dystonia symptoms?

P4: That's hard to answer. I've been on my own with it a lot, so I don't know. I don't talk about it much, it's personal. I have my recipe. I've accepted that things are not the same, but I can play pretty much (as long as it's not too exposed), so it's been successful in that way. I can't say that I'm happy with it though; I still feel like I've been robbed of something. "I do think back a lot. I was so wound up all the time. You don't enjoy it [playing] when you're feeling like cry*p twenty-four seven. It's no wonder I got sick really. Now I can breathe when I play. Even when I can't play, it's in colour again."

Me: Anyway, just to delve a little deeper, can you share any specific examples of improvements you've noticed?

P4: When I'm warmed up and relaxed, my fingers behave, much less curling into the palm, and I can feel the string in the right place again. That's the main one.

Me: Have there been any setbacks or periods of no improvement?

P4: Oh yes. There were weeks where I'd get on a downer. My hand stiff, intonation gone. Worse with worry or stress. Deadlines are still hard. I worry about my students too. I don't want them to get this, so I maybe show that too much. Not all of them know I have dystonia; I tell most it's tendonitis.

Me: Have you been able to regain any skills you thought you had lost?

P4: I'm more relaxed when I play, better posture, definitely better breathing. Vibrato is still a problem, slow and a bit wooden, so confidence there isn't back yet.

Me: Have there been any psychological or emotional effects related to your retraining methods?

P4: Definitely. Patchy overall, but it's taught me patience and acceptance. It's a roller coaster, but I've learned to be less harsh on myself on bad days. Having OCD in the background gave me perspective, but I still get close to the edge sometimes. Now I know what to look out for and I stop sooner. Before, I pushed through, feeling awful most of the time. "When you think about it, you can't separate the two things. When I stopped fighting symptoms and started looking after me as a whole person, I begin to feel better. If I feel better then I retrain better."

Me: So, how do you cope with the emotional highs and lows?

P4: Meditation, always. If I can find some calm, I can get through the day. Once, after a long, good spell, I had a really bad day and almost panicked before a concert. I told myself I didn't care how it went. No big solos, so I tried that mindset. My fingers were all over the place, but I let it go. It was the first time in ages I didn't feel nervous. Liberating, and I keep trying to get that back.

Me: Have you sought psychological support during your retraining, such as therapy or counselling?

P4: During, not really, well, Dr. [redacted], so yes. Invaluable. More guidance than support. I think so much of dystonia is emotional as well as physical; for me it has to be both.

Me: Ok, so moving on to the last part. What challenges have you encountered in implementing your retraining methods?

P4: Knowing what to do and when. Also, for how long. I didn't know if I should be spending hours a day or not. Lots of trial and error. I didn't really have anyone to talk to; I mentioned a few things on the [redacted] group forum, but I always ended up with more questions. Motivation was tough too. Sometimes I wondered why I kept going, but my partner kept encouraging me. Consistency helped, tiny steps daily. "It's so hard, but you have to just do it over and over. A bit of contact every day with the instrument, at least. That's so important, for me at least, to keep motivated." And we really should talk about it more, "We have to be more open about dystonia and talk about it, particularly in orchestras. When you find out that people knew and didn't think to tell you about it, that's makes my blood boil really."

Me: Have you faced any other external obstacles, such as lack of support or resources?

P4: I've been pretty lucky. Online community helps, though I limit what I read, there's a lot of negative stuff too, and I can be a hypochondriac, so I stay away.

Me: What factors would you say have enabled or facilitated the success of your retraining efforts?

P4: Family support, definitely. I know others have a much harder time, especially financially. That's the main thing.

Me: In your opinion, what has made your retraining strategy effective?

P4: Effectiveness depends on what you mean, but consistency and adaptability have been massive. Going at my own pace has been crucial. And keeping the whole-person view front and centre.

Me: If you could give any advice to young musicians or those experiencing dystonia at the moment, what might it be?

P4: Don't panic. Speak to someone or see a doctor. Build an action plan you can actually follow, simple, daily, and kind to yourself. "I know what I need to work at any one time nowadays. I improve as long as I have my action plan in my head."

Me: What unique aspects do you believe are specific to your personal retraining method?

P4: Using Tai Chi as a complementary practice distinguishes my routine. It's not a common choice but has greatly enhanced my coordination and relaxation.

Me: How might your experiences contribute to developing a unified framework for managing musician's dystonia?

P4: Sharing flexible, adaptive strategies rather than rigid programmes. Combining music, mindfulness, and physical techniques is crucial. "When you think about it, you can't separate the two things."

Me: Do you believe a standardized retraining program could be effective, or is individual customization crucial?

P4: A general framework can help, but customization is vital. Everyone's journey is unique.

Me: Is there anything else you would like to share?

P4: Just to emphasise not rushing. Patience and persistence are key to reclaiming one's musical abilities. And I do think back a lot about how I used to be, now I try to breathe when I play; even on the tough days there's colour again.

Me: Do you have any feedback on this interview process or the study in general?

P4: I appreciate the structured yet conversational approach. It allowed me to reflect deeply, which is both helpful and encouraging.

Me: Thank you for your time and valuable insights. Here's what you can expect next in terms of follow-up communication and results sharing.

P4: Thank you. I look forward to seeing how this research can help others facing similar challenges.

P5 Interview

Me: Thank you so much for talking to me. Could you start by telling me a bit about your background as a musician and the instruments you play?

P5: Yes, I'm a violinist. I now play mainly contemporary stuff, less obvious if my hand messes up, although it's been a while since it has, so maybe that's a good sign, right? I started at six and since then I've also picked up the viola. Over the years, I've played with most of the top bands and have done a lot of chamber music.

Me: Great. So, let's talk a little about dystonia. When did you first notice something was off, and how did you identify it as a possible problem like dystonia?

P5: We had a particularly busy concert season in late 2015. Stiffness in my fingers was how it started. I spent hours "warming up" but it didn't seem to work. I put it down to fatigue and stress, as you would, right? When I started to miss notes and fall off the fingerboard, I thought enough was enough. It was like my finger was hesitating, and it got stuck. I couldn't lift it up properly. After about three months of this I finally plucked up the courage to go see someone.

Me: I feel for you. What steps did you take toward finding a solution?

P5: Frustrating is an understatement. I tried several doctors, each offering some different explanation. I was tested for Parkinson's more than once. It was [redacted], a neurologist, who finally diagnosed me. I'd sort of worked it out for myself anyway. I found the [redacted] group online, and it was me to a tee. I followed a lot of the stories on there, and that's when I got really interested in neuroplasticity, I was always interested in neuroscience anyway; if I wasn't a musician I would be a medic, I think. But honestly, "There was no follow-up really. Nothing was really made clear, and I ended up filling in the gaps on my own anyway."

Me: That's great. So, at what point in your retraining did you start developing your own methods?

P5: My methods? I've always used my own ideas, to be honest. I just needed to be sure I was on the right track. I wasn't in a position to spend lots of money going to see [redacted] or [redacted], for example. So, "For me, I don't know. I had to be my own boss; I had no choice. In my situation, there was nothing else to do."

Me: Can you share some details about your methods?

P5: Sure. I suppose what felt most practical to me was combining body-based exercises with mindful work on finger coordination. I began with off-the-instrument finger-lifting, focusing on the third and fourth fingers. Putting the finger down was okay; lifting was the problem. I tried using lolly sticks to splint the fingers, didn't help. That might work on piano, but not violin. A violist friend with dystonia told me to drop it, so I did. Then I got into ideas about muscle chains. You know guitarist [redacted]?

Me: Yep, I've talked with him a bit; I like his book as well.

P5: Well, you know his thoughts then, larger muscles doing the work. I thought, this is the same on the violin; let's try it out. I started by figuring out how to get my whole body to work together. I always practised standing, and my centre of balance sat over the left foot, even sitting in orchestra. So, I centred that up first. Lots of standing and sitting, and I saw a physio for left-hip pain. He helped a lot; I carried on from there. I also started swimming and still do a lot of it.

Me: How did you incorporate your exercises for dystonia into your musical practice?

P5: I started without the violin for a bit. I needed a break, so I didn't play for about six weeks. I "dipped" out the playing and carried on teaching. I didn't do a lot then, I felt pretty down, but I set a date to start again. I took up swimming and was reading a lot about [redacted]'s work. That's when I got into [redacted method] in a serious way. It was nice to focus on something other than "not going wrong" all the time. I also talked to [redacted], who does a lot of [redacted method]; that helped me organise things in my head. In parallel, "I started by just watching how my body reacted in different playing situations. At first, I was quick to criticise myself, but then I realised that simply noticing what happens in my hands or my breath was powerful. It helped me know when to stop or adjust without feeling guilty."

Me: Could you go into a little more detail about what you designed?

P5: I spent time reviewing old recordings. I looked stressed, I didn't smile or breathe. So first, I tried to relax and breathe, going back to basics: scales. It was frustrating; it felt like I hadn't had a break. The left hand was stiff, and I couldn't control the fourth finger at all by then. [redacted] suggested working away from the violin first, which I'm very grateful for. I started doing deep breathing with the fiddle, then added open strings for a while. During that, I realised: fix the rest of the body, then the hand. By then I was doing fewer gigs; no string quartets. I was on a mission. Teaching kept me going, I tried things with students (they must have wondered!). I did lots of full-body work: weight transfer, reconnecting with my body, [redacted method] lessons, jaw release (I'm a tooth grinder). I did lots of open strings, then gradually put the left hand back on. I focused on releasing the thumb, using forearm rotation, and getting the shoulder and elbow to let go. I did slow scales, no vibrato at first, then very light fingering and a free thumb as I added simple repertoire.

Me: That sounds like a journey and a half. Did you encounter any obstacles during the process?

P5: Many. It's slow and monotonous sometimes, tiny gains. Lots of intense frustration. I videoed myself a lot; sometimes I could see progress I couldn't feel.

Me: How long did it take before you started seeing significant results?

P5: Probably a few weeks after I picked up the violin again. The [redacted method] really helped. I was doing lots of finger-pattern work, but the whole-body feeling improved first. The hand took maybe six months to feel meaningfully better. I was back to wedding gigs and low-pressure stuff by then.

Me: Do you remember at what point you went back to playing in public? What was the experience like?

P5: I didn't tell anyone about the dystonia, so no one could tell. I only played second, never first. I chose repertoire with no exposed solos. People thought I'd had tendonitis, so I could "get away" with some things. The finger still wasn't great, but I felt real changes in technique and, importantly, less pressure.

Me: So how do you feel today? What effect has your retraining had on your playing and you as a musician?

P5: Maybe I'm less anxious overall. I don't worry as much about what people think. I had an injury, right? So, the pressure is down a notch.

Me: What about your thoughts on your retraining and outcomes?

P5: I'm more aware of everything, better alignment, posture, not pressing, using gravity. The fourth finger is still ongoing; I adapt fingerings and try not to use 4 when I can avoid it. But I can play; I don't

fall off with the third finger anymore, and I know what's going on. I know when to stop for a bit. I can enjoy playing more instead of worrying I'll fall off the fingerboard.

Me: How has this journey altered your perspective on playing and teaching?

P5: Teaching, hugely. I tried lots of things with students and still do. I listen for problems and look closely at movement; some patterns are pretty fixed. I'm less of an a**hole at work, that's for sure. You can't be pompous and be dystonic, right? I listen more, definitely.

Me: That's great, really encouraging. What message would you give to musicians facing similar challenges?

P5: My advice would be to try [redacted method]; it really helps. And listen to your body sooner. Be vigilant when things don't feel right, see a doctor when you can, don't leave it to chance.

Me: As a final thought, do you think you could have lowered your risk if you'd known about dystonia beforehand?

P5: Hard to say. Maybe. I think I had good training. In hindsight I'd spend more time relaxing, less time hammering notes, more time thinking. More support generally from someone who knows musicians well would have helped.

Me: Earlier you mentioned the clinical side, did you feel supported after diagnosis?

P5: Not really. I got the label and then mostly silence. "There was no follow-up really. Nothing was really made clear, and I ended up filling in the gaps on my own anyway."

Me: And in the absence of that support, what kept you moving forward?

P5: Ultimately, it was on me. "For me, I don't know. I had to be my own boss; I had no choice. In my situation, there was nothing else to do." So, I kept observing, adjusting, and building from small wins, "I started by just watching how my body reacted in different playing situations. At first, I was quick to criticise myself, but then I realised that simply noticing what happens in my hands or my breath was powerful. It helped me know when to stop or adjust without feeling guilty."

Me: Thank you for sharing your insights, [redacted]. Your story is sure to inspire many others in similar situations.

P5: Thank you for having me.

P6 Interview

Me: Firstly, thank you so much for talking to me. Could you start by telling me a bit about your background as a musician and the instruments you play?

P6: Hi, yes, ok then. Well, I'm primarily a guitarist, started playing when I was about eight. Fairly usual story, I suppose, was quite gifted as a kid. My parents got me lessons until I went to [redacted] junior college to study. I spent a lot of time with [redacted], who actually went on to develop dystonia himself at some point. He's still teaching there. I have always wondered about that to be honest; I reached out a few times but got nothing back.

Me: Great. So, let's talk a little about your dystonia. When did you first notice something was off, and how did you identify it as a possible problem like dystonia?

P6: 2016 was the first "bout," I suppose you could say. I was prepping for a tour and beginning to have some really odd experiences when I was playing. A lot of guitarists have curling fingers, right? For me it was the opposite. My third and fourth fingers were sticking out. They'd lock up or twitch. I'd get a weird tremor in my thumb at the same time. I'd had some elbow pain for a while, so I assumed it was related,

maybe something trapped. I wore a glove and put splints over the knuckles. I didn't know much about splinting; I'd read it might help but didn't connect the dots. I'd heard of dystonia, but the pain in my forearm made me dismiss it. I figured it couldn't be dystonia. Fast-forward about three months, I still did the tour somehow: eight solo concerts.

Me: Wow, that's very impressive, especially considering how you were experiencing things like you were.

P6: Yep. To be honest I had to get through, contracts, ticket sales, all that. Traumatic though. I was on my own most of the time, trying to fix things and making them worse, freaking out. I slept badly the whole trip and came home with the mother of colds.

Me: So how did you finally achieve a diagnosis? Was it around this time?

P6: Not yet. For a while I obsessed over elbow inflammation, ice packs, hot baths, ibuprofen on repeat. I finally got referred to physio for my elbow. He was a lifesaver, suggested I get assessed again. He'd treated a few musicians and was pretty clued up on focal dystonia, talked it through with me.

Me: Right, so that was the trigger to go back to the doctor.

P6: Yes. The elbow got good after lots of sessions, but the hand stayed the same. I was referred to neurology at [redacted] and had an EMG. Playing with needles in my arm,horrible,but that sealed it. I was offered Botox or trihexyphenidyl.

Me: How did that go?

P6: Botox wasn't for me. I tried the pills for about three months. They helped the thumb tremor, and I could plant better, but the forearm was the same and my fingers still misbehaved. I was dizzy a lot, so I tapered off.

Me: That must have been quite an ordeal. How were you coping mentally?

P6: Pretty well, all things considered, but I was on my own again after that. I was discharged from neurology pretty quickly. I found [redacted] online via [redacted]. I'd read [redacted]'s book, which made a lot of sense, so I went down that route. I knew I wasn't ok, but I also knew I would be ok. There were dark days; I bored a few friends to death. I'm obsessive, but I never considered quitting. I had a decent private studio, so I wasn't going to starve. Looking back, "I call it ego death. It was really like mourning a real death, and once I got over old 'me', things started to work out. It was a necessary process for me; I needed to do it a long time ago."

Me: Was it around this point you started developing your own methods for retraining?

P6: Yes. I've always been a DIY guy. Even before the diagnosis, I was experimenting, two gloves with splints attached are still in a drawer. I'm pragmatic; I'd rather be proactive than reactive. And early on I realized, "If you try to work to a return date it just gets more and more stressful. You have to let go time limits. You can't improve under duress."

Me: Could you share some details about your methods?

P6: Most of it revolves around muscle memory and coordination. I struggled to get the third and fourth fingers to move independently, even off the guitar. First thing, I rigged a splint for the fourth so I could plant 1–2–3 without reaction. I had a sequence of independence drills. Do you know the Giuliani exercises? Lots of alternating patterns, lift/plant. I did loads of very slow Giuliani daily for weeks. TV on, hands working. No overthinking, just getting fingers to stay where I wanted. And as odd as it sounds, in that early phase, "I was just doing everything slowly, by myself. I probably spent a year really going slow at things. It seemed like the right thing to do, oh, and I was also tying fingers together with lollipop sticks and shoelaces." After a long stretch of that, I applied [redacted] ideas: hanging from the arm, lowering the guitar angle, slight outward push, more grounded. I kept changing footstool positions, staying flexible helped me find a calmer spot for the fingers. I'm not pushing the repertoire now, and I'm fine with that.

Me: How does this work look in your practice sessions?

P6: Honestly, most days the drills are the session. If I feel good, I add repertoire. I also layered in mental work, “I do mindfulness and mental imagery work first. Then, when I do the practical session afterwards, I brain-spot together with the exercises which focuses everything together.”

Me: Specific obstacles during retraining?

P6: Plenty. The daily grind. Some days I’m not mentally up for it; it can feel isolating. I need my mental gymnastics. I get distracted when I’m low. Ruminating about lost opportunities is bad for me, anger still crops up. And, frankly, “It’s simple getting confused about what to do or which way to go next. It can be exhausting until it’s sorted.”

Me: What do you do when you feel that anger?

P6: Varies. Sometimes I do something else and forget the guitar, that can help the fingers, oddly. A day or two off can reset things. Breathing exercises help; sometimes I need TV-level distraction. The trick is not to spiral into feeling useless.

Me: How long before you saw notable progress?

P6: A few months before it felt meaningful. The [redacted] approach was easy to understand, which helped early on. I had to do a couple of recitals in that period, wasn’t great. But I’ve always felt I could get over dystonia. Sometimes now I play and forget the fingers, that’s huge. And more recently, “I can observe myself as I play now without worrying what anyone else thinks. When I was at rock bottom I could see what I needed to do without freaking out.”

Me: Reflecting on playing in public again then, what was that like?

P6: Pretty awful at the time, just surviving. I found shortcuts, missed chords or passages, sometimes skipped pieces. I had to change headspace, stop obsessing over mistakes or a non-cooperative hand. I shifted repertoire, less complex, more contemporary to mask issues. It’s still a balancing act. Also, I learned not to set arbitrary deadlines for “being back”, that only cranked up pressure. You can’t improve under duress.

Me: And how do you feel today? What impact has retraining had on your playing and identity?

P6: I’m a different player. Mentally I’m in a good place, more introspective, less showy. I warm up a lot more, otherwise problems show up quickly. I’m more self-aware and mindful. I feel good playing, but musically there’s a drop-off, I don’t feel as expressive, and dexterity isn’t what it was. Still, I value playing more and can enjoy it with time to prepare.

Me: Overall thoughts on your retraining and outcomes?

P6: Comparisons are hard. I’m more attuned to physical needs and limits. Fingers are still a work in progress, adapted fingerings, avoid heavy use of affected digits. But I can play; I feel good sometimes; chamber music is joyful again and nobody comments on my issues. I also know when to step back or say no, couldn’t do that before. “You always stick at it until it comes right.”

Me: How has this journey changed your approach to playing and teaching?

P6: A lot. Teaching especially, I pass on body mechanics and being in tune with your physical state. I focus on movement and ergonomics, and I truly listen to students’ concerns. I can spot bad practice habits early and address over-detailing. Being humbled made that possible. And in daily work, I try to keep timelines out of it and trust the process.

Me: What message would you give to young musicians and those facing similar challenges?

P6: Listen to your body. I'd recommend the Alexander Technique or anything that builds body awareness. Your body gives signals before things get major. Don't be afraid to ask for help, and don't be afraid to talk about it. Also, "If you try to work to a return date it just gets more and more stressful. You have to let go time limits. You can't improve under duress."

Me: Finally, is there anything you would've done differently if you'd known about dystonia earlier?

P6: More relaxation, maybe anatomy classes. Definitely fewer frantic practice sessions. I'd have pushed teachers harder when pain showed up. A musician-aware support system would've helped. I don't know if I could've avoided dystonia, but earlier awareness might've sped up getting help.

Me: Thank you so much for sharing your insight. It's been great, and really interesting to hear.

P6: Thank you for having me. I'm grateful to share my story and hopefully help others feel less alone in their journey.

P7 Interview

Me: Thank you for talking to me today, P7. To start, can you tell me about your background as a flautist and a bit about your musical journey in music?

P7: Thanks, nice to talk to you as well. Ok, so I've been playing the flute since I was about 10; I played recorder to a fairly good standard before that. I did quite a few competitions as a child. I then met [redacted] after a concert with the [redacted] and I played recorder for him. He suggested that I try the clarinet, which I did for a while, but I never really gelled with the sound. I've always liked the sound of the flute, and my parents got me some lessons and from there I ended up at [redacted] and finally at [redacted] conservatoire studying with [redacted]. She was very difficult to please; I remember always feeling like I was walking on eggshells, and she was away a lot too, which added to the tension. I was always sent away with loads of homework to do, and to be honest, I found it really stressful. It did improve my skills quite a bit, but I can't say I enjoyed playing for her. There were a few other students of hers who had problems too, some worse than my own struggles. I stuck it out though, everything seemed to be working out well, I was getting auditions, playing a lot of freelance gigs with [redacted] and enjoying that part. It was maybe when I was 26 or so that I started noticing some strange problems in my left hand, though. I had absolutely no idea what it was, and neither did any of my colleagues, to be honest. My teacher didn't know either. I went through all these tests, but none of them showed anything. The uncertainty was really unsettling and left me questioning everything I'd worked so hard for. "It made me feel so low. The whole experience was horrible for me. I couldn't sleep, I was losing all my work, and my hand wasn't working properly. I wanted to run and hide, let alone confront it."

Me: Did you see a neurologist at that point?

P7: Oh no, no, no. That wasn't even suggested. This was back in 2010, nobody suggested that. I went to an orthopaedic hand specialist in [redacted] and did lots of tests. He thought it was maybe an ulnar nerve entrapment or something like that. I had some steroid injections for a while, ultrasound, that sort of thing. Nothing helped at all. I did physio which did help my neck quite a lot. I used to get some neck pain, but that was as far as it went. From there though, things got quite a bit worse; I wasn't able to really play at all, and I ended up actually giving up playing for about two years. I was still teaching, but I wasn't playing.

Me: I'm sorry to hear about that.

P7: I actually sold my flutes at one point.

Me: Oh wow. So, you were thinking of doing other things apart from being a musician?

P7: Oh yes, most definitely. I was considering all sorts of things at the time. I was so disappointed, but I didn't want to only teach music, not that I have anything against teaching, I just felt like a fraud, really. I still do a lot of the time; I feel pretty bad a lot of the time, to be honest. I've always had that tendency

though. Low mood and all that. I think it's part of dystonia in my opinion. It was always funny, I felt so much better when I was performing popular stuff by the way. It was always a release, you know.

Me: Did you always play more popular music? Could you explain a little more about the "release"? Why do you think that you feel different when you're playing popular music?

P7: Well, I've always been into playing Irish music. My whole family played something; it was a great social thing. I played recorder a lot in gigs in my hometown; I loved it. It was really only when I was 15 or so that I really went on with the classical stuff. I've always played though.

Me: Do you have an opinion as to why you feel different playing popular stuff?

P7: It's the whole thing, I suppose. It can be frustrating to be involved with things that aren't the same technical or musical quality. There are many amateur musicians about, there are amazing Irish musicians, though. I still enjoy listening to it as well. The dystonia hasn't helped the playing side, obviously. And honestly, "We're conditioned to compete and when you can't, you realise it's part of the problem."

Me: Right. Ok, well can we discuss your early experiences with focal dystonia? When did you first notice something was wrong, how did it present itself?

P7: During 2009 I began to notice my left-hand fourth finger would stick up and straighten out after playing for a while. It was really strange. My hand would get really stiff and slow, playing anything quick. It was early 2010 that it worsened; it became clear it was getting worse. A physio friend recommended that I see my GP and get a referral. That was a really difficult time. We had some family issues as well. I finally saw a neuro[logits] who told me what it was, but then she lost interest. I didn't want Botox, so she suggested I do some physio or something. That was it. As I often say now, "I finally saw a neuro [logits] who told me what it was, but then she lost interest. I didn't want Botox, so she suggested I do some physio or something. That was it." And week to week, "Every week I had more questions than answers. It was the lack of clarity, and I really felt underwhelmed by my progress. I was always suggesting things and I knew that this was a real problem."

Me: Oh right. So, when did you decide to go back to the flute? What made you decide to go back? Was there a particular event?

P7: I just felt empty, I suppose. I didn't want to just forget my music. I saw a piece online about [redacted] and that really got me thinking. I also have a colleague who had similar problems. So, I started trying things out on my own, changing positions and stuff like that. Nothing really worked at first, to be honest. I almost gave up again, but I read about [redacted]; oh, and during the same period, I spoke to my colleague who'd actually been to see [redacted], and she was really enthusiastic. So, I met with her a few times in [redacted] and she basically showed me what she'd done. I didn't have the funds at the time to go as well, so I spoke to her when I could and went off on my own for a while. That's when I decided to look into things properly. I started doing a lot of my own research, and that's when I started to look into other things, some didn't help, some did.

Me: Can you elaborate on those methods?

P7: I was really interested in how my past might have been part of the problem. I've had depression on and off for as long as I can remember. I'm quite an anxious person generally, not so much nowadays, but as a youngster, definitely. At college I really struggled with stage fright at times. I'd freeze. It felt like my brain and body weren't talking. I remember a recital where I had a memory slip near the beginning; I freaked out. I couldn't get the fourth finger down and everything fell apart. I even thought I'd had a seizure. So, when I began retraining, I visualised those images and memories. I use mindfulness a lot, breathing techniques and body scanning. I focused on how I was reacting emotionally when I was playing. That opened my eyes: so many negative reactions and self-comments. I monitored my internal dialogue, The Inner Game of Music by [redacted] was where I got that from. And I've added another piece that helps me integrate mind and body: "If I don't brain-spot first then I get less out of a session. It's definitely a combination of the two but brain-spotting is a powerful thing for me." If I feel grounded physically before I play, I'm better.

I was also doing a lot of exercises my colleague from [redacted] had shown me, mirroring movements with the good hand. I realised I was moving a lot more than I thought in my left hand. So, I aimed for less finger movement and a lighter touch on the key; I used the wrist a little more and lifted as little as possible. That's what I've kept doing, removing excess movement and making everything small and efficient. Along the way, "I realised for myself early on that I couldn't tell how hard I was pressing my fourth finger and when I was releasing. When you start from minimal touch then you feel the key again which is what I couldn't do."

Me: Great. So how did these exercises transfer to your musical practice?

P7: I took a break from the flute for quite a while; I was just so upset and frustrated. I came back after maybe six months: simple scales, trying to regain some fluidity and feel for it again. I like the Inner Game approach, so I kept turning down the inner monologue. I do breathe exercises, alternate nostril breathing, chakra breathing, all of that. That's always helped me a lot, and I brain-spot before I start when I can, because it sets the tone for the session.

Me: Ok, that's great. So, can you tell me a little more about the exercises you use as well, specifically for the fingers?

P7: I tried a lot, rebalancing muscle groups, extensor activation, thumb exercises, but none of that really worked. What I found through physio was that I was putting a lot of weight through my right side. Maybe subconsciously you feel as if you might fall when playing. I did a lot of massage and fascia release. That helped a lot. I worked hard on balanced posture. I watched recordings of past performances; I always looked stiff. I practise with a mirror now; I can see things I couldn't before.

Me: Right, so what are you looking for or regulating, specifically?

P7: Posture, obviously, and I find that if I look at my left hand I can often control movements better. If I'm stressed or haven't slept well I can see it in my body. It's interesting how it changes, like I have a stress default sometimes. I've had some really good periods where I can move pretty well again without too many weird finger curls or jut-outs, but it's still a bit hit or miss. I can feel it more now and as long as I don't lift or push too much I can sort of control it. Nobody sees anything anyway.

Me: That sounds very positive. So how long did it take before you recognised substantial improvement?

P7: About three months after I resumed playing, I think. I did my first solo concert last month, actually.

Me: What was it like returning to the stage?

P7: Very low key, a showcase for local community colleges. I was very, very nervous. Some of it went surprisingly well; some not so well. I had more difficulty with playful stuff. I had control for some of the time, the beginning was awful, but I was ok with it, I suppose. I'm by no means ready yet to fully go back, but I'm happy to be where I am for now.

Me: Right, so how do you feel now, and how has your retraining reshaped your musical identity?

P7: Musical identity is tricky. I have a deeper appreciation for music-making, I suppose. I've been forced to let go of some insecurities. I was always pretty highly strung, maybe many musicians are. I'm more mindful and more in tune with things in general. I actually feel considerably better mentally than maybe I did before, perhaps because I'm in therapy as well. I've had some rough family stuff this year. My focus has changed somewhat. Above all, "I don't play for everyone else now, I play for me. I know my limits and I'm ok with saying no to things."

Me: Ok. So how do you reflect on your retraining outcomes?

P7: It's been worthwhile. I'm making progress, even if I'm not as technically focused as before. I wouldn't say I've lowered my standards, just shifted priorities. My awareness is heightened. I've adapted my playing style and changed stress-inducing habits. My fourth finger still isn't right; I avoid some things, which is frustrating. But I've gained some control and learned to be more adaptable.

Me: You mentioned your teaching schedule before we started. How has all this influenced your approach to teaching?

P7: Definitely changed. I'm focused on setup and awareness of the body, relaxation and lowering stress are crucial. I find I'm counselling more than before; sometimes that's difficult, but important. I remember how tense and worry I was and wonder why it wasn't picked up on more. And with students, clarity helps, because in my own experience, "Every week I had more questions than answers. It was the lack of clarity, and I really felt underwhelmed by my progress. I was always suggesting things and I knew that this was a real problem."

Me: Ok, great, thank you so much. To wrap up, what advice would you give to other musicians, particularly younger ones, who may be dealing with similar challenges?

P7: Be aware of your body. Don't suffer in silence. Get things checked out if you're worried, don't wait, and don't take any prisoners if you don't get answers. Have courage; we're often expected to listen and not question, but advocate for yourself. Taking a step back can help. Patience and perseverance are key. Stand up for yourself and listen to yourself if things feel wrong. "We're conditioned to compete and when you can't, you realise it's part of the problem."

Me: Finally, if you could go back and change anything to potentially reduce your risk of developing dystonia, what would you do differently?

P7: I'm not sure you can reduce the chances entirely. But being open about how you feel, seeing a masseuse, not obsessing, practising little and often, those would help. Don't be bullied into doing things; if it feels wrong, don't go there, or get a second opinion. Get a physio, too.

Me: Right, well thank you so much for sharing your journey and insights, P7. Your story is so interesting. It's been really nice to hear from you.

P7: Ah, thank you for the opportunity to share. It feels nice to talk. I hope I can help in some way.

P8 Interview

Me: Great, yeah, go for it, just tell me a little bit about yourself and how it all started for you.

P8: Okay, so I'm a guitarist, and I was first diagnosed in 2022, but I noticed symptoms around 2018. It showed up any time I needed the fourth finger: it would lock straight out and was very hard to control in certain parts of the neck. It was painless, as many people with dystonia report. I first worked with a physical therapist who thought it was trigger finger; we did a bunch of exercises. As became a theme, something seemed to work for about a week, then it stopped. Same with a physiotherapist. Then an orthopaedic surgeon did X-rays and found nothing structurally wrong. Nobody had suggested dystonia by this point; it wasn't on the table.

Me: Just out of interest, had you heard of focal dystonia before this?

P8: Yes, a long time ago. A student of mine was afraid of it; it seemed foreign to me then. Years later I wondered if this was dystonia and started looking into it. I saw a video of [redacted] talking with [redacted] (author of [redacted] and [redacted]), and the symptoms described were exactly what I felt. I'd been thrown off by "involuntary spasms" in definitions, assuming it would happen all day. But I was getting task-specific involuntary contractions, absurdly specific to the instrument, when I tried to play.

Me: Is it very task-specific for you, any effects on daily activities?

P8: A little with typing, minor. I suspect some involvement in my right/picking hand; some days there's a similar lack of control in the forearm. Writing can fatigue the forearm quickly on certain days. Sometimes when walking, the fingers curl. But mostly it's task-specific.

Me: How did you actually get your diagnosis, was it formal?

P8: Not formal. I purchased [redacted]'s book and became convinced; then I worked with one of [redacted]'s therapists who confirmed it informally. That also pushed a mindset shift for me: "You treat the cause not the symptom. We should do the same with all illnesses, I think."

Me: When you started working with that therapist, what did you do? Straight into techniques like brain-spotting?

P8: Before the therapist, I followed the book. First was an atonement repair exercise, systematically noticing sensations, tightness, instability, and any emotional reactions. Then "zero state," getting in touch with the centre of gravity around the hip area, feeling stability and confidence. Doing that while playing sometimes eased symptoms. The main feature was brain-spotting. It's hard to quantify, but it helped reduce things like breathlessness and chest tightness when teaching and playing at the same time. I'll admit, "I was always very sceptical of anything like that [brain-spotting]. I wish I'd understood why it's important to look inwards at yourself, and work on yourself. Otherwise, you're just treating symptoms." Over time I learned, "If I don't brain-spot first then I get less out of a session. It's definitely a combination of the two but brain-spotting is a powerful thing for me."

Me: How were you coping mentally before that?

P8: Pretty awful. I tried a deep-tissue/Rolfing-style therapy recommended by a teacher, the supposed "be all and end all." After four sessions with no change, I felt I had nothing else. It was baffling, everyone seemed to be treating pain, but I had no pain. The mental strain was heavy: I've practised for years; now I can't do what I love. I eventually realised, "When you learn to deal with your stress ,then you can deal with the dystonia. The two walk hand in hand in my opinion."

Me: There's a big claim of a "cure" in some approaches. How did you respond to that?

P8: Mixed. I was desperate and optimistic. The timeline (e.g., ~25 weeks) was tough; when that didn't happen, it stung. I still believe in the process because I feel meaningful changes, whole-body relaxation, easier breathing, but timetables can mislead. I had to accept, "You have to let go of any expectations of getting back [to playing] quickly. The goalposts always need to be nearer, small steps and expect the ups and downs all the time."

Me: You mentioned other approaches too. Anything you've kept?

P8: Yes. Alongside brain-spotting, I work with [redacted] on an approach centred on "physical logic", retraining the brain to treat the guitar like any object so your system self-organises to healthy alignment, rather than isolated, unnatural motions (like reaching the pinkie alone). It's practical and has helped. But if I focus only on mechanics and ignore emotional/mental state, results dip. My view now: combine something physical that shows healthy movement with something psychological that rebuilds a healthy relationship to music, the instrument, and myself. I also went deeper into somatic: "I spent six months or so studying Moshe's, 'The Feldenkrais Teaching by Handling Method'. We need to wake up all the circuitry before we start to play so that we can really feel movements when we're working on them." Beyond that, "Trying new things all the time just keeps me fresh. Even if something works I'll keep mixing it up. I don't give the dystonia time to catch up anymore."

Me: What does a good practice session look like now?

P8: If I'm dotting the i's and crossing the t's: start with a flow/grounding exercise (I often hold awareness in the chest where tightness used to spike, feel warmth/steadiness), then brain-spot. At the instrument, I check "blueprints": neutral finger curvature (neither straight nor overly curled), supported thumb, forearm continuity, avoid excessive wrist bend, and use fingers as a unit rather than isolated reaching. I sometimes map movements on everyday objects first, then translate to the guitar. Sessions are short and curiosity-driven.

Me: And when a session isn't going well?

P8: These days the physical range between “good” and “bad” is small. What stops me is the mental spiral: I don’t sound good; I’m not creative; maybe none of this will work. If that starts, I stop or switch tasks. My mindset is, “If A plus B plus C equals Z, then so be it. I will find a way through it though.”

Me: Do you practise daily? How do you stay motivated?

P8: I don’t force daily practice. Not playing has been healthy mentally. I read and write more. If I happen to pick up the instrument, it’s more fun. The big dread is finishing album solos, composed lines I can’t currently execute; that’s the most taxing mental block. I improvise or adapt (three-finger lines, tapping) to get through when needed.

Me: Performing, are you still gigging?

P8: I haven’t gigged since [redacted] 2023. I could manage a set with my own band if needed; it just hasn’t been the priority while recording. For composed solos I can’t play as written, I improvise and get through it.

Me: What impact has dystonia had on your identity?

P8: It showed me I can’t hinge everything on being a musician. I’m more present in relationships and I slow down more. I’m reading more, doing transcription/business work. Stripped of the physical struggle, there are positives. “I don’t play for everyone else now, I play for me. I know my limits and I’m ok with saying no to things.”

Me: How has it influenced your teaching?

P8: Lots of good changes. I spot unhealthy pushing sooner (negative self-talk, jaw clenching, bent wrists, isolated finger reaching). I emphasise ergonomics, whole-unit movement, pacing, and encouragement, helping students prioritise what they enjoy. The guiding idea remains: “You treat the cause not the symptom.”

Me: Advice for younger musicians or those facing early signs?

P8: Be ready to learn the “obvious” once you’re ready to accept it. Don’t impose ego on the music, listen to what you genuinely want to hear. Combine physical and psychological work; ditch rigid timelines. Regulate stress: “When you learn to deal with your stress ,then you can deal with the dystonia. The two walk hand in hand in my opinion.”

Me: In your training, did you get any health/awareness guidance, anything that might have helped you avoid or recognise dystonia earlier?

P8: No, and I wish I had. Most teachers were musically supportive, but there wasn’t real discussion about health, awareness, or risk. Some tried to fit students into a box, play it this way or it’s “wrong.” Clearer frameworks for body use, load management, and mental skills would have helped.

Me: If you could change anything pre-dystonia to lower risk, what would it be?

P8: I’m not sure I could have prevented it, origins are complex. I’d have trusted my gut more, valued my own musical voice, refused to be boxed in, and built health education into training. Crucially, “You have to let go of any expectations of getting back [to playing] quickly. The goalposts always need to be nearer, small steps and expect the ups and downs all the time.”

Me: Any final thoughts?

P8: I hope we can get musicians closer to joined-up guidance so we’re not “swinging wildly” to figure out dystonia. For me it’s layered: regulate stress; prime the system somatically; map healthy mechanics; then play and iterate. And if that means many ingredients, so be it: “If A plus B plus C equals Z, then so be it. I will find a way through it though.”

P9 Interview

ME: Okay, well, thank you very much for talking to me once again. And first of all, could you just give me a very brief background of yourself as a musician and the instruments you play?

P9: I started as a very young girl on piano, but I didn't like my piano teacher. I would start making stuff up and it would make her mad instead of her saying that maybe I should get into jazz, which is what I did later in life. Then I started on the tuba in seventh grade and loved it. It was like my salvation, you know, it really was. I went to [redacted] for music, a very good school for jazz in [redacted]. There was a lot of stress there because I was one of very few women and certainly the only tuba player. I'm still kind of the only tuba player. There are some fabulous female tuba players now, and I'm so happy about that, but I was kind of a trailblazer at the time.

My real passion was singing, but I was very shy and had a lot of performance anxiety. Over time I mustered up my courage and started singing as well. I wanted to showcase the tuba in something other than a classical situation and to show its versatility in other idioms. I did quite a few gigs, mostly singing, and then played in a brass quintet. I didn't really blend the two until my recent CD, which I'm working on right now.

I always suffered from crippling performance anxiety, but I still did it anyway, feel the fear, do it anyway. That's what I teach my students.

About 20 years ago, I started exhibiting these weird symptoms: I couldn't control my vibrato. In jazz, you want to sing with a nice straight tone, but this vibrato started happening, and it wasn't a vibrato at all. I recorded my first CD and the recording engineer kept saying, "no vibrato." I was trying not to sing with vibrato, but I couldn't seem to stop it. Take after taking, and the recording engineer treated me not great as a result. I can understand his frustration; I didn't know what was happening. I continued to have this weird shake. Then I stopped playing altogether about seven years ago because of life circumstances, and got back into it five years ago, right during the pandemic, and the shake was awful.

I spoke with a couple of musicians in [redacted] who started talking to me, and I thought I'd better see a neurologist. It was over video, and they just said, "oh, you have dystonia." There was no "I'm sorry to tell you," no sugar-coating at all. The clinician was talking really fast with a thick accent; I had to keep asking her to slow down. I could only see her eyes through the screen. It was awful. I was treated so badly by that neurologist; I eventually fired him. He had his assistant go through everything. It felt like he didn't care, no discussion of options. Then he wanted me to come in, and I did two [redacted] injections, but it almost permanently damaged my embouchure. I still have a little bit of drooling because I think he put in too much.

And honestly, that dismissal still stings. He just said to do something else. I thought to myself, "get me out of here." It's humiliating, you know. To them, it's like playing is a hobby. They suggest you do something else and stop complaining.

ME: Was that the first thing you were offered? Did they offer other alternatives to you? Do you remember what they said at the time?

P9: They offered [redacted] right away and then suggested pills. As you know, the pills don't work for this, and they made me feel crazy. He didn't check my medical file: I have asthma, and propranolol with asthma is a big no-no. I was riding my bike full tilt in [redacted] and thank God I had an inhaler with me. I had to do multiple puffs just to breathe so I could get home. I went to the pharmacy, and the pharmacist told me I shouldn't be on that drug.

ME: Was there any follow-up after that?

P9: The nurse practitioner said, "if you can just get through the bad symptoms." I don't remember the name of that med, something like Artane, and it makes you feel awful. It didn't do anything for the dystonia. They should use it for something else, but it certainly doesn't work for dystonia.

I met a friend who had deep brain stimulation at [redacted], where they're doing studies on musicians with focal dystonia, DBS for hand dystonia. It worked for him: he couldn't even hold his saxophone; his

hand would twist if he went near it. After DBS, he recorded a CD called [redacted], a beautiful piece about his brain surgery and the emotional trauma of being a renowned jazz saxophonist in [redacted] to not being able to play to undergoing surgery.

He helped get me down there. They did all the neurological studies, none of which my neurologist had done with me, touch-your-nose, heel-to-toe, etc. I couldn't do heel-to-toe; my feet buckled. They had me play and sing even though I said I couldn't. They looked at each other and said, "well, tricky to treat." I was ineligible for the study because they can't do DBS for embouchure dystonia, only for hand dystonia. It cost thousands of dollars, and I was treated poorly because I was from [redacted], and it was during COVID. They showed up in hazmat suits. It was absurd. Anyway.

I went back to [redacted], joined a [redacted] group for musicians with focal dystonia, and people kept talking about brain-spotting. I went to a musician's clinic in [redacted], and they put me on CBD oil, which has helped the hand tremors, I also have a bit of essential tremor. That's been helpful, and I take it regularly. Then I started brain-spotting.

Now, it hasn't fixed everything, I am doing another CD, but it's taken after taking to get the shake out. Before brain-spotting, I couldn't touch my nose with my left hand, I'd land on my upper lip every time and do a wiggle. Now I can, with only a little intention tremor. I can also walk a straight line, heel-to-toe.

ME: So, is the intention tremor on your left side?

P9: Yes. Everything seems to be on the left side.

ME: Are you familiar with brain-spotting?

P9: I am. I know quite a bit, and the people who do it.

ME: Was that recommended to you, or did you come across it in the [redacted] group?

P9: I found it in the [redacted] group and called the [redacted] brain-spotting society. They were fantastic and gave me a list of therapists in [redacted]. Here, you have to be a licensed clinician and then certify in brain-spotting. These aren't "she-she-la-la" folks claiming to heal you with magic. There are plenty of quacks out there taking advantage of desperate people, I even encountered one in that same [redacted] group, someone who said he'd teach me to practice properly. He turned abusive, "did I tell you to keep playing?", really nasty. I blocked him out.

ME: That sounds abusive. Do you think that affected your subsequent experiences with brain-spotting?

P9: No. He wasn't a brain-spotting therapist, just quackery. Brain-spotting itself has been exceptionally helpful to me.

ME: Could you walk me through how you approach your brain-spotting? How do you incorporate it with playing?

P9: I'm still experimenting. I'm doing brain-spotting now with a psychiatrist who specializes in it and trains other therapists in [redacted]. I listen to bilateral/EMDR-style music that pans left-right, right-left, I often "see" a figure eight. Then I find a spot in the room where I feel activated, depending on what we're working on. I've worked on my hands; for example, I used pointers on my hands to target spots that go dystonic. My right hand will be immobilized for six weeks due to surgery, so I'm trying to get the left, my dystonic hand, more functional. It's so spazzy; I don't quite know how I'm going to manage.

It honestly feels like an entity, my brain says, "I'm going to do this," and the dystonia goes, "No, you're not." Often, when I go deep into brain-spotting, my head starts to move, and my hands shake; sometimes my whole body shakes for the whole 40 minutes. Then I come out of it. Lately, I go really deep with eyes closed, almost like sleeping, but not, and I just let the process happen.

ME: Almost like a hypnotic state.

P9: Yeah, I'd say so.

ME: Do you apply that directly to playing?

P9: Not really, not yet. I tried practicing with EMDR music in the background; it's a trip, hearing one thing and playing another. I don't quite know how to incorporate it into actual practice, and I'm almost afraid to, worried it'll be "another thing that doesn't work," and my brain will decide it doesn't.

That said, when things do line up, I can tell when I'm going in the right direction. I think, why didn't I always do this? You know? I've learned to enjoy those moments; it's managing the ups and downs that is hard. And linked to that, I feel a lot more confident in my ability to recover when I don't focus on what's not working, more on the small wins over time.

ME: If it's working and you feel more control, you'll want to stay in that state, right?

P9: Exactly. I don't want to mess it up. I did apply some things in the studio: I was pushing really hard on this side of my neck to get sound out. I was told by a voice clinic in [redacted] to stand on a strap and pull up to engage my core and breathe differently. I know how to breathe, I'm a tuba player. Singing isn't the same as tuba playing, but you still need subglottal pressure for vocal fold vibration, and air pressure for lip vibration on the horn. Nothing seems to work; I'm fighting all the way through it. It's not enjoyable; I don't feel like I can be emotive, and it affects my metre. My brain doesn't make the connection soon enough, so I'm late. As a tuba player you have to be the time. With dystonia, the synchronisation is off.

ME: More often than not, you feel your metre has been disturbed.

P9: Yes. I'm glad you said that I thought my time was just really that bad. It's actually a miscommunication between my brain, air, tongue, and the note I'm hearing, it's all just that much later. I'm more aware of it now; I wasn't before. I've also noticed it in my speaking voice sometimes, which worries me. I don't want to sound like [redacted], you know.

ME: You talked about crippling stage anxiety. Has that changed during brain-spotting?

P9: The problem is I haven't been able to perform. I can't sing a song through without it sounding like a cross between [redacted] and [redacted]. On the one hand, it's devastating, it's part of my identity. On the other hand, I don't miss the performance anxiety. In the past, if someone called to book me for New Year's, I'd say yes and then panic until the gig. As it got closer, I'd be so crippled with anxiety I couldn't even practice. Then I'd cram, pace backstage, have physical symptoms, then get on stage and be fine. The last couple gigs, the voice was shaking at the beginning, people assumed I was nervous. It's the dystonia: it shakes badly at first, then gets better.

ME: Besides brain-spotting, anything else you apply now when playing?

P9: Redirecting focus physically. When my embouchure starts to shake, which it inevitably will, I try to relax my whole body. It's also in my neck and shoulders; everything jams up. I keep pulling my shoulders down and stretching my neck. I put focus into my feet, ground myself. And in terms of day-to-day practice, I spend a lot of my time always playing things as slowly as I can stand. I get the fingers to react as little as I can.

ME: What about Body Mapping, Rolfing, or similar therapies?

P9: The body relaxation piece is partly from you and partly from reading [redacted]'s book. I find it a misnomer to call it a "cure." She's made her money whether I get cured or not. I want actual studies, so people don't get sucked in. A famous player like [redacted] reportedly followed that approach and still had to adapt drastically, so even if it helps psychologically, physically you don't often see lasting results. I'm wary of claims. That's why I chose brain-spotting first. As a therapy, there's merit, but it's dangerous to tell musicians "this will cure you." For me, I'll be honest: I was expecting a magic bullet, I suppose. That hype was short-lived in my case. It's interesting as a therapy looking back after a year of it. It helped with my anxiety, I think, but it did nothing for my playing.

ME: You feel it's more than only brain-spotting?

P9: Yes. Brain-spotting helped me tremendously with trauma. We're talking complex PTSD; now it feels further away. I don't get a visceral reaction thinking about it. That alone has been a real gift. I'm fortunate psychiatry is covered in [redacted], so I just pay transportation.

ME: How has your identity as a musician changed, now that you've come back to playing/creating?

P9: I'm back to myself; it's given me joy again. I didn't realize I was in a holding pattern. I took up painting two years ago and can't keep up with commissions. I found this gift. My realization was: it doesn't matter what dystonia does; it doesn't take your creative soul. You just find another way to express yourself. I'm painting and recording my compositions, some old, some new, on a CD to bring awareness to musicians with focal dystonia. We hide it, especially if our instrument is our income and our identity. People don't even know what's happening at first. I had heard of dystonia because of players in [redacted], but I didn't know much. You learn a lot once you get it. And there's how you're treated by other musicians, almost excluded, like they might "catch" it. I felt it. It was unspoken but there: I wasn't invited to sing or do anything. I'd like the opportunity to say no. Let me decide. Instead, it was absolute exclusion. That's part of why nowadays, I really don't care what anybody else thinks. If I'm making music and enjoying it, then that's ok. And honestly, nobody knows what you're going through, really. That's life though, what doesn't kill you makes you stronger, right?

ME: You've been open about your diagnosis?

P9: I am now. Initially, no, most people don't understand; they think it's psychological. I agree there's a psychological component, but it's neurological, and I'm not faking it. I even had a recording engineer say someone he knew went to a clinic and was "cured," implying I could be if I wanted to be. That was horrible; I lost all respect then and there.

ME: You've covered most of what I was going to ask. Given your interest in awareness and prevention, what would your message be to musicians facing similar challenges?

P9: Never give up. Keep trying different things. Everyone's different. You'll find a way to get your creativity back. It may not be the form you wanted, but you will find a way to be a creative soul.

ME: Anything you would have done differently in your training if you'd known about dystonia beforehand?

P9: I would've loved not to be treated like crap for being a woman. The things I'd change are environmental, not within me. I went in confident; I loved the tuba and wanted to be a good musician, that's why I went to college. But this was the late '70s. We women weren't invited to jams unless there were strings attached. People said, "this is a jazz school, what are you doing here?" I pushed back: "this is a music school; I'm here to learn." Some teachers were wonderful; others came on to all the women. I remember a virtuoso trombonist asking me to play; I was a wreck. He noticed a shake and told me to practice performing, play for anybody who'd listen. It worked: I performed my jury piece flawlessly and got the highest mark,98. Instead of respect, I got disdain and ridicule, "you're not as good as so-and-so; he should have gotten that." I felt like an imposter because everyone said I didn't deserve it, except the teacher who gave me the mark.

I also joined a professional-level concert band in [redacted]. The conductor, [redacted], was supportive of women and helped get me in. But another conductor in that circle was an ass with women. Whenever there was a tuba mistake, usually from someone else, he'd stop the band and ridicule me. Nobody said anything. After months, I complained to the supportive conductor; he apparently pushed behind the scenes. At rehearsal, the other conductor and his assistant (who called me "Pet") told me, with drinks in hand, "we're doing The Planets; if you get through without a mistake, we'll give you a mess dinner gig,$35." I was furious. I played my heart out; the trumpet players were looking over because I was nailing it. Then I got a waft of scotch, and I felt his tongue in my ear, trying to make me make a mistake so they wouldn't have to pay me. I shifted my horn and clipped him. I still didn't make a mistake. I don't think they gave me that gig. I called the supportive conductor and quit. I lasted two weeks, then thought: they've won if I stop. I have to do this for other women and for my right to do what I love. So, I kept going.

ME: Do you feel those experiences are linked to your dystonic symptoms?

P9: I have to admit, probably. It's a hard pill to swallow that trauma succeeded in making me not play. Childhood trauma from two alcoholic parents was also a factor. Brain-spotting has helped me a lot with that. I've done sessions on the experiences I just shared, though not always as in-depth, I still get upset talking about it.

ME: Is there anything else you'd like to add before we stop the recording? I'm interested in exercises or conscious practice you can share, things that helped you or your students/colleagues.

P9: Two things. First, focus and grounding: drop attention into the feet, unlock knees, soften the jaw, let the ribs expand 360°, and consciously de-escalate the neck/shoulder brace, over and over. Second, ultra-slow, low-amplitude practice: reduce force, range, and complexity until the dystonia quiets, then build up one variable at a time (tempo, articulation, dynamic), always backing off before symptoms spike. Little by little, I can tell when I'm heading the right way. And when nothing seems to help, I remind myself to keep perspective and keep going. Nobody really knows what you're going through, but you can still shape a path forward.

P10 Interview

ME: Hi [redacted], thanks for taking the time to speak with me, I really appreciate it. So, to start with, could you share a bit about your background and how you became a professional musician?

P10: Hi [redacted]. Thank you for having me, I'm looking forward to getting things out in the open, I don't get the chance to do this. Great. Well, music has been a central part of my life for as long as I can remember. I was immersed in it from a young age. My parents were both music enthusiasts, and my sister played violin. She was five years older, so I remember being inspired by her and wanting to follow her into playing something. I started on the piano at first, like many children do, but the moment I heard the cello I wanted that sound. I was about eight when I convinced my parents to get me a few lessons. From that point on, the cello was me. I loved it. I'm a real goody two shoes, so hours into practicing, and by my teens I was attending [redacted] to pursue it seriously. I studied with [redacted];do you know her? She's great, terrifying, but she always managed to make me want to play better. She was hard though, no way of slipping through the net.

ME: I never met her, but I know who she is definitely, I bet that was amazing.

P10: Ha, yes, I learnt so much from her, really, but she was a difficult person. We all fell out of favour at some point or other. I had some really interesting moments; she wanted to fail me for the semester once for not turning up to a lesson on time.

ME: I'd like to hear about that, I'll double back to it. Could you describe when you first started noticing symptoms of focal dystonia and what your initial reaction was?

P10: Right, well I'm [redacted] years old now, so it was 2013. I left college in [redacted], so 27 more or less. It came out of the blue. I started feeling stiffness and a lack of control in my left hand, particularly between my thumb and first finger. They would sometimes feel as though they were locked in place. I thought perhaps I was just fatigued from over-practicing, but it didn't improve at all. I started to get really worried because, as I'm sure you know, there are some pretty nasty things that can cause things like that. I was convinced that I was dying, I usually am, so I was terrified to be honest. I thought it might be a tumour or something like that.

ME: Wow. I bet that was really challenging to deal with. Can you talk about the process you went through to get a diagnosis in the end?

P10: Once I'd found out that I wasn't going to die, it became really frustrating, really, really frustrating. Initially, nobody knew what was wrong with me. They were eliminating all the bad ones like MS, and a PT I consulted thought it was probably RSI. The first doctor I saw said that because I was pregnant at the time, it was probably carpel tunnel. I had no symptoms of that, so I was sent away again and again.

I was doing massage, some weird meditations (some good ones), and some homeopathy, all of that stuff, but same old, same old. Then I saw a neuro in [redacted] who had treated [redacted] for dystonia, and that's who diagnosed me pretty much as soon as I opened my mouth. She sent me for some exams and blood tests, but I only really understood more about what was happening when I got home and looked online. I wasn't offered much support; I found what was available on my own. It was more of a "this is what you have," and I was left to figure out the rest for myself. You're on your own at the beginning. That needs to change. I had no idea what to do, who to turn to.

ME: I think a lot of us relate to that feeling. What kept you motivated during those tough times, especially when it felt overwhelming?

P10: Honestly, I don't know. I had to read up on it first because I really had no idea. There were many times when I panicked and felt like packing it in, but music is who I am, it's my language; my life is built around it. My friends are all musos too, my social life, music, etc. Giving it up has never been an option. The main thing for me back then was knowing it wasn't just me. We've all got our own stories to tell. Motivation is hard; I found it in small victories. I tried all the usual stuff first, after my son was born I tried [redacted], but it made me quite weak. It didn't make things worse as such, but it didn't get any better. I didn't like it. It helped with stiffness a bit, but the weakness lasted throughout. On some days, just holding the cello and playing a few notes was enough. I've always been self-employed, so I earned money teaching. I couldn't demonstrate, though, which always kills me. You teach, right?

ME: Yes, I do. Undergrads mainly.

P10: I like telling other people what to do, at least that's what my partner will tell you. I like teaching. I did a PGCE a few years back, before the dystonia, so maybe I knew something would happen.

ME: Were you thinking of performing less at some point before that?

P10: No. I'm freelance, but [redacted] changed a lot in [redacted]. My diary hasn't recovered and, to be honest, the money is so much better in teaching anyway. I do some [redacted] and extra stuff with [redacted],well, I did, not at the moment. I'm okay with teaching more than performing. My partner is in the [redacted], so we have some stability. My family have been incredibly supportive. They know the problems I've had; they keep me sane when things get mushy. I think about that a lot, the fact that if I was on my own it would be so much harder. I found it difficult to tell colleagues; it makes you feel weak and feeble (which I'm not). I've had negative comments, like a violinist telling me I should just practice more and not be so easily distracted. That really hurt. We haven't talked since. My family help me navigate all of that. And to be honest, I had a lot of false start[s]. Some lasted for ages and ages. It's hard to know when you've got something right, but I've an open mind to most things nowadays, to be honest.

ME: It's great to hear you had support. It can be such a lonely place. Okay, could you fill me in on some of the techniques or methods you've incorporated into your retraining process?

P10: Sure. I'm all about big ideas; I visualise them like that, big ideas I gradually fill in with content.

ME: That sounds familiar. How does that look for you?

P10: I realised I couldn't focus solely on my hands; I needed to consider my whole body. Dystonia makes that really hard. My hand was in charge for a long time. I was obsessed with playing in tune with a "good form" to begin with. [Redacted] always talked about "correct form." Years spent trying to find my "correct form," whatever that is. So, I stopped focusing on the hand and focused on my elbow, trying to get it feeling freer. I like a lot of [redacted]'s teaching, circles, no angles. That made sense. Things got a bit easier for a while, and then they got worse. I took a few weeks off because I felt so bad about that, but when I started again it seemed better.

I had worked with [redacted] at college who was an Alexander Technique person, so I went to see him for a while. We talked about his thoughts on dystonia, muscles working in groups, and that maybe dystonia is a miscommunication between groups, like a signal being blocked. We spent a lot of time getting me to move more efficiently and with less tension. I became miles more aware of my posture and how energy moves through my body. Engaging my core was another thing I didn't understand well.

Basically, instead of fixating on what my fingers couldn't do, he got me focusing on optimising what the rest of my body could do to support them.

By chance, I ran into a friend who had just seen him, and she recommended Body Mapping. She signed me up for an online seminar about breathing. That was such an eye-opener. I was so bad at breathing when playing, dystonia makes you forget all that. I had no idea how much. That really made sense to me.

ME: It sounds like a very effective approach. Did it also help your psychological state? How were you dealing with things mentally?

P10: Absolutely. My mental health has been quite fragile for as long as I can remember. The pressure I placed on myself, especially during college with [redacted], who was very strict and demanding, left a lasting impact. It was a challenge to separate my self-worth from the dystonia. I know my limits, and when I'm down I know the importance of mental conditioning as much as physical. I've had to deal with some heavy situations, so it's important for me to look after my mental state. I really like meditating and I've made that a regular thing. It helps with anxiety, and I sleep better, which I need. If I sleep badly, I always find it harder to play. When you learn to deal with your stress, then you can deal with the dystonia. The two walk hand in hand in my opinion.

ME: You mentioned meditation and separating dystonia from self-worth. Could you tell me more?

P10: Self-worth is a big one. It sounds obvious that if you're dystonic and can't play then your self-worth will feel low. For me it was about letting go. I couldn't enjoy anything for a long time, I only thought about music, how I couldn't play, and that I was an abject failure. It's destructive, like I'm nothing if I'm not playing. Then I started asking if that's really all I am. That took time. I'm still trying to accept where I'm at, that it's not my fault, for a start. I always think "if only" about situations I should've avoided or when I should've been kinder to myself. College is critical for that; we were all comparing ourselves. I do think there's a spiritual aspect to dystonia; I don't see how there can't be.

ME: Does that tie into your meditation? What does it look like, and how does it help?

P10: The main thing is to calm things down. I like mindfulness meditations that slow thinking, breath-focused, focusing on sounds, body sensations. If I get into that state, I always feel better. I try to do one before any practical retraining; it helps connect the dots. I feel things better, like I have more senses in my fingers. I'm an emotional person, so sometimes it's overwhelming; stress makes me more emotional. I also sometimes do mantra chanting, positive affirmations like "I deserve to play well." I use mantra before sleep too; my mum says it helps her nightmares and migraines.

ME: Say you're playing one day, after meditating, feeling connected, physically and mentally in a good place. What does that feel like when you're playing? Do you feel recovered, to what extent?

P10: I'm not sure, do you mean am I cured?

ME: No, I mean when things are going well, how do you consider that state? Is that your aim, always trying to reach a new level of recovery?

P10: It's not that black and white. I've had to change how I think of myself as a musician. I can't do the same things; that me doesn't exist. I don't compare myself now to before, there's no point. If I do, it doesn't help, and I spiral. I'm happy with where I am with me, not against me. I can enjoy other things, which helps me enjoy playing more. Feeling "to the same level as before" isn't relevant now. If I can feel connected to my body and let go of the stress connected to my hand, sometimes I can just play for a while, and then realise I haven't thought about the hand problems. That's it: I'm more aware of the whole me, not the hand. It's liberating. If I then mentally compare that feeling to before, it takes time to get back to the new state. So, I try to distribute my focus all the time and not let it all go onto my hand. It sounds simple, but it's not. I wouldn't say I'm cured, rather, things have changed and that has to be.

ME: Very interesting. Any other influences, methods, or strategies that shaped your retraining?

P10: I did a lot of reading and researching about dystonia. I joined the [redacted] group online where people talked about brain-spotting, and some mentioned the [redacted] programme. A lot of it is interesting, but in my case my Alexander contact was my hook. I feel lucky; a lot of these things are expensive. Musicians aren't the richest, right? I'm certainly not, so it's been mainly up to me.

ME: Painfully true sometimes.

P10: Oh yes, so my lawyer friends always tell me!

ME: Changing tack: is there anything you wish you'd known earlier that might have changed your risk of focal dystonia? Any red flags looking back?

P10: I wish I'd had help with my mental health earlier. My parents were very anti talking about that. I had social problems as a child, and they chose to ignore it. Same when I began playing, they'd put me in local music festivals and I'd be really anxious, over the top. I still remembered those feelings on stage right through to college, anxiety dreams that I can't play, never seen the piece before, all of that. It's part of the inferiority complex we can have as musicians. So yes, looking after that side of things. I didn't feel listened to. I had to do things because they had to be done.

ME: Do you think if you'd been treated differently you might have been less susceptible?

P10: Maybe. I always struggled with speaking up; I'm not good at confrontation. At college I should've spoken up when I felt bullied into things. My teacher could be a bully, my way or the highway. Technically, I was forcing a square peg into a round hole a lot of the time, left hand position, vibrato, all of that. Some radical stuff definitely didn't work. I backtracked on a few things after leaving. I had difficulty with left-hand position change, which may be involved in my dystonia. I never quite understood in my head what I needed to do; when I got dystonia it was like a hardcore version of that. I couldn't work out how to hold my hand properly on the cello. Also, knowing more about the risk of dystonia, the things we now know, would have helped. I always repeated things obsessively; I'm inclined that way in life. I would have worked on not doing that. So yes, knowing more about focal dystonia, muscle-brain connections, or early signs could've been useful. I might have changed my approach. Having more support during college would have made a difference, I'd have liked a mentor to guide me, someone who could give advice and tell you where to go with your problems. High-pressure environments like college are daunting and definitely a risk for stress-related issues.

ME: Have you shared your experiences and retraining efforts with others? How has that affected you?

P10: Only with a few trusted colleagues and some students. I'm hesitant because I don't like being seen as less capable. I've had a lot of support though, and I don't feel like I'm hiding anything. Discussing it is therapeutic now. It's reassuring to know that when I share, I'm adding to the dialogue. I'm getting more involved in advocacy in musicians' health. We need more help. I'm aware of so many musicians in serious positions because of a lack of healthcare in this country at the moment. [Redacted] messed things up big time, but there are so many of us suffering on our own right now. You're on your own at the beginning. That needs to change. I had no idea what to do, who to turn to.

ME: That openness is commendable. Any advice for musicians going through similar challenges?

P10: First and foremost, don't isolate yourself. Reach out and talk about what you're going through, friends, family, fellow musicians, whoever. Listen to what your body and mind are telling you; they give you clues. If something feels off, get it checked out. If you're feeling bad, tell someone and go see someone. College culture can be against "looking weak," but that's absolute BS. Speak up, and if you're paying for your education, they owe you, not the other way around. Remember your worth isn't tied to being technically perfect. You need to enjoy playing; if you don't, talk about it or change teacher. Let that be your guide. Practice is good, but don't overdo it, and don't give up your hobbies. And be patient: I had a lot of false start[s]. Some lasted for ages and ages. It's hard to know when you've got something right, but I've an open mind to most things nowadays, to be honest.

ME: Brilliant, thank you, P10. Any final thoughts before we conclude?

P10: No, I think that's all for now. Thank you for letting me share, it helps me get things straight in my head. It's been cathartic. And I'd add: embrace change and adaptability. Dystonia can lead you to discover new aspects of yourself you wouldn't have explored otherwise, just go with that. And remember, when you learn to deal with your stress, then you can deal with the dystonia. The two walk hand in hand in my opinion.

ME: Thank you, P10. It's been a pleasure talking with you. I'll just press stop on the record.

P11 Interview

Me: P11, thank you for talking with me today. I know it's quite early where you are at the moment so really, thanks.

P11: No problem, [redacted]. It's always a pleasure especially if it's research as well. Good for you doing this especially at the end of the year.

Me: Well, it's my pleasure, thanks again. So, if it's ok let's start by talking about your background briefly, before your dystonia.

P11: Sure, I'd be happy to share. I started playing when I was about 10 years old. I grew up in a small town, and my school had a great music program there. I was drawn to the trumpet, but there were so many trumpet players in our local band, so my teacher handed me a trombone and said, "Give this a try." It went from there. There was something about the slide and the sound, it felt unique, expressive. I was a [redacted] fan as well, did you watch it?

Me: Yes I did. I used to love it.

P11: Right, so [redacted], trombone, starships. I love sci-fi, always have done. Then playing on recordings for certain things [redacted]-related has been a real childhood accomplishment, as you can imagine.
So anyway, I studied music in college with [redacted] and eventually went professional, playing with [redacted] in orchestras. I was involved with the [redacted] jazz band for more than 15 years, and the rest has been studio work and the teaching side as well. It was my life. I practiced every day, seven days a week, lived and breathed the life until early 2015, when things started to fall apart pretty dramatically.

Me: Right. So, what changed in 2015?

P11: It started very subtly; I didn't really know what was happening for a long time. I noticed my top lip shaking a little, then one day at [redacted] I was recording some fills for an animated film, just stabs, and low and behold, I couldn't get the note out clean. I had a sort of delay at the beginning. Nobody could tell so I thought ok, it's just strain, and I had already booked a week off with the family, so I didn't think much more about it. So, I came back from vacation and back to the same studios, different group this time. I had to hold pedal notes for hour after hour one day. Then suddenly my lip just let go, I describe it like it fainted. I had no control of the sound. Everyone thought I was fooling around so there was some laughter at first but then [redacted], who I was playing next to, asked me what was up. I told [redacted] and [redacted] just looked at me and said, you need to go see a neurologist. I knew that [redacted] had had some issues in the past; it was only then that [redacted] really told me about work with dystonic brass players and said that I needed to go see a neurologist. So, I did just that. I was very lucky that I had [redacted] as a colleague, I know that. One of the chosen few, I suppose, right? [redacted] really took me under [redacted] wing after that. I was told what I needed to know. I needed to hear some home truths as well. My lifestyle back then was pretty atrocious.

Me: Right, ok, that's very interesting, so you were literally sat next to somebody that knew what dystonia was all about and retrains musicians? So, [redacted] was a mentor for all things dystonia? How did that play out?

P11: Well, I know, I was incredibly fortunate although at the time I was pretty sceptical, or maybe just in denial about dystonia. I just assumed really that I could play my way out of it. [redacted] had to treat me like a child having a tantrum for a while. Obviously we worked together a lot, so there was no escape for [redacted].
Anyway, it was only a matter of a few weeks, though maybe a month, from when I felt things begin to happen that I was diagnosed. I remember not being too alarmed by it either to be honest; [redacted] had pretty much filled me in on most of the details by then and had already suggested a plan of action. I remember talking about it with the neurologist at [redacted]; [redacted] seemed pretty impressed by my plans. I'm not sure if there was anything else to be done, to be honest, as far as recommending treatments, there's really nothing to try that actually works in any predictable way. That's what the neurologist said, not me.

Me: Ah, ok, great stuff, so you had a diagnosis and a close colleague that was helping, so what was the next step?

P11: Well, [redacted] I consider a guide. [redacted] has [redacted] own exercises that I also follow, things like straw breathing, all the stuff to get the buccinators back in sync as well. I spent a lot of time with no trombone in the beginning, maybe six weeks or so. I was recommended to get back to basics with it all, so that's what I did. I've always had a pretty tight embouchure really; maybe the mouthpieces I learnt on didn't always help. Looking back, I can definitely recognise some things that I'd started to do subconsciously. For one, I was constantly hesitating before beginning, there was so much second guessing going on in my head. It was as if the world would fall if I slipped up. I've always been a solid player so I'm not really sure as to why that became such an issue in my head. Then I started to second guess myself, is it hesitation causing the fear or is it fear causing the hesitation? I'm still not sure. I've always been a fairly confident player, I enjoy what I do, and I wouldn't say that I get stage fright or anything, but the dystonia makes you question everything, I suppose. I talked a lot with [redacted] in the beginning, about fearful playing, [redacted], and so on. It was pretty liberating in some ways. I'm very private about my setup and technique, I'm not a big teacher either, so I prefer to keep my head down and play.

Me: Right. So, could you tell me a little about your retraining around that time? What were your aims and objectives, how did you begin to develop your own way of doing things?

P11: Ok, so, I'm a pretty stubborn so-and-so sometimes. I was doing a lot of breathing exercises, sensory-motor retuning stuff with [redacted] in the beginning. That really helped for a while but when I went back into the playing I was always struggling. I tried everything I could think of. I took breaks, did stretches, diet, exercise. Nothing really got me feeling close to normal, whatever that is. I remember one rehearsal where I just froze in the middle of a piece. I couldn't move the slide; it was freak in' horrible. My colleagues were understanding; I managed to get things out in the end, but I could see the concern on their faces. I was freaking out big time.

Me: So, what did you do next?

P11: I didn't know what to do. I was losing work because I couldn't perform reliably, and I was starting to panic. I took a sabbatical and stopped performing or recording for a while. I'd decided on six months or so. That at least gave me some head space. I was poorer but I wasn't going mental at least.

Me: That must have been devastating.

P11: It was. I remember sitting in my car after a rehearsal, just crying. It felt like my life was being taken away from me. I couldn't accept it. I reached out to [redacted] again and started an online programme with [redacted]. Now that was an eye opener for me. I used to sing as a tenor in choirs back home. So, I decided to go sing. That was great for me, I think. No pressure, and I spent a lot of time really working on how I breathe. I sort of discovered by chance that I was tensing lots of muscles on my left side. It was as if I had two bodies, I know, weird, right? Have you heard that one before?

Me: Similar maybe, it's intriguing though. What was your thought process along with that?

P11: Well, I'm right-handed, right-hand slide, all of that, but I realised that even when singing I was holding far too much of my posture on the left. Then I was sort of compensating by reaching up with my

left side and then I could feel my neck holding more on the left; my jaw was also not free to the left compared to the right, and when singing I would get tired on the left side of the throat. It just felt off. I mentioned this to [redacted] and was recommended that I do some [redacted], massage stuff to see what happened. I did maybe six in a month, and the practitioner said the same to me, that my left side was a lot tighter than the right.
So, the lip tremors are on the left side as well. I was then pointed to a site that talks about Body Mapping, you know [redacted].

Me: Yes, I do. Very good stuff on there.

P11: Right, so from there I went down a rabbit hole,3D X-ray videos, seminars on shoulder joints, courses, you name it, I was in. I found it really fascinating to be honest. It just made so much sense to me really; I've always been interested in anatomy anyway, so it was pretty fun, and that's when I trained myself up to be a practitioner. Additionally, I work a lot at improving muscle chain connections, I read a lot about that from [redacted], but there's not much that focuses on dystonic musicians. I've spent a lot of time working at re-connecting big muscles to small ones when I try and play. And to support that approach, I spent six months or so studying [redacted]'s '[redacted]'. We need to wake up all the circuitry before we start to play so that we can really feel movements when we're working on them.

Me: Wow, that's really great. A big achievement for you, obviously.

P11: Yes, but it wasn't easy. I was broken by then. I'd lost most of my work because I couldn't perform, and I had to find ways to keep going. I took odd jobs, teaching lessons, working at a music store, even doing some landscaping, to pay for the Body Mapping training, but I knew I had to keep moving forward and it's worth it.

Me: How did the Body Mapping training process work?

P11: Mainly online to be honest. I've been down to [redacted] a few times as well for the in-person stuff. There are always musicians there, I've met a few with dystonia. I think that there should be more. Anyway, I was encouraged to take the trombone when I went. It's a difficult instrument to play without putting yourself into tension at the best of times, and it was a good way to show how the body responds to changes when you learn what not to do.
Breathing as well, we learn how to breathe, we perfect our techniques, but there are so many things that don't always make sense to our bodies. I find it fascinating that we do so many things that actually punish or go against our physiology when we play. The embouchure is a great example of that. We're always sacrificing our physiology to get better sound, you know. Trombone is so bad for that; even some of the very best players have really unhealthy chops.
So, I got to grips with it all first, and when I started to pick up the trombone again I was literally just re-learning how to put it up to the lips. It's like learning how to walk again. I was using my hips better; I could feel how much stronger I was just by understanding what I was doing when I was moving. That was the key for me. And from there…

Me: Yes, so how do you think this links in with your work with [redacted]?

P11: Right, so yeah. I just put two and two together. From there I've managed to find a balance of things. I sing first, low notes or some sequences up and down, just to get connected to my body. I do this in a quiet place usually or using a mute to cover the sound; it helps to reset the jaw if I do it right. Sometimes it works better depending on what I'm playing. At home I still do the straw breathing stuff, but I'm fading that out a bit now I have less tremor to worry about. I do a lot of breathing exercises; I'm even doing some tai chi moves to keep my shoulders balanced and looser. All in all, it's about 30 minutes of warmup, maybe half with the trombone; I've always had a routine, so it works for me pretty well. And to be clear, it's pretty time-consuming, I admit. I probably do around an hour a day thereabouts. It's the most important thing for me. A lot of the embouchure work is TMJ [temporomandibular joint] based and it's so good for getting release prior.

Me: Right, that's pretty comprehensive. Is there anything else that you've put into your retraining or developed yourself, do you think?

P11: That's pretty much it I think up until now.

Me: Right, so where are you now in relation to your dystonia?

P11: Do you mean how far along am I?

Me: Yes, I suppose. Yes, where are you on your journey?

P11: Well, I'm in a good place at the moment. I'm not going to say that I'm cured, I'm not, but I can play most things. I avoid some things because I try to minimise my stress, but I'm ok. I still play regularly with [redacted], which is so good for me. I suppose [redacted] sees me as a success story, which I suppose I am to an extent. I'm not going to pretend that it's anything but f*caking hard though. I got divorced pretty recently, which was a big setback as well. A lot of symptoms came back around that time, so I've been doing some counselling as well. It's hard to stay focused and happy, and the dystonia knows that.

Me: Yeah, that's very true, I think. So, do you feel as though you're still improving/recovering?

P11: I couldn't tell you that. I think that what I was expecting to happen is so far from reality that it's not a real question at the moment. I'm happier with who I am as a person, yes. Do I feel like an inferior musician, yes, in some ways, but I'm maybe a better colleague. I'm not such an egotistical git anymore, that's for sure. I might be a cynical sod, but I try to look out for my colleagues. They come to me for advice now, especially if they're bothered about their playing.

Me: Right, so it sounds like you've developed a whole-body approach to retraining to me. To what extent would you agree/disagree with that?

P11: Yeah, I agree. That's what I have now, a whole-body approach to playing. It's not as if I could have done anything different, I think. It just is that way for me, or I don't play at all. It's not cured, I know that. I have good days and bad days but I'm a lot more relaxed as a player and I don't need to second guess people anymore. If I mess up I don't care. That's a nice feeling, you know?

Me: That's an important insight. Do you wish you'd known that earlier in your training?

P11: Absolutely. I wish I'd understood things like mindful practice during my early years. It's not about quantity; it's about quality. I've seen so many young musicians fall into the same trap.

Me: So, moving the conversation on a little. What insights have you gained from this experience that you think could help other musicians who might be struggling with similar issues?

P11: Well, here's the deal, your body doesn't lie. If something feels off, it's not just going to magically get better by ignoring it or hoping you'll play your way out. You have to be brutally honest with yourself and tackle the problem head-on. And don't go it alone. Connect with anyone who understands or even knows what they're talking about. Having someone to guide you can make all the difference when you're stuck in the weeds. I think that we're all guilty of too much self-obsession sometimes, we need to drop the pretence that we're the next big thing or stop comparing ourselves. That's also true.

Me: Ok, yes, and have there been specific lessons you've learned during your dystonia that have changed the way you view your musicianship?

P11: Oh, for sure. Before all this, I used to think it was all about technical skill and hours of sweat. Now I know that being a musician is about survival and adaptability just as much. You've got to be resilient as hell, ready to roll with the punches and come back swinging. It's like being in a constant battle with yourself; only you can't use brute force, you need a level head and finesse. There's no place for inflated egos either. I think that when we fall as musicians, it's hard. Dystonia is one of those levellers.

Me: Given all you've been through, what advice would you give to musicians facing similar challenges?

P11: Hang in there, even when everything feels like it's falling apart. It's going to take grit and a thick skin. Don't expect things to magically fix themselves overnight. It's a slow, painful process, but every step forward, no matter how tiny, counts. Go beyond just playing; dig into your physical and mental

health. Try different things, yoga, mindfulness, whatever it takes to keep yourself grounded. And remember, at the end of the day, music is more than just hitting the right notes, it's a damn lifeline. Use it to keep yourself afloat.

Me: Great, well finally can I ask, do you think that if you'd known about dystonia prior to it happening to you, you could have mitigated some of the risk factors?

P11: Hm, well I don't know how to answer that really. I suppose no, not specifically, but I wish that I'd done things like Body Mapping a lot earlier in my career. So yes, maybe, I don't know. I think that being more aware of you, what you are alongside your instrument and your technique, is important. I suppose that also means being aware of things that include your brain health, so to answer that, yes, I think so. I mean, if I'd been clued into things like Body Mapping earlier, that's a definite yes, it might have helped. Having a better understanding of how my whole body interacts with my playing could've nipped some issues in the bud. But the reality is, we're all just figuring it out as we go, aren't we? Being aware of your mental and physical health as it ties into your music, that's crucial. So yeah, in hindsight, perhaps I could've avoided some of the mess. But hindsight's always 20/20, right?

Me: P11, thanks so much for being so open and sharing your experiences; it's been eye-opening. I've really enjoyed listening to you. So, let me press stop here.

P11: No worries, [redacted]. It's good to get it off my chest as well. And hey, if it helps avoid going down the rabbit hole I did, then it's worth it. Sure, let's stop it there.

P12 Interview

Me: [redacted], thank you for taking the time to talk to me, I really appreciate it. It's nice to speak to a guitarist as well; it's important to listen to guitarists, there's so much going on there with dystonia. So, firstly, what were your first thoughts when you started getting symptoms?

P12: You know, I thought, oh, I'll be back within a month. I thought this was like having a little strain or something in my finger, and it was just a lack of understanding. When I first heard the term and then went and looked it up, it was denial. And then once I looked it up more and I saw the statistics and the numbers and just the reality of the situation that I was in, it just turned into pure defiance. It was almost just like, well, this is a mountain I've got to climb then, if only this percent of people recovers from it or rehabilitate fully, I will be one of those few.
It wasn't even a consideration of, well, I'm going to give up my instrument or I'm going to take a break. It was just this: I can overcome this. I can figure it out.

Me: And do you think that motivation, that resilience, was something you've always had, or what do you think was the driving factor behind it?

P12: At the time I would have told you, yeah, I'm just a very resilient person. I would have said something along the lines of; music is the thing I love to do; it's the thing I'm on this planet to do. So, this is just another challenge on the road, and I'll get over it. I now know, looking back, that I had an unhealthy attachment to the egoic part of playing an instrument. I saw that as part of my identity. So, it was like someone trying to take away part of who I thought I was. Of course I wasn't going to let that happen easily. Of course, I was going to fight with everything I had to hold on to what I perceived as a part of myself.
It was very much that level of defiance, no, I'm not letting go of this. I'm going to fight it from start to end.

Me: And do you think there was an element of fear in there, or was it pure defiance?

P12: Right, yes, exactly. So, I know now from studying as a therapist that, especially for men, the first reaction that comes to any challenging thing is anger or defiance. Usually, underneath that it's sadness and fear, and we just don't want to show the vulnerable part. At the time I would have sworn to you that no, this is defiance: I am going to make it through this. But now I look back and I'd say, no, you're fearful that if you let go of this, you will no longer exist as a person. No one will pay attention to you. You won't

know who you are. You just won't have a self to go back to, essentially. That's what I was really running from, I think.

Me: That's obviously part of your transformation, ego death or whatever you call it. Do you remember when that became clear? Gradual or lightning bolt?

P12: The "ego death" part started when I looked into therapy and body-based approaches. By the end of 2021 I'd become aware of somatic therapies. As I researched and received them, I started to see patterns, people who had, in various ways, lost contact with their body. At first it was easy to think, that's other people, not me. But as I trained and received therapy through 2022, it became undeniable. The more it benefited me, the more it showed me: that person over there is you. And the fact that it was working so well for me was like proof. I started to realise I had a lot of these traits and behaviours, and I had dystonia; I could see how that pattern could lead there. So, 2022 was me gradually accepting how I ended up here, rather than seeing myself as a victim. It felt more like a consequence of different things coming together.

Me: So, in your head, do you now have a picture of what your dystonia is or where it comes from?

P12: Yes. To me, it was my body saying "enough." I was mind-driven, whatever my mind decided, my body got dragged along. It did that as long as it could. Then the edges frayed. My Pinky, one of the smallest parts, was first to twitch and refuse to listen. My body rebelled because it was tired of me telling it what to do without listening to its feedback, tired, sore, this practice doesn't feel good. It ultimately showed me something I couldn't deny so I had to listen. That's how I conceptualise it: the body shouting to deal with the issue. It would make me ill until I listened.

Me: Do you still see it as brain versus body?

P12: I see it as the body and nervous system having their own knowing, and the mind thinking it knows. My body knew I needed a break and couldn't keep going the way I had been; my mind was convinced I could. So, one side was going to lose. I see the dystonia as a mercy now, the body saying, this won't work; you won't make it to the finish line. It took away my smallest finger in effect so I couldn't play the way I wanted, so maybe I'd finally listen.

Me: Has your relationship with your mind changed since then?

P12: Completely. I didn't speak to myself with compassion growing up. It was very much; this is what needs to be done. Now it's more: how are we feeling today? A day-to-day awareness mentally and physically. The way I speak to myself has changed, less telling, more asking: what do we want to do? What would be best for me here?

Me: Does that give you more space and time to make decisions?

P12: Exactly. Ultimately it's self-acceptance. I wasn't open to accepting parts of myself that didn't fit my egoic self-image. Now it's much more open. For instance, when I was in [redacted], I started going to the gym a lot. I used to make fun of that, but I really enjoyed it. If I'd still been immersed in classical music the same way, I wouldn't have had the time or headspace. Now I'd happily try things like dance classes or winter sports in [redacted]. It's a lot more asking myself questions rather than telling myself who I am.
And in the practical day-to-day, I'm always changing things up. Sometimes I change a fingering or work with a new position, it might work, who knows. If I do the same thing every day, then I feel things start to drop off.

Me: That theme comes across a lot; people describe significant change without disappearing.

P12: You know, it's a story of significant change without disappearing. I'm sceptical when I hear, I got a few injections, did some exercises, rescheduled, and everything was fine. Maybe if you're very early, but if you don't change the record, I think it repeats.

Me: I'd say most dystonic musicians need to know about this part early on.

P12: It's so far away from standard medical care. Even the best clinicians don't usually signpost people toward this. Certain approaches come up again and again, there's something there. As a community, we need to look into it. That's where I'd like to go.

Me: Could you tell me a little about what happened post the first phase, how you summarise that process?

P12: The best summary I've heard was from [redacted]: first you have to rescue the person. Not the instrument, not which finger, the person lost in dystonia. That's what therapy did for me. From journaling, I kept writing, it's like I'm having myself revealed to myself. When my eyes locked to a spot in sessions, it was like a capsule opened, body sensations, memories, connections. Suddenly I became aware of parts of myself. It revealed these parts gradually, in bite-sized ways I could integrate. Talking therapies didn't go deep enough for that in my case; they interacted with language and didn't reach the primal, body-knowing. This did, for me. That's why I trained in it.

Me: And during training, what were the main things you found?

P12: First I felt it myself, then I saw it in others. I worked with experienced therapists-in-training; things emerged that surprised even them. That kept happening. My notes from early phases say: everyone just wants to connect. Breakthroughs happened when the person connected safely with me, and more importantly, when that opened a connection back to themselves. If someone is suffering as I was, some inner connection hasn't been made or has been lost or damaged. That's a big part of the suffering. And I think dystonia often represents a diminished connection to the self.

Me: When you were playing, how did the therapy translate to your practice?

P12: The more I did it, the more I could feel micro-movements and postures in my hand, wrist, and fingers. I noticed stomach gurgles, a quick spike in my chest, flushing, shivers, fleeting states while doing rehab movements. Before, I focused only on fingers, as if that's all that existed. Afterward, I cared more about how I felt internally while doing them. That gave me relief and maybe 50% improvement. But I hit a plateau, possibly tied to hypermobility, no matter what, the motion would switch on. I could sense when but not remove it. From there, the inner connection mattered more than grinding exercises. Ironically, the more aware I became, the more toxic the grind felt. I resented having to do it. That wasn't why I got into music. Around summer 2023, I wrote: if this is my life as a musician now, I don't want it to keep going. So, I began asking what else I that could aligning with my wellbeing.
Alongside that shift, practicing self-observation felt like taking a step back and becoming my own witness. I stopped judging every mistake as a failure. Instead, I saw them as moments of data. It made the whole endless journey a bit less daunting.

Me: Do you know where that realisation came from in yourself?

P12: That was recent,2023. But it connects back to my teens. I'm highly likely an undiagnosed, hyperlexic autistic person; I learned academics and perfectionism as a way to get attention, love, respect. So, I did three to four hours of homework a night. I didn't always enjoy it. I'd rather be out with friends, reading, doing anything else, but I was told it mattered. That translated into music too: external achievement equals internal reward. If you asked, do you love playing the cello? I might say: do I love playing? Not always. Do I love music? Sometimes.

Me: Many musicians recognise that, external achievement and internal reward.

P12: Exactly. For most, when you dig down, the reward is misaligned. Only a lucky few fly above that. And on the practical side, to help me hold onto that inner state, I meditate most days. My challenge has always been to play without losing the effects. There's a lot of discipline needed to do that.

Me: I'm interested in the interoception angle, the insula, temperature changes, heartbeats, links to motor skill. Do you see that connection?

P12: Yes. You can be 24/7 anxious, hyper-focused on heartbeat, or you can be disconnected, and therapy can bring you toward the middle. To your point about regulation: from my first or second session, I went into natural tremors, what some call trauma release exercises. My eyes stayed on a spot; my

shoulders shuddered, neck twitched, hands lifted. I became intensely hot and had to remove a layer. My legs jittered under the table. It wasn't deliberate; my body was viscerally moving as connections lit up. Later I learned specific ways to invite that tremor along the psoas and let it pass through. For me, it went into hands, forearms, neck, shoulder, sometimes flipping me to my side. It's powerful and hard to explain until you experience it.

Me: It's helpful to frame that for musicians, understanding tremor as a trauma-linked response that can be worked with.

P12: Exactly. Knowing that would have saved me time, less quagmire, more directed work.

Me: This is inspiring. The profession needs more of these conversations, teacher-student dynamics, institutional pressures, all of it.

P12: It's missing. That's why I'm doing public speaking, mainly in therapeutic contexts now, using dystonia to show disconnection between brain and body. I do intend to speak directly to performing arts as well.

Me: Have you thought about writing a book, or even a PhD?

P12: I've heard that suggestion. Thank you, [redacted]. I hope we move toward this way of thinking about the profession. That's my desire.

Me: Thank you very much for your time, P12.

P12: Thank you for all you do, [redacted]. And one last thing that helps me keep progress from stalling: I'm always changing things up, sometimes I change a fingering or work with a new position; it might work, who knows. If I do the same thing every day, I feel things start to drop off.

P13 Interview

Me: You want to record it? Okay, there we go. Thank you for talking with me today. To start, could you run through a little about your diagnostic process, how it occurred, who gave you the diagnosis, and what that was like?

P13: I initially started noticing symptoms around Christmas of 2015. Through 2016 I had a lot going on, performances at [redacted] and other events, and I was putting a lot of stress on myself. I visited a colleague in [redacted] who had embouchure and hand dystonia. They didn't diagnose me but said it looked familiar. I then saw a neurologist who was supposedly trained in working with musicians with dystonia. They said, yes, you have dystonia, and suggested Botox. I said no, thank you, especially as recent studies by [redacted] had said Botox isn't effective for embouchure dystonia. A friend suggested I see [redacted], and I did in March 2018. That started me on understanding more about it and I got several exercises. It helped to some degree, but I was under a lot of caregiving stress for an elderly parent. I mark the beginning of my real retraining as January 2020, after my mom passed in late 2019. Having that pressure lift made space to work.

Me: Was there a specific reason you decided to really start then?

P13: I'd been trying since 2018, but the caregiving and work made it ineffective. In January 2020 I could finally give it time. Looking back, one of my big milestones was being willing to examine who I am as a person. Recovery begins when you accept the dystonia, get curious about why it developed, and examine psychological and emotional aspects. Another milestone was developing agency, seeking a team and the approaches I needed. I worked with a psychiatrist around 2019 on performance anxiety, but that wasn't very effective. Two weeks before my mom passed, I found an occupational therapist at [redacted] who did facial neuromuscular retraining (FMDR), originally developed for Bell's palsy and facial neuroma, very neuroplasticity-based. He hadn't worked with dystonic musicians, but we dug in together: re-education of facial muscles, stretches and movements, then building efficient patterns.

Me: By re-education, you mean learning precise facial anatomy, vectors, origins/insertions, function, and balance?

P13: Exactly. In parallel, I finally dug into [redacted] Body Mapping training I'd long wanted to complete and got licensed in 2021. Body Mapping exposed "mishaps" everywhere, standing, sitting, balance over sit bones, not over-arching my back, not dumping weight into ankles, aligning hips/shoulders, and balancing the head at the AO joint. Breathing was huge, I hadn't allowed true ribcage expansion. Undoing unconscious chains when bringing the instrument to the face became key: do I really need that much muscle? Constant refinement. Around then, I also diversified my somatic work. I spent six months or so studying Moshe's, 'The Feldenkrais Teaching by Handling Method'. We need to wake up all the circuitry before we start to play so that we can really feel movements when we're working on them.

Me: That aligns with what many describe, different routes, similar conclusions.

P13: Yes, whether Body Mapping, Alexander, Feldenkrais, Tai Chi, the core aims converge. My retraining had three strands: somatic re-examination of playing, facial neuromuscular retraining, and psychotherapy. I tried a number of things, including biofeedback with [redacted], which wasn't very effective. Eventually I sought a counsellor who used brain-spotting, covered by my insurance, rather than paying high out-of-pocket costs. Honestly, I don't have money to burn, and I feel like I wasted a lot for very little. I was doing most of it myself anyway.

Me: How did you experience brain-spotting personally?

P13: I was always very sceptical of anything like that [brain-spotting]. I wish I'd understood why it's important to look inwards at yourself, and work on yourself. Otherwise, you're just treating symptoms. For me it was a tool, not a cure-all. I used it with my counsellor; I don't really do self-brain-spotting. The main benefit was cultivating awareness of physical sensations and possible emotional links, catching triggers. No single breakthrough moment, but the therapeutic relationship helped me examine patterns, and we used resources and readings. Parallel to that, I kept working on the cognitive side, self-compassion, perfectionism, noticing distortions, and reframing. For example, focusing on the notes I can play rather than those I can't.

Me: Could you describe a typical practice session now?

P13: My husband jokes our downstairs bathroom is my third practice room because of the big mirror. I start by observing, balanced now between sides, but I still check. My best tool is a simple coffee straw. Long tones through the straw align things, so I begin there. If I skip a day or two, it feels like the neuroplasticity chain weakens, so I return to neutral frequently. I'll play a bit, assess resonance and openness, then return to straw work if needed. Breaks are frequent, and I remind myself to be kinder. I'm back to ensemble parts, student pieces, technique, and I'm rebuilding articulation. When tension creeps in, I use alternative strategies, like a back-of-tongue "Koo" so the front stays stable, while monitoring in the mirror. I also keep this mindset: If something stops working or doesn't work it's ok. Try something else. You have to know when to stop and step back, but when you have, then try another way.

Me: How are you negotiating perfectionism through that?

P13: By being kinder and using markers to gauge progress, like recurring seasonal gigs where I can compare year to year. Some days dystonia is more active. I explore alternatives, push myself to demonstrate small excerpts for students, and play duets again, starting simple and building.

Me: Has your teaching changed across this journey?

P13: Definitely. I left [redacted] during COVID and leaned into Body Mapping and a community of teachers focused on transformational, less top-down approaches. I bring more somatic awareness, standing, balance, breath, into lessons. I ask more questions, cultivate student responsibility, and I'm less content-driven. Dystonia is part of why I shifted, but so were broader pedagogical changes. On the advocacy side, we discussed how traditional teaching can generate trauma. I think we need to face that. We should be aware of what to expect at the outset. I think about how much time I wasted and sometimes I think, maybe it made me worse.

Me: What would be your message to young musicians at risk or in early stages?

P13: Cultivate awareness of physical sensations, pain, discomfort, temperature, tension, and notice their links to emotions. Establish a headspace before practice: find balance points, notice how you bring the instrument up, use slow, intentional movements, build kinaesthetic and proprioceptive awareness. Psychologically, catch negative patterns and be willing to explore them, even if young. And take small, frequent breaks, always returning to baseline.

Me: Would you have done anything differently if you had known about dystonia beforehand?

P13: I would have nurtured body awareness much earlier, gotten curious about what I do and why, rather than accepting "this is the way." I would also have questioned methods and noticed triggers sooner. And I would have saved money by being more selective. We should be aware of what to expect at the outset. I think about how much time I wasted and sometimes I think, maybe it made me worse. Also, a big healing step for me was coming out of the closet about dystonia, reducing shame and loss of self-worth. Just get it out there. People that need-to-know ought to know, period.

Me: Are you still using brain-spotting when you play?

P13: Not really, only occasionally in sessions. The lasting value is the habit of self-observation and linking sensations to triggers.

Me: Has dystonia enhanced your musicianship in any way?

P13: It's helped me learn about myself and be kinder, reshaped my thinking, and given me confidence as I see improvement. I've found alternative musical voices and, when I can loosen enough, more resonance. I'm finally thinking musically again, not just technically. I think about flow, line, intention, breath shaping phrase, and how the brain allows the phrase when intention is clear. That's been a gift. At the same time, I'm realistic: dystonia may be with me long-term; I'm grateful it's task-specific and not debilitating.

Me: Anything else you'd like to add?

P13: Yes, about access and expectations. I was paying out-of-pocket for so much early on. I don't have money to burn, and I feel like I wasted a lot for very little. I was doing most of it myself anyway. Clearer guidance early would have helped me choose better, cheaper, and more relevant options. And for the record, I was always very sceptical of anything like that [brain-spotting]. I wish I'd understood why it's important to look inwards and work on yourself. Otherwise, you're just treating symptoms.

Me: Thank you, P13. I appreciate your openness and insights.

P13: Thank you. And one last thing: If something stops working or doesn't work it's ok. Try something else. You have to know when to stop and step back, but when you have, then try another way.

P14 interview

ME: Hey P14, thanks again. Same questions as before, but could you answer with a bit more variation in how long you talk?

P14: Teetotally. Thanks for the heads-up.
I'm based in [redacted], mostly on [redacted], and I split time between playing, composing, and teaching.
I trained at [redacted], did the freelance circuit with [redacted] and [redacted] for years.
These days I'm still performing, just… the ratio changed after the dystonia.
More chamber work, more studio stuff, and a lot more teaching.
It wasn't a grand plan, more like following what my nervous system can actually handle.
I still love being on stage; I just choose my moments more carefully now.
And I'm weirdly happier with the mix than I expected.

ME: When did the symptoms first show up and what did they feel like?

P14: Quiet at first. One rehearsal in [redacted], an easy line, and my index and middle fingers grabbed each other for a heartbeat. I thought, tired, move on. A few months later, it had a personality. Certain shifts would snag, certain articulations were cursed, and anything fast at soft dynamics was a guaranteed mess. I also noticed I was holding my breath at entries, which made everything clamp up more. It felt like the signal overshot the target, like the instruction got too loud right at the last moment. I tried resting, stretching, all the usual "good citizen" things; nothing changed. Honestly, it was scarier because it was so specific, like the body had written a rule I couldn't see.

ME: What was the diagnosis process like?

P14: Messy. A GP said "rest," a physio said "RSI," and a hand specialist said "maybe nerve compression. "A colleague finally said, "look up focal dystonia," which sent me to a neurologist in [redacted]. The neuro watched me play for, I don't know, three minutes and said "task-specific dystonia." EMG ruled out neuropathy; a couple of follow-ups later I had a label. The worst part was after the diagnosis. I second guess myself a lot of the time. I think that's just part of the process but when you feel like you don't know what you're doing and there's no-one to ask, it's a lonely place.
I walked out with a name and no map.
So, I made one, badly, then better.

ME: What did those first months look like?

P14: I did the classic wrong thing, tried to push through.
More warmups, shorter sets, stubbornness.
It backfired.

P14: I stopped for six weeks.
Came back with tiny sessions, lots of listening, lots of breathing, and I stopped before things unravelled.

I kept a scrappy log, sleep, stress, caffeine, tempo, who was in the room.
Eventually the pattern showed itself: fast plus quiet plus perfection mindset equalled a car crash.
Weirdly, a ten-minute walk outside before playing calmed things more than any indoor warmup.
And if I had to teach, trying the demo silently once before speaking helped a ton.

ME: What actually moved the needle?

P14: Breathing and variability. Alexander lessons in [redacted], Feldenkrais online, both pulled me away from “fix the fingers” to “organize the whole you.” And then absurdly slow practice with constant tiny changes so my brain couldn’t auto-choose the same trap every time. Yeah, it’s changing movement patterns when I do the slow work, you know, to stop always doing things the same way, breathing properly as well is a massive help. It sounds boring, but it’s where the lights came back on, one dimmer switch at a time.
Also, I learned to stop while it’s still going well.

ME: Can you describe the slow work, but keep it human, not technical?

P14: I’d take two bars and stretch time until it felt silly. Change one thing: where I look, how I sit, how much weight, which fingering, whether I’m barefoot. Change the dynamic shape. Close my eyes. Open them. Breathe on purpose, you know. The point wasn’t to find the one right way; it was to show my system there are many safe ways. For ages it felt like nothing, and then one day a spot that always jammed just… didn’t. I didn’t celebrate, I just noted it, oh, there you are. Retraining myself has been like watching my child grow. It’s happening, I know, but most of the time I can’t tell. It’s a very proximal thing.

ME: How did you fold breath into that without overthinking?

P14: Two minutes of easy breathing before I touch the instrument, hum a note on the exhale, then play one utterly simple tone. If I catch myself bracing or holding my breath, I stop and reset.
Also, I tie movements to the exhale, shifts, releases, so the system doesn’t brace by default’s the reset doesn’t take, I walk away for ten minutes. It’s like telling my nervous system, “We’re not doing this as a fight. “It’s not fancy; it’s just consistent.

ME: Did you try any medical interventions?

P14: One micro-dose of [redacted].
It softened co-contraction in everyday stuff but made playing feel mushy.
I passed on round two.

P14: Propranolol helped with public-speaking nerves, did nothing useful for fine-motor playing.
Honestly, sleep beat all of it.
Timing caffeine helped too, no late coffee or the morning was jumpy.
I wish the “magic pill” existed; I just haven’t met it.

ME: So, what did your notes teach you over time?

P14: That sleep is the boss. Under six and a half hours and the triggers screens poison the next morning. If the first practice block is exploratory, I have fewer setbacks. Outdoor movement before I play probably saves me more than anything. And when I demonstrate for students, I do a silent pass first, it’s like it reassures the system before the social pressure lands.

ME: How did other people respond,, your colleagues, or peers?

P14: Mixed, honestly. A couple of colleagues were amazing, swapped parts, took the springy bits, made it a team problem. A few tossed “just practice more” at me, which… yeah, no.

P14: Institutions mostly want outcomes.
I lowered my expectations there and built a tiny support ring: two peers in [redacted], one teacher outside my instrument family, and a therapist who gets performance.
Small circle, big relief.
Sometimes all you need is two people who say “yep, makes sense” at the right moment.

ME: Did it change your identity as a musician?

P14: Completely I used to be “I execute at a high level.” Now I’m “I cultivate music through multiple doors”, still playing, but also arranging, electronics, and teaching with way more embodiment.
I grieve the old fluency some days. That’s honest. But I don’t force a version of me my nervous system can’t sustain. We’re not at war anymore. It’s more partnership.

ME: What’s a good practice day feel like now?

P14: Short. Honest.

P14: I ease in, I don’t chase symptoms, and I end while it’s still going well so my brain tags practice as safe. If something spikes twice, I step back one notch, stack a few easy reps, and walk away. That “leave while it works” habit changed everything.

ME: Any mental strategies you rely on?

P14: I point my attention at sound colour and phrase shape, why, not how. If I stare at the fingers, they clamp also clean up my language: not “my dystonia,” just “the pattern.”

P14: And I practice uncertainty on purpose, “I don’t know yet, and that’s okay. “It drops the need to micromanage. It’s amazing how much better the body behaves when you stop barking orders.

ME: How did you rebuild performing?

P14: In layers. For gigs I get there early, do a mini breath reset, and negotiate parts, give me the lyrical lines and let someone else sprint. If that flexibility isn’t there, sometimes I say no. Honesty beats spiralling on stage.

ME: Which approaches clicked most, Alexander, Feldenkrais, Body Mapping?

P14: Bits of each. Alexander gave me the pause, “inhibit, direct, then go. “Feldenkrais separated elbow–wrist–shoulder timing so I didn’t move like a single block. Body Mapping, my internal map, joints, ribs, spine, hand arches.

ME: Has this changed how you teach?

P14: Oh yeah. It it’s posture options, permission to stop. Students define success beyond “did I nail it”: kept breathing, jaw stayed soft, tried three ways. We do five-minute experiments where the goal is learning how they learn, not fixing a bar. There’s a lot less shame and a lot more curiosity in the room now.

ME: Where is it still the hardest?

P14: Patience.
I adore clean metrics and this process gives mist, not mile markers. I second guess myself a lot of the time. I think that’s just part of the process but when you feel like you don’t know what you’re doing and there’s no-one to ask, it’s a lonely place. On those days I grab one tiny win, one phrase on a full, easy breath, and then I go outside. Touch a tree, drink water, call it.
That tiny win keeps the door open for tomorrow.

ME: How big a role does stress play?

P14: Massive. Almost one-to-one with symptoms. Family stuff, money stuff, the hands tattle immediately. So, I downshift first, or I don’t play. Few calm breaths, quick walk, splash cold water on face and forearms, then instrument. Not heroic it’s just maintenance.
It keeps me from lighting the fuse.

ME: Do you get moments that feel like the old you?

P14: Wehrlite windows. Suddenly the glass is clean and everything's transparent and easy. They're more frequent now. I just play music while the window's open and try not to analyse it to death.
If it closes, fine. Another will open. That mindset keeps me steady.

ME: Any odd exercises that ended up mattering?

P14: Whispered long tones while barely touching the instrument, relink sound in my head to gentle contact.
Feather-light "ghost" shifts on an exhale, then layer weight back in.
And a timing game: slightly behind the click, on it, slightly ahead, so my system doesn't freak when time wobbles.

ME: Did tech or apps help?

P14: Small doses only. Thirty-second clips to check outcomes, not to nitpick myself to bits. A breathing app early on, now I just count.

P14: A heart-rate monitor told me my pulse jumped the instant I picked up the instrument. Seeing that data made breath work feel practical, not woo. It's nice when your body gives you receipts.

ME: If you could send a message back to pre-dystonia you, what would it be?

P14: Don't put your whole identity in one skill. Guard your sleep like a contract. Learn to breathe with your playing now, not "when you have time.".

ME: What would you say to someone newly diagnosed?

P14: Don't sprint. Settle your system breath, simple routines. Find one movement person you trust, not five then go on your own.

P14: Keep practice slow, variable, and low-stakes. Jot a tiny log, just enough to spot patterns. And pick two humans you can text on bad days. You don't need a committee, just anchors.

ME: How do you know you're progressing day to day?

P14: It's quieter. Less drama, fewer spikes, more choices. That "it has to be one way" voice loosens.

P14: Sometimes joy sneaks back in when you're not looking. That's my favourite metric. It's not flashy, but it's real.

ME: That's fantastic. A lot of such interesting stuff. Thank you. Anything else you'd like to mention.?

P14: The boring things work, sleep, breath, pacing, kinder language. Give yourself time to make different choices. The slow work isn't just slow notes; it's slow decisions. Andaya, it's changing movement patterns when I do the slow work, you know, to stop always doing things the same way, breathing properly as well is a massive help. Also, if progress feels invisible, it might still be moving.
Retraining myself has been like watching my child grow. It's happening, I know, but most of the time I can't tell. It's a very proximal thing. Keep going; the windows do get clearer and longer.

ME: Thanks, that's great. Ok, I'll press stop here.

Appendix M: Axial Code Book – Study 2

Study 2 Axial Coding
1. P1

Theme	Code	Exemplar
Theme 1 - A Lack of Prior Awareness	Diagnosis Journey	"It took three years before I found out what it was."
	Initial Symptoms	"My little finger had started to curl inwards while playing."
	Medical Interactions	"Several GPs were baffled until I finally saw a neurologist."
	Societal Perceptions	"Back then, performance-related diseases were virtually unknown."
	Cultural Influences	"In rural New South Wales, awareness of performance-related diseases was like being on the moon."
	Mental Health Awareness	"Acceptance and dealing with the emotional toll was as important as physical recovery."
Theme 2 - Retraining Journeys: Choices and Commitment	Recovery Journey	"I started to look for alternatives and followed Nancy Byl's research."
	Retraining Experiences	"I stopped trying to play like before and revisited basics."
	Barriers to Recovery	"The standard wisdom was you never got better from focal dystonia."
	Therapeutic Approaches	"I learned to read Braille and do dominoes by touch, none of which helped but felt proactive."
	Pain Management	"Acupuncture was one method I explored despite the lack of progress."
	Coping Mechanisms	"I tried acupuncture and various manipulative therapies."
	Role Models	"Following research from Professor Nancy Byl was a turning point."
Theme 3 - Impact of Retraining on Rehabilitation	Emotional Connection	"I'm a better player now, more connected emotionally to the music."
	Identity Change	"I was obsessive with classical guitar before. Now it's just music."
	Learning and Growth	"I'm technically not as good, but I'm a better player now with emotional connection."
	Wellness Habits	"I've focused on tone and dynamics to improve my musical wellness."
	Creative Expression	"Exploring different playing approaches helped creatively manage my condition."
	Innovation in Adaptation	"Small, precise finger movements became my adaptive technique."
Theme 4 - Retraining Experience and Support Satisfaction	Future Aspirations	"I hope to continue improving and reconnect fully with my music."
	Support Systems	"I showed my wife the video, she was the first to notice the finger curling."
	Community Involvement	"Connecting with others online was crucial to my recovery journey."
	Knowledge Sharing	"I started to correspond with others and share experiences online."
	Spiritual Beliefs	"The laying of hands in Brazil or spiritual practices were part of my journey."
	Resilience Factors	"Meeting others and realizing they could improve gave me hope."

	Resource Availability	"Early on, there were limited resources available, but international connections helped later."

2. P2

Theme	Code	Exemplar
Theme 1 - A Lack of Prior Awareness	Diagnosis Journey	"I noticed a tendency for my fifth finger to retract and suspected focal dystonia."
	Initial Symptoms	"The fifth finger would retract to my fourth finger, indicating loss of control."
	Medical Interactions	"Different professionals suggested it wasn't focal dystonia, delaying proper diagnosis."
	Societal Perceptions	"Concerns about perceptions of musical deficiencies due to dystonia among colleagues and students."
	Mental Health Awareness	"Exploration of emotional impact on physical symptoms and the need to resolve psychological challenges."
	Cultural Influences	"Using Suzuki pedagogy on finger movement influenced my playing style."
Theme 2 - Retraining Journeys: Choices and Commitment	Recovery Journey	"I went to Seville for a session and continued to practice self-study at home."
	Therapeutic Approaches	"Exploring brain spotting techniques with Ruth Chiles for cognitive understanding of dystonia."
	Barriers to Recovery	"A violinist I connected with was banned from a bulletin board for sharing advice."
	Movement Retraining Choices	"Shadow practicing lightly on the keys helped during periods of physical distress."
	Support Systems	"Finding support in online communities and mentors like Joaquin and Ruth."
	Role Models	"Studying under a prominent teacher like Zafia profoundly shaped my musical approach."
Theme 3 - Impact of Retraining on Rehabilitation	Emotional Connection	"Playing with Reiko helped deactivate any interference stress that might happen."
	Understanding Dystonia	"I feel like the fifth finger needs to be resurrected due to brain mapping issues."
	Learning and Growth	"The ordeal spurred a deeper hunger to devote myself more to music after dystonia resolution."
	Emotional Well-being	"There was an existential crisis of self-doubt about being a pianist and teacher."
	Creative Expression	"Adapting musical pieces to compensate for technical difficulties creatively."
	Identity Change	"For now, I feel a little bit like a failure or a loser as a pianist."
Theme 4 - Retraining Experience and Support Satisfaction	Future Aspirations	"Assuming I get better, I hope to dedicate myself more to my playing."
	Community Involvement	"Being part of the Abbey Whiteside Music Foundation and organizing concerts."
	Knowledge Sharing	"Participating in online communities to find and offer mutual support."
	Resilience Factors	"Belief in a complementary approach combining Joaquin's and Ruth's teachings for eventual recovery."
	Acceptance Journey	"Acceptance of not playing allowed focus on resolving the underlying issues from the ground up."

	Wellness Habits	"Working on systematic exercises that align with my type of dystonia."
	Resource Availability	"Using online platforms and professional workshops to network and gain support in dystonia treatment."

3. P3

Theme	Code	Exemplar
Theme 1 - A Lack of Prior Awareness	Initial Symptoms	"The note had a slight vibrato, slight tremor that was not intentional."
	Diagnosis Journey	"Spoke to my GP and was referred to the Musicians' Clinics of Canada."
	Barriers to Recovery	"Initial self-diagnosis and traditional medical channels were slow to recognize dystonia."
	Cultural Influences	"Arnold Jacobs' school approach to breathing contrasted with Bronwen's techniques."
Theme 2 - Retraining Journeys: Choices and Commitment	Recovery Journey	"Started meditating and doing aerobic exercise as part of the treatment."
	Therapeutic Approaches	"Working with Bronwen on muscular retraining exercises."
	Therapeutic Challenges	"EMDR did absolutely nothing for me."
	Coping Mechanisms	"I tried Ativan, which lessened the tremor, but I knew it wasn't the answer."
	Role Models	"Influenced by mentors like Dr. Chong and Bronwen Ackerman in exploring treatment options."
Theme 3 - Impact of Retraining on Rehabilitation	Emotional Connection	"When by myself, I can forget myself and just play musically."
	Teaching Influence	"I've been completely open about the dystonia with my students and colleagues."
	Wellness Habits	"Without a doubt, I'm much healthier and less stressed now."
	Identity Change	"I am OK to retire, so I don't feel bitter about the dystonia."
	Personal Growth	"The dystonia became a little friend, a teacher to me, offering growth."
Theme 4 - Retraining Experience and Support Satisfaction	Professional Impact	"The dystonia is still inhibiting my career."
	Support Systems	"My colleagues were amazing and reassured me despite the tremor."
	Knowledge Sharing	"Master classes discussing the experience and treatment with students."
	Resilience Factors	"Encouraged by progress with muscular changes despite ongoing challenges."
	Therapeutic Collaboration	"Two-way collaboration with Bronwen in evolving effective practices and exercises."
	Communication and Openness	"Openly discussing the condition with students to remove stigma and share strategies."

4. P4

Theme	Code	Exemplar
Theme 1 - A Lack of Prior Awareness	Initial Symptoms	"The next day, my arm playing the fiddle no longer worked properly."

	Diagnosis Journey	"Formally diagnosed with dystonia by Roberta Brockman around 1998."
	Barriers to Recovery	"The invisible nature of dystonia made it difficult for others to understand and accept."
	Cultural Influences	"Felt pressure to show off during performances, contributing to stress and eventual dystonia."
Theme 2 - Retraining Journeys: Choices and Commitment	Recovery Journey	"Trial and error approach to exploring neuroplasticity for recovery."
	Therapeutic Approaches	"Focused on stress reduction and neuroplasticity for therapy."
	Therapeutic Challenges	"Initially struggled finding effective retraining resources, leading to a self-directed journey."
	Coping Mechanisms	"Stopped playing the fiddle and devoted more time to therapy and stress reduction."
	Support Systems	"Shared my experiences with colleagues, although not everyone understood the invisible disability."
Theme 3 - Impact of Retraining on Rehabilitation	Emotional Connection	"I feel totally alienated from my body due to dystonia."
	Identity Change	"I have taken more control over my personal life, feeling like a different person."
	Personal Growth	"Learned to connect more with my body and understand its reactions, both physically and emotionally."
	Innovative Practices	"Development of a fiddle harness to facilitate playing without traditional clamping."
	Resilience Factors	"Developed new techniques to overcome challenges, including retraining to play left-handed on the banjo."
	Emotional Well-being	"The connection between my autism and dystonia presents unique emotional challenges."
Theme 4 - Retraining Experience and Support Satisfaction	Professional Impact	"Undertook a straight job in 1984 but continued playing part-time."
	Knowledge Sharing	"Shared ideas of movement retraining and experiences across forums and with friends."
	Therapeutic Collaboration	"Collaborated with physical therapists to uncover effective movement retraining solutions."
	Communication and Openness	"Discussed openly with friends and community, though met with mixed understanding and empathy."
	Resilience Factors	"Encouragement and guidance from a banjo player friend to pursue professional diagnosis and therapy routes."
	Learning and Growth	"Applying neuroplastic understanding into daily routines and long-term therapy approaches."

5. P5

Theme	**Code**	**Exemplar**
Theme 1 - A Lack of Prior Awareness	Initial Symptoms	"I started noticing my right hand was doing crazy things, around 2005-6."
	Diagnosis Journey	"David Leisner diagnosed me with a mild focal dystonia."
	Barriers to Recovery	"Multiple methods tried but none fully rehabilitated me to classical standards."

	Cultural Influences	"Challenged cultural expectations of practice perfection influenced by the Juilliard approach."
Theme 2 - Retraining Journeys: Choices and Commitment	Recovery Journey	"Tried various retraining methods, including the Leisner Method and Fabra's techniques."
	Therapeutic Approaches	"Used Leisner's approach focusing on larger body movements rather than finger movements."
	Therapeutic Challenges	"Leisner method helped marginally, but Pedro Dominic Frasca's fear-based approach was challenging."
	Coping Mechanisms	"During COVID, I did exercises to leave my hand on the guitar strings to cope with fear."
	Role Models	"Followed advice from renowned guitarists like Leisner, trying their methodologies."
Theme 3 - Impact of Retraining on Rehabilitation	Emotional Connection	"I felt betrayed by my guitar and devastated about having focal dystonia."
	Identity Change	"Struggled with the idea of self-worth tied to musical ability, working to separate identity from playing."
	Personal Growth	"Focused on broadening my musical experience, finding joy beyond the classical guitar stereotype."
	Innovative Practices	"Experimented with new music forms and genres to stay engaged creatively, like mandolin and violin."
	Resilience Factors	"Believing in improvement, I persisted with exercises despite setbacks, learning to enjoy music again."
	Emotional Well-being	"The realization of dystonia was a blow, questioning beliefs on practice equals perfection."
Theme 4 - Retraining Experience and Support Satisfaction	Professional Impact	"Devastated that I couldn't play some classical pieces like recuerdos alhambre anymore."
	Knowledge Sharing	"Shared experiences of focal dystonia within guitar circles and online communities."
	Therapeutic Collaboration	"Collaborative approach with Kevin Gallagher using Joaquín Fabra's philosophy provided temporary relief."
	Communication and Openness	"Open dialogues regarding fear-based symptoms and potential solutions brought to light collective experiences."
	Resilience Factors	"Seeking shared understanding and empathy through discussions with musicians."
	Learning and Growth	"Incorporated diverse musical style lessons into routine, reflecting new primary happiness sources."

6. P6

Theme	**Code**	**Exemplar**
Theme 1 - A Lack of Prior Awareness	Initial Symptoms	"I started seeing symptoms in the fall of 2015 before knowing they were dystonia."
	Diagnosis Journey	"In August 2016, I went to a neurologist who suggested Botox, but I was hesitant about it."
	Barriers to Recovery	"Faced emotional challenges and external stressors which made retraining initially difficult."
	Cultural Influences	"Experiencing music conservatory's competitive nature encouraged personal reflection on identity."

Theme 2 - Retraining Journeys: Choices and Commitment	Recovery Journey	"I have engaged in body mapping, neuromuscular retraining, and worked with various therapists."
	Therapeutic Approaches	"Worked with Farias in 2018 for a week, which marked the start of my recovery journey."
	Therapeutic Challenges	"Balancing commitments and therapies was challenging, creating obstacles in personal advancement."
	Coping Mechanisms	"Pursuing various kinds of research and training, keeping a sense of perseverance throughout."
	Support Systems	"The guidance from fellow musicians who had similar experiences helped me navigate my condition."
Theme 3 - Impact of Retraining on Rehabilitation	Emotional Connection	"My whole identity was tied up in being a flute player and teacher, making it hard to adjust."
	Identity Change	"I've grown to accept that being a musician is just one part of who I am."
	Personal Growth	"Increased self-awareness and understanding of teaching strategies as a result of facing focal dystonia."
	Innovative Practices	"Working with crossover methodologies like body mapping to diversify strategy during retraining."
	Resilience Factors	"Perseverance is a gift from my parents that keeps me working hard through challenges."
	Emotional Well-being	"Balancing life roles alongside musical identity presented emotional challenges."
Theme 4 - Retraining Experience and Support Satisfaction	Professional Impact	"Stopped university teaching and performing regularly but continued to play and teach privately."
	Knowledge Sharing	"Participating in transformational teaching groups to improve approaches to instruction."
	Therapeutic Collaboration	"Engagement with peers and other musicians enhanced understanding of multi-faceted recovery approaches."
	Communication and Openness	"Discussed condition candidly with older students, reinforcing teaching about awareness and adjustment."
	Resilience Factors	"Social support from friends and community facilitated management of the process."
	Learning and Growth	"Integrating learnings from therapy led to a more holistic approach to personal life and musical engagement."

7. P7

Theme	Code	Exemplar
Theme 1 - A Lack of Prior Awareness	Initial Symptoms	"My index finger started going under the medium, affecting my plucking."
	Diagnosis Journey	"Diagnosed with task-specific focal dystonia at Roosevelt Hospital but received no treatment initially."
	Barriers to Recovery	"Reported worsened symptoms after attending the Terrassa clinic in Spain."
	Cultural Influences	"Cultural stigma around classical guitar in the 60s influenced career changes."

Theme 2 - Retraining Journeys: Choices and Commitment	Recovery Journey	"Worked with David Leisner and attended a retraining clinic in Spain."
	Therapeutic Approaches	"Partial recovery through Leisner's method emphasizing arm rather than finger movement."
	Therapeutic Challenges	"Noted that splinting and brain confusion therapies worsened his condition."
	Coping Mechanisms	"Pursued sculpting as an alternative creative outlet when playing guitar was no longer enjoyable."
	Support Systems	"Engaged with Facebook communities and peers to discuss experiences with dystonia."
Theme 3 - Impact of Retraining on Rehabilitation	Emotional Connection	"The condition wiped me out, affecting my identity as a musician."
	Identity Change	"Described self-reflection after dystonia as challenging, resulting in a shift toward visual arts."
	Personal Growth	"Gained deeper insights into music and ergonomics through learning and teacher interactions."
	Innovative Practices	"Explored unique methods like brain confusion but found limited success."
	Resilience Factors	"Persevered through various therapies despite limited success, maintaining hope for improvement."
	Emotional Well-being	"Described living with dystonia as a lingering and frustrating experience."
Theme 4 - Retraining Experience and Support Satisfaction	Professional Impact	"Unable to perform, transitioned to sculpture while maintaining music as a secondary passion."
	Knowledge Sharing	"Shared insights on genetic links of dystonia with peers and in public forums."
	Therapeutic Collaboration	"Worked with multiple therapists seeking holistic understanding of dystonia management techniques."
	Communication and Openness	"Discussed dystonia openly within guitarist circles, despite prevalent fear and lack of understanding."
	Resilience Factors	"Peers were often concerned about dystonia, affecting general perception within music communities."
	Learning and Growth	"Adopted education about genetics and ergonomics in personal and community discussions."

8. P8

Theme	**Code**	**Exemplar**
Theme 1 - A Lack of Prior Awareness	Initial Symptoms	"Noticed something wrong with my third and fourth fingers; they were not cooperating."
	Diagnosis Journey	"First noticed focal dystonia symptoms while preparing for the Trinity licentiate."
	Barriers to Recovery	"Struggled with online training due to lack of motivation and structured reward system."
	Cultural Influences	"Instrumental adaptability, such as switching from left hand to right, reflects flexibilities in practice."

Theme 2 - Retraining Journeys: Choices and Commitment	Recovery Journey	"Used Alexander Technique for movement awareness and began using weights during exercise for improvement."
	Therapeutic Approaches	"Tried Dr. Farias' online workshops and movement retraining methods but found limited success."
	Therapeutic Challenges	"Unable to sustain progress due to lack of a systematic reward and feedback system in online programs."
	Coping Mechanisms	"Focuses on motivation and reward systems for perseverance, leveraging positive performance experiences."
	Support Systems	"Friend's insistence led to unexpected successful performance preparation."
Theme 3 - Impact of Retraining on Rehabilitation	Emotional Connection	"Felt a disconnect with my hand but experienced improvement through focused practice."
	Identity Change	"Reevaluated expectations and embraced new approaches to remain musically active."
	Personal Growth	"Learned to connect more with my body and understand its reactions, both physically and emotionally."
	Innovative Practices	"Discovered exercising with weights improved tactile sensory feedback in hand."
	Resilience Factors	"Persistence due to motivation and love for music despite the challenges posed by dystonia."
	Emotional Well-being	"Acknowledges stress impacts symptoms; uses self-management and compensation strategies."
Theme 4 - Retraining Experience and Support Satisfaction	Professional Impact	"Post-diagnosis adjusted how and where to perform, as well as practice methodologies."
	Knowledge Sharing	"Learned from and shared insights with a violin professor about beneficial practice patterns."
	Therapeutic Collaboration	"Developed exercises after consulting with Alexander Technique and multiple specialists guiding adaptation."
	Communication and Openness	"Shared challenges of selecting weighted and non-weighted exercises with a peer group to find improvement."
	Resilience Factors	"Experimented with advice from peers knowledgeable in both music and medical subjects advancing improvement."
	Learning and Growth	"Integration of new practice techniques emphasizing stability informed by learned expertise improved education focus."

9. P9

Theme	Code	Exemplar
Theme 1 - A Lack of Prior Awareness	Initial Symptoms	"Experienced inability to control ring finger and pinkie, feeling it could be due to stress or lack of practice."
	Diagnosis Journey	"A hand specialist suggested it might be focal dystonia, confirmed later by other neurologists."
	Barriers to Recovery	"Initial diagnoses led to confusion and suggestions to quit music creating emotional barriers."

	Cultural Influences	"Pressures from classical music culture initially impacted the acceptance of necessary technique adaptations."
Theme 2 - Retraining Journeys: Choices and Commitment	Recovery Journey	"Travelled to Seville for retraining with Dr. Farias after being encouraged by my wife."
	Therapeutic Approaches	"Dr. Farias' retraining focused on perception and self-awareness techniques that improved finger coordination."
	Therapeutic Challenges	"Initial hopelessness did not vanish quickly, necessitating commitment to retraining methodologies."
	Coping Mechanisms	"Accepted the need for retraining and adopted an open mindset to explore recovery avenues."
	Support Systems	"Encouragement from my wife was pivotal in seeking further treatment options."
Theme 3 - Impact of Retraining on Rehabilitation	Emotional Connection	"Felt hopeless due to abnormal finger movements, regained hope through retraining progress."
	Identity Change	"Rediscovered my musical self through therapeutic exercises and refined self-perception techniques."
	Personal Growth	"Gained deeper insights into music and ergonomics through learning and teacher interactions."
	Innovative Practices	"Utilized specific conscious exercises designed by Dr. Farias to tackle focal dystonia's unique challenges."
	Resilience Factors	"Recovered motivation from seeing improvement with Dr. Farias' methods, renewing hope for full recovery."
	Emotional Well-being	"Experienced emotional lows and highs, feeling powerful at times and incapable at others."
Theme 4 - Retraining Experience and Support Satisfaction	Professional Impact	"Faced with the prospect of quitting music due to physical limitations, retraining offered a way back."
	Knowledge Sharing	"Shared insights about focal dystonia and the critical role of self-perception in playing."
	Therapeutic Collaboration	"Engaged in individualized therapy with Dr. Farias emphasizing patient-centred progress benchmarks."
	Communication and Openness	"Disclosed experiences and treatment progress to normalize conversations about dystonia among musicians."
	Resilience Factors	"Peers' sharing of successful recovery journeys reinforced belief in therapeutic possibilities."
	Learning and Growth	"Incorporated learned techniques into everyday practice, improving ease and musical enjoyment."

Appendix N: Axial Code Book – Study 3

Axial Code Book – Study 3
1.P1.

Main Theme	Sub-theme	Related Theme	Description	Code Name	Quote
Personal Journeys of Adaptation	Impact of Diagnosis	Emotional and Psychological Impact	Process and challenges in receiving a diagnosis affected emotional health.	Diagnostic Frustration	" The family doctor had no idea what was going on, so I got a referral to an orthopaedic specialist. I wasted a lot of time for nothing."
Personal Journeys of Adaptation	Impact of Diagnosis	Emotional and Psychological Impact	Understanding the condition as incurable caused emotional distress.	Rejection of No Cure	"You don't cure yourself by just treating symptoms."
Personal Journeys of Adaptation	Impact of Diagnosis	Emotional and Psychological Impact	Feeling abandoned by medical professionals impacted emotional well-being.	Feeling Abandoned	"I took six weeks off at the beginning expecting to be back at work for the start of the season. You just have no notion of how long this stuff takes until you're in it."
Personal Journeys of Adaptation	Resilience and Motivation	Innovation and Creativity in Retraining	Motivation to address issues independently drove creative retraining methods.	Seeking Personal Solutions	"Started looking for ways to address the issue myself."
Personal Journeys of Adaptation	Resilience and Motivation	Emotional and Psychological Impact	Realising the need to focus on self rather than others.	Emotional Growth	"I compared myself to others and was [always] getting down about it. Then this [dystonia] just slaps you in the face. It's such a waste of time, nobody cares how you play anyway, let's be honest."

Personal Journeys of Adaptation	Resilience and Motivation	Innovation and Creativity in Retraining	Drive to self-teach and solve problems creatively.	Learning Tricks; Hands-On Problem Solving	" “I need to feel fully connected to my movements, not just going through a sequence of exercises.”
Personal Journeys of Adaptation	Coping Strategies	Emotional and Psychological Impact	Utilising Tai Chi and alternative methods as coping and rehabilitation strategies.	Tai Chi Influence; Seeking Alternative Methods	"Tai Chi has been the most helpful and significant factor in my improvement."
Innovation and Creativity in Retraining	Self-Developed Techniques	Personal Journeys of Adaptation	Developing personalised approaches informed by personal experiences for retraining.	Tai Chi Adoption; Personalised Rehabilitation	"Adopting Tai Chi as a form of rehabilitation."
Innovation and Creativity in Retraining	Multi-facetted Approaches	Emotional and Psychological Impact	Using parallels between Tai Chi and piano techniques enhanced adaptability.	Similarity in Movement	“I can really connect the body, so I feel strong. One example that’s good to do, balancing work like the ‘single whip’, moving outwards, every limb It’s a common tai-chi sequence. Then I sit at the piano, repeat and then I play. It lets you feel all the sensations of the hands and fingers on the keys.”
Innovation and Creativity in Retraining	Integrating Approaches	Emotional and Psychological Impact	Merging Western and Chinese medicine helped gain emotional support through diverse methods.	Use of Both Medical Systems	"Living in Hong Kong, we have access to both Chinese medicine and Western doctors..."
Impact of Self-Developed Retraining on Musicians' MD	Positive Impacts	Innovation and Creativity in Retraining	Improvement attributed to self-developed techniques like Tai Chi.	Improvement through Tai Chi; Personal Belief in Cure	"Tai Chi has been the most helpful...I believe I’ve cured the issue."

Impact of Self-Developed Retraining on Musicians' MD	Negative Impacts	Emotional and Psychological Impact	Encountered persistent challenges and frustration due to self-methods initially not solving the issue.	Diagnostic Challenges	"None of them could explain what was happening."
Impact of Self-Developed Retraining on Musicians' MD	Strategies for Balance	Personal Journeys of Adaptation	Balancing personal experimentation with structured learning experiences.	Adaptive Learning Experience	“When I have to think about how I move I lose the expression. Sometimes I’m playing and then realise that I have no idea what I’m trying to say, musically. That is still the worst thing for me sometimes”.
Emotional and Psychological Impact	Anxiety and Stress	Personal Journeys of Adaptation	Performance challenges increased anxiety and stress levels.	Performance Pressure	“I like to make quiet time to think about what I’m doing or it’s just too stressful to focus. When I’m in that state I can try things out without overthinking things.”
Emotional and Psychological Impact	Emotional Well-Being	Innovation and Creativity in Retraining	Positive emotional outcomes from continuous personal improvement.	Continuity of Progress	“When I’m calm then I work things out well. I always try to be in a calm state. If I can’t then I do something else. I need a positive experience when I play or there’s no point.”
Emotional and Psychological Impact	Emotional Support Systems	Personal Journeys of Adaptation	Support from family and networks proved essential for emotional resilience.	Social Support Systems	“I like to keep connected to people online otherwise I can get pretty fussed up on

					my own. I like to share my ideas as well."
Retrospective Insight	Self-Reflection	Personal Journeys of Adaptation	Reflection on alternative practices like Tai Chi revealed personal growth.	Adoption of Alternative Practices	"Because of this, I began searching for another method."
Retrospective Insight	Lessons Learned	Emotional and Psychological Impact	Observations and insights gained fostered self-awareness and growth.	Sharing Observations	"I share a lot of my thoughts and ideas online. I get a lot of feedback which I need to have. I'm less unsure about things then."
Retrospective Insight	Regrets and Missed Opportunities	Innovation and Creativity in Retraining	Past regrets about inefficacy led to the drive for new methods and problem solving.	Proving Oneself	"I really dedicated myself...to prove to myself that I could play the piano."

2.P2

Main Theme	**Sub-theme**	**Related Theme**	**Description**	**Code Name**	**Quote**
Personal Journeys of Adaptation	Impact of Diagnosis	Emotional and Psychological Impact	The experience and process of receiving a diagnosis affected emotional health.	Diagnosis of Focal Dystonia; Formal Diagnosis	I was actually only diagnosed last year. I have had so many tests over the past few years, and I was repeatedly told I was physically fine, that it was psychological. I kind of found out first on my own, that it wasn't."
Personal Journeys of Adaptation	Impact of Diagnosis	Emotional and Psychological Impact	Misdiagnosis or misunderstanding by professionals initially hampered emotional resilience.	Initial Misdiagnosis; Misjudgement by Professionals	"Initially, a physiotherapist and orthopaedist believed I had injured connective or muscle tissue."
Personal Journeys of Adaptation	Impact of Diagnosis	Emotional and	Limited treatment options offered	Lack of treatment options	"The only suggestion at the clinic was

		Psychological Impact	at time of diagnosis.	suggested by Professionals	Botox [botulinum toxin injections]. No one was there to do it and I was quickly going downhill, so I left. I thought sod it, I'm on my own."
Personal Journeys of Adaptation	Resilience and Motivation	Innovation and Creativity in Retraining	Motivation to address issues and pursue retraining fuelled by the desire to play again.	Motivation for Retraining; Rationale Behind Retraining	"My primary motivation was to play again."
Personal Journeys of Adaptation	Coping Strategies	Emotional and Psychological Impact	Developing methods to manage performance anxiety and face dystonia challenges.	Mental Approach	"One promising method was Dr Joaquin Fabra's mental and emotional approach—allowing mistakes and working through them."
Innovation and Creativity in Retraining	Self-Developed Techniques	Personal Journeys of Adaptation	Developing new strategies and training protocols informed by personal experiences.	Developing Protocols; Conditioning Background Influence	"My background in conditioning helped develop behavioural intervention protocols for retraining."
Innovation and Creativity in Retraining	Self-Developed Techniques	Personal Journeys of Adaptation	Focus and understanding of retraining	Developing Protocols; Conditioning Background Influence	"If I really understand what it is I'm working at then I just carry on until it's better. I treat it like a project more than rehabilitation."
Innovation and Creativity in Retraining	Multi-faceted Approaches	Emotional and Psychological Impact	Utilising varied approaches and external expert input to manage dystonia creatively.	Slow Practice; Sports Techniques Application	"I then explored slow practice exercises by Dr Nagataka Sakai in Japan, which allowed me to improve somewhat."
Innovation and Creativity in Retraining	Integrating Approaches	Emotional and Psychological Impact	Combining sports and music techniques to enhance adaptation and	Influence of Sports Techniques	"Much like neural circuit training in sports, he proposed that applying speed bursts could

			creativity in retraining.		address focal dystonia."
Impact of Self-Developed Retraining on Musicians' MD	Positive Impacts	Innovation and Creativity in Retraining	Successful self-developed training showing improvement and progression.	Gradual Progress; Transitioning from Splint	“I’ll give most things a try, really. My thoughts are, there’s no cure out there for me, so I’ll stir the pot until there is.”
Innovation and Creativity in Retraining	Multi-faceted Approaches	Personal Journeys of Adaptation	Developing and adjusting techniques to accommodate and account for dystonia's impact.	Seeing the big picture	“When you can see the big picture, that’s when all the bad days start to mean less and less.”
Impact of Self-Developed Retraining on Musicians' MD	Negative Impacts	Emotional and Psychological Impact	Initial missteps in self-developed methods and recovery setbacks required adjustment.	Sense of Achievement; Syndrome Awareness	"I began researching dystonia...reading every paper on dystonia available at the time."
Impact of Self-Developed Retraining on Musicians' MD	Strategies for Balance	Personal Journeys of Adaptation	Balancing practice perfection with room for error allowed progression without strain.	Balancing Perfectionism; Emotional Resilience	“We need to know where our centre is and be balanced inside, then you can start working properly on the playing.”
Emotional and Psychological Impact	Anxiety and Stress	Personal Journeys of Adaptation	Managing anxiety related to performance pressure through strategic mental approaches.	Mental Approach	"One promising method was Dr Joaquin Fabra's mental and emotional approach—allowing mistakes and working through them."
Emotional and Psychological Impact	Emotional Well-Being	Innovation and Creativity in Retraining	Emotional resilience was boosted by acknowledging imperfections as part of recovery.	Emotional Resilience	“There was no two-way contact really. You need to take a big leap of faith to believe it’ll work.”
Emotional and Psychological Impact	Emotional Support Systems	Personal Journeys of Adaptation	Peer support and expert consultation were essential in managing	Encouragement from Peers	"Speaking with redacted in the U.S., a musician familiar with focal dystonia..."

			emotional challenges.		
Retrospective Insight	Self-Reflection	Personal Journeys of Adaptation	Reflecting on training protocols and discovering effective solutions through experimentation.	Experimentation with Techniques; Methodological Exploration	"Applying speed bursts in unconventional contexts like block chords."
Retrospective Insight	Lessons Learned	Emotional and Psychological Impact	Learning from missteps in previous practices to optimize future playing techniques.	Viewing Mistakes as Learning	"Allowing mistakes and working through them."
Retrospective Insight	Regrets and Missed Opportunities	Innovation and Creativity in Retraining	Developing flexibility and reevaluating prior stringent habits enabled advanced recovery.	Flexibility in Approach	"I tried several approaches."

3.P3

Main Theme	**Sub-theme**	**Related Theme**	**Description**	**Code Name**	**Quote**
Personal Journeys of Adaptation	Impact of Diagnosis	Emotional and Psychological Impact	The journey of receiving a diagnosis and its emotional aftermath significantly affected Oliver.	Diagnosis Timeline; Initial Misdiagnosis; Impact of Incorrect Diagnosis; Emotional Impact of Diagnosis	"He told me there was no cure, and that it would be best for me to give up playing the violin." "Hearing something like that from a professional is very hard to process."
Personal Journeys of Adaptation	Resilience and Motivation	Innovation and Creativity in Retraining	Oliver's motivation to continue with music or consider alternative paths showcased his resilience.	Exploring Alternative Music Paths; Isolation in Dealing with Symptoms; Role of Faith in Treatment	"Waiting for my doctor wasn't helpful. Feeling useless doesn't help either. I just got my f* you hat on and went for it."
Personal Journeys of Adaptation	Coping Strategies	Emotional and	Coping with professional advice, social	Conflicting Advice from Professionals;	"Some colleagues noticed as

		Psychological Impact	misconceptions, and isolation was challenging but necessary for Oliver.	Social Misconceptions	well, and it was quite hard to bear, hearing comments implying that... I simply wanted a leisurely life..."
Innovation and Creativity in Retraining	Self-Developed Techniques	Personal Journeys of Adaptation	Developing and adjusting techniques to accommodate and account for dystonia's impact.	Teacher Influence on Dystonia Development; Adaptation of Technique; Evolving Practice Strategies	"Introduce relaxation space for the fingers, identifying my tension existed in the palm."
Innovation and Creativity in Retraining	Multi-faceted Approaches	Emotional and Psychological Impact	Exploring various methods and adjusting strategies in response to perceived limitations.	Vision vs. Reality of Physical Ability; Realization of Prior Unhealthy Techniques; Emphasis on Balance and Perception	"Perfectionism likely contributes more than dystonia."
Innovation and Creativity in Retraining	Integrating Approaches	Emotional and Psychological Impact	Combining self-reliance with professional insights to innovate new practice methods.	Process of Retraining and Belief; Emotional and Psychological Effects of Retraining	"Faith: you resolved to do it daily."
Impact of Self-Developed Retraining on Musicians' MD	Positive Impacts	Innovation and Creativity in Retraining	Progress and personal growth witnessed through individual retraining efforts.	Initial Progress in Retraining; Personal Growth and Development with slow work.	“Doing twenty minutes of it [mindfulness] before my slow exercise work, and there you go. I can play stuff better. It makes a big difference.”
Impact of Self-Developed Retraining on Musicians' MD	Negative Impacts	Emotional and Psychological Impact	Emotional scarring and frustrations from past experiences sought redemption through retraining.	Emotional Scarring from Early Teaching Experiences; Coping with Setbacks	"Considering everything... times when it felt like progress wasn’t happening."
Impact of Self-Developed	Strategies for Balance	Personal Journeys of Adaptation	Balancing practice perfectionism	Emphasis on Balance and Perception;	"Subsequently, things

Retraining on Musicians' MD			with flexibility facilitated progress.	Shift from Rigidity to Flexibility; Understanding Changes in Technique	became more flexible."
Emotional and Psychological Impact	Anxiety and Stress	Personal Journeys of Adaptation	Emotional struggles in coping and accepting dystonia while pursuing personal development.	Emotional Impact of Diagnosis; Emotional and Psychological Effects of Retraining	“It’s no fun worrying about things you try not working out. I always make sure I begin exercise sessions in a calm state. It makes a lot of sense to me nowadays. If I’m feeling stressed out, there’s no point.”
Emotional and Psychological Impact	Emotional Well-Being	Innovation and Creativity in Retraining	Transformation and a new-found sense of self improved emotional well-being.	Redemption through Self-Acceptance; Internal Transformation; Changing Self-Perception	“It’s hard to deal with the dead ends or things that don’t work. That’s when I’m thinking, should I just give up?”
Emotional and Psychological Impact	Emotional Support Systems	Personal Journeys of Adaptation	Support from professional networks and social circles enhanced coping ability.	Support Networks; Professional Support	“You have to be humble. Dystonia doesn’t have room for ego."
Retrospective Insight	Self-Reflection	Personal Journeys of Adaptation	Reflecting on early experiences brought awareness of previously unhealthy practices.	Emotional Scarring from Early Teaching Experiences; Challenge of Altering Ingrained Habits	“I started noticing, there was also an emotional connection that had to be addressed. Without getting into that, I was up against it, I think."
Retrospective Insight	Lessons Learned	Emotional and Psychological Impact	Gained insight led to refined techniques and corrective approaches towards healthy playing techniques.	Understanding Changes in Technique; Importance of Rhythm in Recovery	"In classes... adaptation in fingering came naturally."

Retrospective Insight	Lessons Learned	Emotional and Psychological Impact	Learnt that dealing with stress was fundamental to the process.	Understanding Changes in Technique; Importance of Rhythm in Recovery	“When you learn to deal with your stress, then you can deal with the dystonia. The two walk hand in hand in my opinion.”
Retrospective Insight	Regrets and Missed Opportunities	Innovation and Creativity in Retraining	Moving beyond previous setbacks enabled exploring new avenues for musical expression.	Perception of Physical Appearance; Adaptability as Strength	"Adaptability or the capacity for change is something not everyone possesses."

4.P4

Main Theme	**Sub-theme**	**Related Theme**	**Description**	**Code Name**	**Quote**
Personal Journeys of Adaptation	Impact of Diagnosis	Emotional and Psychological Impact	The process of receiving the dystonia diagnosis, along with emotional struggles and additional diagnoses.	Diagnostic Challenges; Emotional Challenges with Diagnosis	"I have had so many tests over the past few years, and I was repeatedly told I was physically fine."
Personal Journeys of Adaptation	Resilience and Motivation	Innovation and Creativity in Retraining	Motivation to adapt lifestyle and music practice, integrating various therapeutic methods.	Meditation and Yoga Practices; Yoga's Role in Preparation for Playing; Relearning Techniques	“I was [still] really confused after deciding I needed to retrain myself. I needed a quick fix. I remember being so worried all the time. Obviously, this was counter intuitive.”
Personal Journeys of Adaptation	Coping Strategies	Emotional and Psychological Impact	Developing coping mechanisms and emotional release to manage stress	Childhood OCD Impact; Emotional Release Through Music; Coping	"Meditation. I always go back to that really."

			and anxiety associated with dystonia.	Mechanisms for Emotional Lows	
Innovation and Creativity in Retraining	Self-Developed Techniques	Personal Journeys of Adaptation	Personalised techniques and adjustments informed by body feedback and community insights.	Simplified Repertoire for Retraining; Flexible Routine Adjustments; Body-Mapping Awareness	"Adjust my routine based on feedback from my body."
Innovation and Creativity in Retraining	Multi-faceted Approaches	Emotional and Psychological Impact	Exploring variety in therapies, dietary changes, and body awareness to manage symptoms.	Alternative Therapies and Treatments; Dietary Changes	"He suggested that I do therapeutic massage as well as carry on with what I'd been doing with yoga."
Innovation and Creativity in Retraining	Integrating Approaches	Emotional and Psychological Impact	Integration of music-specific practice techniques with broader wellness practices for holistic retraining.	Multiple Medical Opinions; Physical Therapy Insights; Self-Assessment Through Recordings	"I do some position changes, like 1st to 4th position."
Impact of Self-Developed Retraining on Musicians' MD	Positive Impacts	Innovation and Creativity in Retraining	Positive improvements noticed in musical technique and emotional stability through retraining.	Notable Improvements in Technique; Regaining Skills	"I do think back a lot. I was so wound up all the time. You don't enjoy it [playing] when you're feeling like cr*p twenty-four seven. It's no wonder I got sick really. Now I can breathe when I play. Even when I can't play, it's in colour again."
Impact of Self-Developed Retraining on Musicians' MD	Negative Impacts	Emotional and Psychological Impact	Setbacks and stress persist, necessitating continuous adaptation and management.	Feeling of Loss and Frustration; Managing Setbacks and Stress	"Every time I played; I was expecting it to fail. Musically, I was empty really, no idea what to do at the time. Like a student again with

					shaky fingers, I suppose.”
Impact of Self-Developed Retraining on Musicians' MD	Strategies for Balance	Personal Journeys of Adaptation	Balancing consistent practice with flexibility in routine to accommodate changing conditions.	Effectiveness of Methods; Challenges in Retraining Execution	"Knowing what to do and when I think. Also, for how long."
Emotional and Psychological Impact	Anxiety and Stress	Personal Journeys of Adaptation	Emotional challenges due to perfectionism and associated stress with performance and practice.	Effects of Perfectionism; Managing Setbacks and Stress	"Perfectionism is a symptom of dystonia right? I would get stuck sometimes..."
Emotional and Psychological Impact	Emotional Well-Being	Innovation and Creativity in Retraining	Enhanced emotional well-being through acceptance and community interaction.	Connection with Other Musicians; Retraining’s Psychological Impact	“I know what I need to work at any one time nowadays. I improve as long as I have my action plan in my head.”
Emotional and Psychological Impact	Emotional Support Systems	Personal Journeys of Adaptation	Reliance on family and community support systems for emotional resilience and encouragement.	Community Support Importance; Value of Family Support	"Family support definitely. I’m really lucky in that way."
Retrospective Insight	Self-Reflection	Personal Journeys of Adaptation	Reflection on personal growth and learning experiences through self-driven retraining.	Independence in Retraining; Importance of Customization	“It’s so hard, but you have to just do it over and over. A bit of contact every day with the instrument, at least. That’s so important, for me at least, to keep motivated.”
Retrospective Insight	Lessons Learned	Emotional and Psychological Impact	Insights gained facilitated better self-management of both emotional and physical responses.	Awareness of Muscular Tension; Challenges with Vibrato	"I realised that my vibrato makes me push too hard with the thumb..."

Retrospective Insight	Regrets and Missed Opportunities	Innovation and Creativity in Retraining	Adaptation and flexibility helped reclaim missed opportunities in musical expression.	Advice for Others with Dystonia; Motivation and Perseverance	“We have to be more open about dystonia and talk about it, particularly in orchestras. When you find out that people knew and didn’t think to tell you about it, that’s makes my blood boil really.”

5. P5

Main Theme	Sub-theme	Related Theme	Description	Code Name	Quote
Personal Journeys of Adaptation	Impact of Diagnosis	Emotional and Psychological Impact	Recognising and diagnosing dystonia was challenging and emotionally distressing.	Onset of Dystonia Symptoms; Diagnostic Challenges	“There was no follow-up really. Nothing was really made clear, and I ended up filling in the gaps on my own anyway.”
Personal Journeys of Adaptation	Resilience and Motivation	Innovation and Creativity in Retraining	Eli's motivation and interest in neuroscience led to exploring neuroplasticity and self-retraining.	Self-diagnosis and Research; Interest in Neuroplasticity	"I found the [redacted] group online... that’s when I really got interested in neuroplasticity. "
Personal Journeys of Adaptation	Coping Strategies	Emotional and Psychological Impact	Coping mechanisms included taking breaks from playing and focusing on mindfulness and bodily awareness.	Importance of Breaks; Focus on Mindfulness	“For me, I don’t know. I had to be my own boss; I had no choice. In my situation, there was nothing else to do.”
Innovation and Creativity in Retraining	Self-Developed Techniques	Personal Journeys of Adaptation	Eli developed personalised retraining techniques focusing on biomechanics	Focus on Full-Body Coordination; Personalised Exercises	"I then got into the whole stuff about muscle chains...I started doing some

			and full-body awareness.		swimming as well."
Innovation and Creativity in Retraining	Multi-faceted Approaches	Emotional and Psychological Impact	Eli integrated techniques from various disciplines like Feldenkrais to aid in body awareness and retraining.	Integration of Feldenkrais Techniques; Comprehensive Approaches	“I started by just watching how my body reacted in different playing situations. At first, I was quick to criticise myself, but then I realised that simply noticing what happens in my hands or my breath was powerful. It helped me know when to stop or adjust without feeling guilty.”
Innovation and Creativity in Retraining	Integrating Approaches	Emotional and Psychological Impact	Techniques combined physical therapy insights with psychological and emotional readiness.	Emotional Readiness; Physical Therapy Insights	"Fix the rest and then the hand, you know?"
Impact of Self-Developed Retraining on Musicians' MD	Positive Impacts	Innovation and Creativity in Retraining	Witnessed physical improvement and reduced anxiety through personalised retraining strategies.	Physical Improvement; Reduced Anxiety	"I feel like, ‘no pressure’ which was really good."
Impact of Self-Developed Retraining on Musicians' MD	Negative Impacts	Emotional and Psychological Impact	Frustrations with slow progress and sustaining motivation were ongoing challenges during retraining.	Frustration with Slow Progress	"It’s slow and monotonous after a while, slow progress."
Impact of Self-Developed Retraining on Musicians' MD	Strategies for Balance	Personal Journeys of Adaptation	Emphasizes the balance of rest, practice, and adapting new techniques to accommodate changing	Balance of Rest and Practice; Adaptation to Physical Needs	"I know when I need to stop for a bit."

			physical needs.		
Emotional and Psychological Impact	Anxiety and Stress	Personal Journeys of Adaptation	Music performance anxiety decreased with the development of self-awareness and acceptance.	Decreased Performance Anxiety; Development of Self-awareness	"Maybe I am less anxious about things in general."
Emotional and Psychological Impact	Emotional Well-Being	Innovation and Creativity in Retraining	Emotional resilience was enhanced through the use of diverse retraining methodologies and community support.	Emotional Resilience through Retraining; Community Support	"I certainly have an open ear for any problems they might have as well."
Emotional and Psychological Impact	Emotional Support Systems	Personal Journeys of Adaptation	Support from peers and experts was crucial for emotional stability and practical guidance.	Importance of Peer Support; Expert Guidance	"I also talked to [redacted] who does a lot of Feldenkrais, she really helped me."
Retrospective Insight	Self-Reflection	Personal Journeys of Adaptation	Reflection on past practices and openness to trying new methods improved self-knowledge and adaptability.	Reflection on Past Practices; Openness to New Methods	"I suppose I wish that I'd listened to my body more as well."
Retrospective Insight	Lessons Learned	Emotional and Psychological Impact	Learning to listen to his body and prioritize well-being offered valuable insights for future practice.	Prioritising Well-being; Valuable Insights for Future	"I don't feel invincible anymore, it sometimes feels a bit late."
Retrospective Insight	Regrets and Missed Opportunities	Innovation and Creativity in Retraining	Openness to adopt creative methods was spurred by the necessity to manage dystonia, overcoming prior limitations.	Overcoming Limitations; Creative Method Adoption	"I'm definitely more aware of everything. I think that I've improved my overall feeling..."

6. P6

Main Theme	Sub-theme	Related Theme	Description	Code Name	Quote
Personal Journeys of Adaptation	Impact of Diagnosis	Emotional and Psychological Impact	Frank's journey to recognising and accepting his dystonia was marked by confusion and emotional struggle.	First Signs of Dystonia; Physical Symptoms Description; Misinterpretation of Symptoms	"2016 was the first “bout” I suppose you could say."
Personal Journeys of Adaptation	Resilience and Motivation	Innovation and Creativity in Retraining	Frank's determination to continue his music career led to developing new coping and retraining strategies.	Exercise for Retraining; Pragmatic Approach to Challenges	“I was just doing everything slowly, by myself. I probably spent a year really going slow at things. It seemed like the right thing to do, oh, and I was also tying fingers together with lollipop sticks and shoelaces.”
Personal Journeys of Adaptation	Coping Strategies	Emotional and Psychological Impact	Frank managed his symptoms with self-reliance and DIY techniques, navigating undiagnosed symptoms.	Coping with Undiagnosed Symptoms; DIY Approach to Solutions; Innovative Splinting Techniques	"I've always been a bit of a DIY guy, so even before knowing about the dystonia..."
Innovation and Creativity in Retraining	Self-Developed Techniques	Personal Journeys of Adaptation	Developed personalised techniques to maintain musical role, including changes to his instrument setup.	Focus on Muscle Memory; Routine Adaptation	“I do mindfulness and mental imagery work first. Then, when I do the practical session afterwards, I brain-spot together with the exercises which focuses everything together.”

Innovation and Creativity in Retraining	Multi-faceted Approaches	Emotional and Psychological Impact	Integration of various therapeutic methods and practices to enhance physical awareness and retraining.	Need for Body Awareness Techniques; Flexible Practice Approach	“You always stick at it until it comes right.”
Innovation and Creativity in Retraining	Integrating Approaches	Emotional and Psychological Impact	Combined physical and mental exercises to adapt techniques in response to dystonia.	Impact on Social Relationships; Mental Coping Strategies	"I knew that I wasn’t ok, but I knew that I would be ok."
Impact of Self-Developed Retraining on Musicians' MD	Positive Impacts	Innovation and Creativity in Retraining	Frank witnessed notable progress in performance and teaching style through his efforts.	Notable Progress Timeframe; Increased Mindfulness and Self-Awareness	"I’m definitely far more self-aware and mindful."
Impact of Self-Developed Retraining on Musicians' MD	Negative Impacts	Emotional and Psychological Impact	Struggled with isolation and the emotional consequences of self-developed treatment.	Isolation During Challenges; Isolation as a Challenge	“It’s simple getting confused about what to do or which way to go next. It can be exhausting until it’s sorted.”
Impact of Self-Developed Retraining on Musicians' MD	Strategies for Balance	Personal Journeys of Adaptation	Balancing technical adjustments with musical expression helped maintain performance abilities.	Balancing Technical and Musical Aspects; Survival During Performances	"I’m definitely very different now, as a player."
Emotional and Psychological Impact	Anxiety and Stress	Personal Journeys of Adaptation	Anxiety and stress were managed through positive reflections and adjusting expectations.	Enjoyment Despite Limitations; Distractions as Coping Mechanism	“If you try to work to a return date it just gets more and more stressful. You have to let go time limits. You can’t improve under duress.”

Emotional and Psychological Impact	Emotional Well-Being	Innovation and Creativity in Retraining	Emotional stability achieved through positive support networks and effective coping mechanisms.	Valuing Chamber Music; Influence on Teaching Style	"Teaching especially—I try to pass on what I've learned about body mechanics... "
Emotional and Psychological Impact	Emotional Support Systems	Personal Journeys of Adaptation	Support from teaching and mentorship roles offered necessary emotional support and connection.	Teaching as a Stable Element; Personal Humility in Teaching	"there's definitely a personal connection there that I don't think I had before."
Retrospective Insight	Self-Reflection	Personal Journeys of Adaptation	Reflected on teaching methods and personal growth, illustrating enhanced connection with students.	Advice for Young Musicians; Impact on Musical Identity	"I can observe myself as I play now without worrying what anyone else thinks. When I was at rock bottom I could see what I needed to do without freaking out."
Retrospective Insight	Lessons Learned	Emotional and Psychological Impact	Recognition of previous limitations facilitated the adoption of improved approaches and habits.	Dealing with Negative Emotions; Adjusting Musical Repertoire	I call it ego death. It was really like mourning a real death, and once I got over old "me", things started to work out. It was a necessary process for me, I needed to do it a long time ago."
Retrospective Insight	Regrets and Missed Opportunities	Innovation and Creativity in Retraining	Valued the ability to improve personal and musical identity while overcoming prior	Reflection on Past Training; Medication Side Effects	"I'd definitely recommend doing things like the Alexander Technique..."

			misconceptions .		

7. P7

Main Theme	Sub-theme	Related Theme	Description	Code Name	Quote
Personal Journeys of Adaptation	Impact of Diagnosis	Emotional and Psychological Impact	Nelly experienced emotional upheaval and uncertainty due to dystonia diagnoses and misdiagnoses.	Emotional Impact of Uncertain Diagnoses; Inadequate Early Medical Diagnosis	“I finally saw a neuro [logist] who told me what it was, but then she lost interest. I didn’t want Botox, so she suggested I do some physio or something. That was it.”
Personal Journeys of Adaptation	Resilience and Motivation	Innovation and Creativity in Retraining	Nelly's determination to re-engage with her music fueled her exploration of self-retraining techniques.	Personal Determination to Return to Music; Innovations in Self-Retraining Techniques	"I started trying things out on my own. Changing positions and stuff like that."
Personal Journeys of Adaptation	Coping Strategies	Emotional and Psychological Impact	Nelly utilised mindfulness, family support, and community music-making to manage stress and emotional health.	Positive Impact of Performing Popular Music; Mindfulness and Emotional Regulation Strategies; Influence of Family and Social Music-Making	"I use mindfulness techniques a lot, breathing techniques and body scanning."
Innovation and Creativity in Retraining	Self-Developed Techniques	Personal Journeys of Adaptation	Developed personal exercises and techniques to regain mobility and musical ability after physical limitations.	Innovations in Self-Retraining Techniques; Small but Effective Self-Developed Exercises; Impact on Musical Practice and Routine	"I came back to it after maybe 6 months, just simple scales and trying to regain some fluidity..."
Innovation and Creativity in Retraining	Multi-faceted Approaches	Emotional and Psychological Impact	Integration of mindfulness and physical therapy insights to create	Mindfulness Exercises and Control Techniques; Physiotherapy	“If I don’t brain-spot first then I get less out of a

			comprehensive retraining methods.	Insights and Posture Awareness	session. It's definitely a combination of the two but brain-spotting is a powerful thing for me."
Innovation and Creativity in Retraining	Integrating Approaches	Emotional and Psychological Impact	Techniques blend visualization, body awareness, and emotional regulation to manage dystonia symptoms.	Visualization Techniques in Coping and Adaptation; Continuous Self-Monitoring and Internal Dialogue	"everything was a negative reaction to things, I was really negative."
Impact of Self-Developed Retraining on Musicians' MD	Positive Impacts	Innovation and Creativity in Retraining	Nelly's personalised retraining led to regained musical identity and improved emotional resilience.	Rediscovering Musical Identity; Mental Well-Being Improvements	"I have a deeper appreciation for music-making, I suppose."
Impact of Self-Developed Retraining on Musicians' MD	Negative Impacts	Emotional and Psychological Impact	Emotional challenges and lifestyle changes persisted during the retraining process.	Loss and Grief of Selling Instruments; Depression and Disappointment	"I actually sold my flutes at one point."
Impact of Self-Developed Retraining on Musicians' MD	Strategies for Balance	Personal Journeys of Adaptation	Achieving balance between technical skills and emotional well-being informed new practice approaches.	Reflections on Resilience and Perseverance; Changes in Teaching Approach and Focus	"I realised for myself early on that I couldn't tell how hard I was pressing my fourth finger and when I was releasing. When you start from minimal touch then you feel the key again which is what I couldn't do."
Emotional and	Anxiety and Stress	Personal Journeys of Adaptation	Nelly's experience with anxiety and	Performance Anxiety; Personal	"I remember spending

Psychological Impact			stress during performance and life changes required careful management.	Anxieties and Stage Fright Experiences	some time at college really struggling with stage fright."
Emotional and Psychological Impact	Emotional Well-Being	Innovation and Creativity in Retraining	Emotional resilience fostered through a supportive environment and conducive practices.	Peer Support and Influence; Importance of Mental Health Acknowledgment	“It made me feel so low. The whole experience was horrible for me. I couldn’t sleep, I was losing all my work, and my hand wasn’t working properly. I wanted to run and hide, let alone confront it.”
Emotional and Psychological Impact	Emotional Support Systems	Personal Journeys of Adaptation	Family, peers, and educators played a vital role in maintaining stability and encouragement.	Peer Support and Influence; Family Health Impacts	"I also have a colleague of mine that has had similar problems."
Retrospective Insight	Self-Reflection	Personal Journeys of Adaptation	Reflective insights led to suitable personal adjustments and better understanding of personal needs.	Impact of Personality Traits on Dystonia; Retrospective Insights and Changes to Mitigate Dystonia Risks	“I don’t play for everyone else now, I play for me. I know my limits and I’m ok with saying no to things.”
Retrospective Insight	Lessons Learned	Emotional and Psychological Impact	Experiences with stage fright and mental health issues offered lessons for future well-being.	Neurological Exploration Avoidance; Continuous Self-Monitoring and Internal Dialogue	"everything was a negative reaction to things, I was really negative."
Retrospective Insight	Regrets and Missed Opportunities	Innovation and Creativity in Retraining	Nelly's journey strengthened her adaptability, redirecting focus on positive engagements.	Pursuing Non-Musical Career Options; Influence of The Inner Game of Music on Mindset	"The Inner Game of Music by Barry Greene was where I got that from originally."

8. P8

Main Theme	Sub-theme	Related Theme	Description	Code Name	Quote
Personal Journeys of Adaptation	Impact of Diagnosis	Emotional and Psychological Impact	The challenge of identifying and emotionally processing dystonia symptoms.	Diagnosis Timeline; Perception of Dystonia Before Diagnosis; Misunderstanding of Dystonia	"I first was diagnosed in 2022, but I noticed the symptoms...probably around 2018."
Personal Journeys of Adaptation	Resilience and Motivation	Innovation and Creativity in Retraining	Self-driven exploration of techniques and motivation to recover and adapt musical practices.	Self-Initiated Research; Misunderstanding of Dystonia; Motivation and Resilience	"I generally won't, unless I feel really good... For me, actually, not practising has been a very good thing."
Personal Journeys of Adaptation	Coping Strategies	Emotional and Psychological Impact	Navigating emotional challenges through alternative therapies and mental strategies.	Emotional and Mental Exploration; Mindfulness and Emotional Regulation Strategies	“If A plus B plus C equals Z, then so be it. I will find a way through it though.”
Innovation and Creativity in Retraining	Self-Developed Techniques	Personal Journeys of Adaptation	Developing personal exercises to regain control and ability over specific hand movements.	Finding Ruth's Book; Physical Logic Concept	"I would do some of the exercises from Ruth's book, like she has one called the flow state..."
Innovation and Creativity in Retraining	Multi-faceted Approaches	Emotional and Psychological Impact	Integration of various therapeutic methods and practices to enhance understanding and recovery.	Integrated Approach to Retraining; Discovering Personal Connections	“You treat the cause not the symptom. We should do the same with all illnesses, I think.”
Innovation and Creativity in Retraining	Integrating Approaches	Emotional and Psychological Impact	Techniques that blend physical exercises with mental awareness for a holistic recovery.	Engagement with Ruth’s Therapy; Mental Impact of Retraining	"Every week, I felt like I discovered a new thing that was like, in my head wrong with me..."
Impact of Self-	Positive Impacts	Innovation and	Witnessed a deeper	Preventing Dystonia for	"I feel like I'll catch students, like, with

Developed Retraining on Musicians' MD		Creativity in Retraining	understanding of musical and personal identity through retraining.	Others; Increased Awareness in Teaching Technique	their, like, the wrist bent a lot..."
Impact of Self-Developed Retraining on Musicians' MD	Negative Impacts	Emotional and Psychological Impact	Challenges in adjusting to new expectations, frustration with slow progress.	Frustration with Lack of Pain and Treatment Efficacy; Coping with Frustration	"Frustration with lack of pain and treatment efficacy..."
Impact of Self-Developed Retraining on Musicians' MD	Strategies for Balance	Personal Journeys of Adaptation	Balancing practice with rest to accommodate changing physical and mental conditions.	Short-term Effectiveness of Treatments; Balancing Periods of Practice	"If I don't have to play that day, I generally won't, unless I feel really good..."
Emotional and Psychological Impact	Anxiety and Stress	Personal Journeys of Adaptation	Anxiety about performance provoked introspection and a reassessment of musical goals.	Elements Leading to Mental Setbacks; Notable Progress Timeframe	“When you learn to deal with your stress ,then you can deal with the dystonia. The two walk hand in hand in my opinion.”
Emotional and Psychological Impact	Emotional Well-Being	Innovation and Creativity in Retraining	Enhanced self-awareness and emotional resilience through supportive retraining methods.	Reflection on Student-Teacher Relationships; Brain Spotting Technique	"The brain spotting thing...it's kind of difficult to describe how it's like benefited me..."
Emotional and Psychological Impact	Emotional Support Systems	Personal Journeys of Adaptation	Support from community and personal exploration offered necessary emotional support.	Advice on Avoiding Excessive Practice; Zero State Technique	"Getting in touch with your centre of gravity, sort of like around your hip area..."
Retrospective Insight	Self-Reflection	Personal Journeys of Adaptation	Reflection led to a better understanding of self-efficacy and teaching adaptability.	Increased Awareness in Teaching Technique; Hindrance of Technical Abilities	"I have solos to do. And soloing is the absolute hardest thing for me to do right now."
Retrospective Insight	Lessons Learned	Emotional and	Experiences offered insights	Advice on Avoiding Excessive	“Trying new things all the time just keeps me fresh.

		Psychological Impact	leading to a new perspective on teaching and personal ambition.	Practice; Continued Exploration of Techniques	Even if something works I'll keep mixing it up. I don't give the dystonia time to catch up anymore."
Retrospective Insight	Regrets and Missed Opportunities	Innovation and Creativity in Retraining	Openness to adopt creative methods, strengthened future outlook and identity realignment.	Realising Multi-Faceted Identity; Increased Awareness in Teaching Technique	"I really, wouldn't want anyone to have to go through this..."

9. P9

Personal Journeys of Adaptation

Sub-theme	Related Theme	Description	Quote
Impact of Diagnosis	Emotional and Psychological Impact	The initial reaction to the dystonia diagnosis was one of shock and confusion, affecting emotional well-being.	"And they just said, oh, you have dystonia...there was no sugar coating at all. It was just like, oh, you have dystonia."
Resilience and Motivation	Innovation and Creativity in Retraining	Despite challenges, showed resilience by continually seeking ways to perform and improve.	"...feel the fear, do it anyway. That's what I teach my students."
Coping Strategies	Emotional and Psychological Impact	Adaptation involved using creative and supportive measures like brain spotting and CBD oil.	"He just said to do something else. I thought to myself, 'get me out of here'. It's humiliating, you know. To them, it's like playing is a hobby. They suggest you do something else and stop complaining."

Innovation and Creativity in Retraining

Sub-theme	Related Theme	Description	Quote
Self-Developed Techniques	Personal Journeys of Adaptation	Personal journey informed her approach to create unique techniques for retraining.	"I wanted to kind of showcase the tuba in something other than a classical situation and to show its versatility in other idioms."
Multi-faceted Approaches	Emotional and Psychological Impact	Combined different therapeutic approaches to address both physical and emotional challenges.	"I feel a lot more confident in my ability to recover when I don't focus on what's not working, more on the small wins over time."
Integrating Approaches	Emotional and Psychological Impact	The integration of music therapy techniques and emotional processing facilitated adaptation.	"I'm just experimenting with what happens during the session."

Impact of Self-Developed Retraining on Musicians' MD

Sub-theme	Related Theme	Description	Quote
Positive Impacts	Innovation and Creativity in Retraining	witnessed improvements in her condition and creativity through personalised retraining.	"None of the touch your nose, I can do this now, but I'll get to that about what I've found that's helped me."
Negative Impacts	Emotional and Psychological Impact	The challenges and occasional failures in self-developed methods brought emotional distress.	"But it certainly doesn't work for dystonia...it made me crazy."
Strategies for Balance	Personal Journeys of Adaptation	Balancing self-reliant techniques with professional advice was critical for physical and emotional health.	"Finding a spot in the room where I feel activated..."

Emotional and Psychological Impact

Sub-theme	Related Theme	Description	Quote
Anxiety and Stress	Personal Journeys of Adaptation	The pressure and stress of performance and medical issues compounded over time.	"...always suffered from crippling performance anxiety. But still did it anyway..."
Emotional Well-Being	Innovation and Creativity in Retraining	A supportive environment and creative outlets improved emotional resilience.	"My real passion was singing, but I was very shy and had a lot of performance anxiety."
Emotional Support Systems	Personal Journeys of Adaptation	Connecting with supportive communities and professionals provided essential psychological relief.	"And these people started talking about brain spotting, brain spotting, brain spotting."

Retrospective Insight

Sub-theme	Related Theme	Description	Quote
Self-Reflection	Personal Journeys of Adaptation	Evaluated methods and acknowledged areas for improvement in her practice.	"And then they had me sing something, same thing. And they both looked at each other and said, well, tricky to treat. And that was it."
Lessons Learned	Emotional and Psychological Impact	Learning about limitations and possibilities led to greater self-awareness and growth.	"I mean, we're not talking about your ability to play. You're talking about one's very identity."
Regrets and Missed Opportunities	Innovation and Creativity in Retraining	While experiencing feelings of regret motivated to pursue new approaches and avoid past mistakes.	"...you can, you know, heal yourself. There were plenty of those, unfortunately."

10. P10

Main Theme	Sub-theme	Related Themes	Description of Interconnections	Exemplars from Kerry
Personal Journeys of Adaptation	Impact of Diagnosis	Initial Symptoms, Diagnosis Journey, Anxiety and Fear, Acceptance of	How musicians navigate the emotional and psychological impact	"I just started feeling stiffness

		Change, Acceptance of New Norms	of dystonia diagnosis and adjust to new norms.	and a lack of control in my left hand... I thought I was dying."
	Resilience and Motivation	Music as Identity, Motivation, Emotional Release, Courage in Vulnerability	Music as a central part of identity motivates overcoming, while emotional release and vulnerability aid personal growth.	"Music has been a central part of my life for as long as I can remember."
	Coping Strategies	Coping with Comparisons, Coping Mechanisms, Handling Self-Worth, Scepticism of Traditional Views	Developing strategies to manage comparisons, self-worth issues, and questioning traditional approaches.	“You’re on your own at the beginning. That needs to change. I had no idea what to do, who to turn to.”
Innovation and Creativity in Retraining	Self-Developed Techniques	Exploring Alternate Methods, Discovery of New Techniques, Creativity in Adaptation, Emotional Coping Mechanisms	Personal innovation in retraining through exploration and creativity in adapting playing styles.	"I did a lot of reading at the beginning... about dystonia."
	Multi-faceted Approaches	Mind-Body Connection, Integration of Practices, Integrating Approaches, Innovation in Creativity	Incorporating physical and mindful strategies in creative retraining while offering emotional support.	"I realised I couldn't focus solely on my hands; I needed to consider my whole body."
Impact of Self-Developed Retraining on Musicians' MD	Positive Impacts	Healing through Understanding, Valuing the Process	Enhancements in understanding and performance resulting from a deeper appreciation of the retraining journey.	"I had a lot of false start[s]. Some lasted for ages and ages. It’s hard to know when you’ve got something right, but I’ve an open mind to most things nowadays to be honest.”

	Negative Impacts	Reality of Chronic Condition, Long-Term Effects of Dystonia	Understanding chronic dystonia's long-term emotional and physical effects.	"I know how difficult I found it to tell any of my colleagues about it..."
	Strategies for Balance	Mindful Presence, Lifestyle Adjustments	Balancing self-developed techniques with lifestyle changes to enhance rehabilitation and reduce stress.	"I try and do one before I do any practical retraining stuff."
Emotional and Psychological Impact	Anxiety and Stress	Impact of College Pressure, Stress Management	Handling stress from high-pressure environments and learning effective management techniques.	“When you learn to deal with your stress ,then you can deal with the dystonia. The two walk hand in hand in my opinion.”
	Emotional Well-being	Meditation Practices, Mindfulness and Presence	Utilising meditation and mindfulness to enhance emotional well-being and concentration.	"I like meditations that slow down your thinking."
Retrospective Insight	Self-Reflection	Learning from Experiences, Personal Reflection	Reflecting on past experiences to improve current practices and emotional resilience.	"Maybe knowing more about the risk of getting dystonia... would have been useful."
	Lessons Learned	Emotional Acknowledgment, Emotional Support Systems	Recognising the emotional journey and the importance of support systems in overcoming challenges.	"My family have been incredibly supportive."

11. P11

Main Theme	Sub-theme	Related Themes	Description of Interconnections	Exemplars from Peter
Personal Journeys of Adaptation	Impact of Diagnosis	Initial Symptoms, Denial and Scepticism, Psychological Struggles, Acceptance of Limitations	Navigating the journey from initial confusion and denial to acceptance of dystonia's impact and finding ways to manage limitations.	"I was pretty sceptical, or maybe just in denial about dystonia."
	Resilience and Adaptability	Growth through Adversity, Resilience and Adaptability, Advice for Musicians	Resilience born from adversity, with a focus on adapting to ongoing challenges and offering advice to fellow musicians.	"Now I know that being a musician is about survival and adaptability just as much."
	Coping Strategies	Focus on Breathing, Singing as Relief, Mindful Practice, Routine Development	Developing strategies like mindful practice and routines to manage stress and improve playing ability.	"I spent six months or so studying Moshe's, 'The Feldenkrais Teaching by Handling Method'. We need to wake up all the circuitry before we start to play so that we can really feel movements when we're working on them."
Innovation and Creativity in Retraining	Exploration of Techniques	Exploration of Techniques, Therapy and Bodywork, Integration of Practices, Fascination with Anatomy	Employing diverse techniques and therapies, and integrating them creatively for retraining and mitigating dystonia effects.	"He recommended that I do some Rolfing... my left side was a lot tighter than the right."
	Multi-faceted Approaches	Whole-Body Approach, Body Awareness, Online Learning	A holistic view, combining online learning and physical awareness to address musicianship challenges comprehensively.	"I work a lot at improving muscle chain connections, I read a lot about that from [redacted], but there's not much that focuses on dystonic musicians. I've

				spent a lot of time working at re-connecting big muscles to small ones when I try and play.”
Impact of Self-Developed Retraining on Musicians' MD	Positive Impacts	Routine Development, Integration of Practices, Understanding Whole-Body Approach	Self-developed routines and understanding contribute positively to managing and performing despite dystonia.	“It’s pretty time-consuming, I admit. I probably do around an hour a day thereabouts. It’s the most important thing for me. A lot of the embouchure work is TMJ [temporomandibular joint] based and it’s so good for getting release prior.”
	Negative Impacts	Impact on Career, Emotional Response	Acknowledging the career and emotional impacts of dystonia and the need for careful evaluation of self-developed techniques.	"I was losing work because I couldn’t perform reliably, and I was starting to panic."
	Strategies for Balance	Singing as Relief, Integration of Practices	Finding a balance between self-developed methods and maintaining a positive outlook through practices like singing.	"I used to sing as a tenor in choirs back home. So I decided to go sing."
Emotional and Psychological Impact	Panic and Fear	Experience of Panic, Psychological Struggles, Emotional Response	Exploring how panic, fear, and emotional upheavals affect musicians' performance and mental health.	"I remember one rehearsal where I just froze in the middle of a piece... I was freaking out big time."

	Emotional Well-being	Supportive Colleagues, Guidance and Mentorship, Importance of Connection	Emotional support and mentorship provide stability and guidance, enhancing emotional well-being.	"Having someone to guide you can make all the difference when you're stuck in the weeds."
Retrospective Insight	Self-Reflection	Reflection on Risk Mitigation, Lessons for Others, Resilience and Adaptability	Insights from past experiences help in risk assessment and offer lessons to others, fostering a culture of resilience.	"I wish that I'd done things like body mapping a lot earlier in my career."
	Lessons Learned	Growth through Adversity, Advice for Musicians	Lessons drawn from hardship inform personal growth and practical advice sharing with peers.	"Your body doesn't lie... you have to be brutally honest with yourself."

12. P12

Main Theme	**Sub-theme**	**Related Themes**	**Description of Interconnections**	**Exemplars from Gary**
Personal Journeys of Adaptation	Impact of Diagnosis	Initial Reactions, Denial and Defiance, Ego Death, Underlying Emotions, Accepting the Journey	Navigating the emotional and psychological changes from denial to acceptance of dystonia's impact on life and identity.	"I thought, oh, I'll be back within a month... it was just a lack of understanding." "It was just this, I can overcome this. I can figure it out."
	Resilience and Adaptability	Growth through Adversity, Resilience in the Face of Adversity, Challenges of Recovery	Developing resilience and adaptability through adversities associated with dystonia.	"I meditate most days. My challenge has always been to play without losing the effects. There's a lot of discipline needed to do that."
	Coping Strategies	Openness to New Experiences, Reflection on Past Practices, Need for Holistic Approaches	Employing new experiences and holistic methods to cope with challenges and manage recovery.	"I would happily go into something like that... I've never been able to ice skate." "If this is going to be my life as a musician, I don't want it to keep going."

Innovation and Creativity in Retraining	Therapeutic Exploration	Exploring Alternatives, Limitations of Traditional Therapy, Somatic Awareness, Mind-Body Communication	Exploring diverse therapies and communication between mind and body to foster innovative retraining strategies.	“Practicing self-observation felt like taking a step back and becoming my own witness. I stopped judging every mistake as a failure. Instead, I saw them as moments of data. It made the whole endless journey a bit less daunting.”
	Multi-faceted Approaches	Body-Mind Duality, Interoception, Embracing Movement, Integration of Experience	Integrating mental and physical practices to enhance awareness and performance capabilities.	“I’m always changing things up. Sometimes I change a fingering or work with a new position, it might work, who knows. If I do the same thing though every day, then I feel things start to drop off.”
Impact of Self-Developed Retraining on Musicians' MD	Transformative Insights	Self-Realization, Integration of Experience, Mindful Practice	Insights lead to changes in understanding and implementation of self-developed retraining methods.	"I could really feel the difference in my fingers and in my hand and wrist." "The more I became aware of myself, the more toxic and poisonous sitting doing those exercises became..."
	Emotional Response	Emotional Turmoil, Underlying Emotions	Processing emotions such as sadness and fear that accompany dystonia and impact strategy development.	"Underneath that it's sadness and fear." "It felt my life was being taken away from me. I couldn’t accept it."
	Self-Acceptance	Importance of Self-Acceptance, Healing the Self	Understanding and acceptance of oneself contributes to emotional healing and effective retraining.	"I wasn't open to accepting parts of myself that didn't fit into the egoic structure." "I am one of those people too. You're just projecting."
Emotional and Psychological Impact	Vulnerability in Performance	Acceptance of Vulnerability, Vulnerability in Performance, Connection to Self	Embracing vulnerability and connecting with inner emotions improve performance and self-awareness.	"Especially for men, the first thing reaction is anger or defiance." "Journaling and things... it’s like I’m having myself revealed to myself."
	Support and Community	Connection and Community, Support of Peers, Advocacy for Musicians	Community and peer support facilitate understanding and coping with dystonia's challenges.	"This is something a bit different. I just knew that it was something." "Whenever we got a breakthrough... the person was connecting with me."

Retrospective Insight	Realization of Patterns	Self-Reflection, Awareness of Dialectical Processes, Exploration of Alternatives	Reflecting on past patterns and exploring new approaches leads to adaptations in personal and professional paths.	"Once I started studying therapy and once I started receiving it myself... I started to see patterns." "It's almost like instead it folds in upon itself."
	Lessons Learned	Growth through Adversity, Desire for Change, Shifting Relationships	Learning from adversity promotes change and growth in personal and professional relationships.	"A lot of musicians need to know about this part early on in their experience." "My colleagues were understanding... I'd even connect with them differently now."

14. P14

Main Theme	**Sub-theme**	**Related Themes**	**Description of Interconnections**	**Exemplars from Holly**
Personal Journeys of Adaptation	Initial Musical Experiences	Alternative Techniques, Exploration of Identity, Changing Goals and Expectations	Early involvement in music and how exploring alternative techniques impacted her musical path.	"I started playing in some flute ensembles with alto and bass flute." "I got a different alternative kind of head joint for the flute... it's a wooden head joint."
	Growth Through Challenge	Unravelling Old Patterns, Growth Through Challenge, Developing Compassion	Developing resilience and understanding through confronting challenges posed by dystonia.	"Dystonia has helped me to learn to be kinder to myself." "I have this term that I thought about... called just saying unravelling."
	Changing Goals and Expectations	Reflection on the Teaching Process, Shifting Perceptions of Music, Acceptance of Vulnerability	Reevaluating personal goals and expectations in light of new experiences and insights.	"I think that... this is not why I got into music. This is not what I had in my head." "Allowing vulnerability into your life, and being willing to take a risk that fear of taking a risk or being wrong."
Innovation and Creativity in Retraining	Creative Solutions	Exploring Facial Neuromuscular Retraining, Body Mapping, Integrating Alternative Approaches	Employing innovative strategies and techniques for musical improvement and recovery.	“Yeah, it’s changing movement patterns when I do the slow work, you know, to stop always doing things the same way, breathing properly as well is a massive help.”

	Integrating Alternative Approaches	Mismapping Awareness, Cognitive Behavioural Approaches, Integration of Different Modalities	Blending various therapeutic and educational strategies to address personal and professional challenges.	"I think brain spotting... was just a tool." "I found so many different mismaps of the way I approach flute playing."
Impact of Self-Developed Retraining on Musicians' MD	Reflection on the Teaching Process	Self-Discovery through Music, Emotional Healing, Role of Environment	Insights from the retraining process lead to changes in teaching and a better understanding of the environment's role.	"I think if I had the wherewithal, to question... people are just going to go and do what their teacher says." "I'm finally able to start thinking musically again now."
	Emotional Response	Emotional and Cognitive Distortions, Awareness of Pain Sensations	Coping with the emotional impact of dystonia through awareness and adjustment of negative cognitive patterns.	"I'm a recovering perfectionist... to kind of review any cognitive distortions you might have." "I think it's important to notice... any uncomfortable things that you might be experiencing."
	Self-Compassion	Developing Compassion, Psychological Factors, Emotional Healing	Cultivating understanding and kindness towards oneself in the process of emotional and physical recovery.	"I've become a lot kinder with myself... where I've come from." "There's just so much shame associated with it... loss of self-worth."
Emotional and Psychological Impact	Support and Community	Involvement in Communities, Interpersonal Relationships, Sense of Community	The significance of community and relationships in supporting emotional wellbeing and recovery from dystonia.	"I teamed up with a colleague... we started the Transformational Teacher during COVID." "I think, feeling alone in these things is really troubling, and just having support from people."
	Cognitive Behavioural Approaches	Awareness of Dialectical Processes, Constructive Comparisons	Using cognitive strategies to alter negative thinking and improve mental clarity and resilience.	"I try to catch yourself when you're falling back into some negative thought patterns." "Instead of focusing on the note I can't play, why not focus on the notes I can play?"
Retrospective Insight	Identifying Triggers	Identifying Triggers, Role of Environment,	Recognising triggers and practicing mindfulness foster reflection and	"Just cultivate an awareness of physical sensations that you're experiencing in your

		Emphasis on Mindfulness	adaptive strategies for managing dystonia's effects.	body." "I was still under a lot of stress with elderly parent caregiving."
	Lessons Learned	Continuous Learning, Integration of Different Modalities, Self-Discovery through Music	Ongoing learning and integration of lessons from diverse experiences support Holly's development as both a musician and teacher.	"But I think, you know, I'm still on the path." "It's just more the relationship that we developed and having... this person was just really helpful."

Appendix O: Study 1 - Music and Medicine - Journal Version

1035 Gardner
Musicians' Focal Dystonia Awareness and Performance-related Health Discourse Within the One-to-One Conservatoire Teaching Environment: A Comparative Analysis

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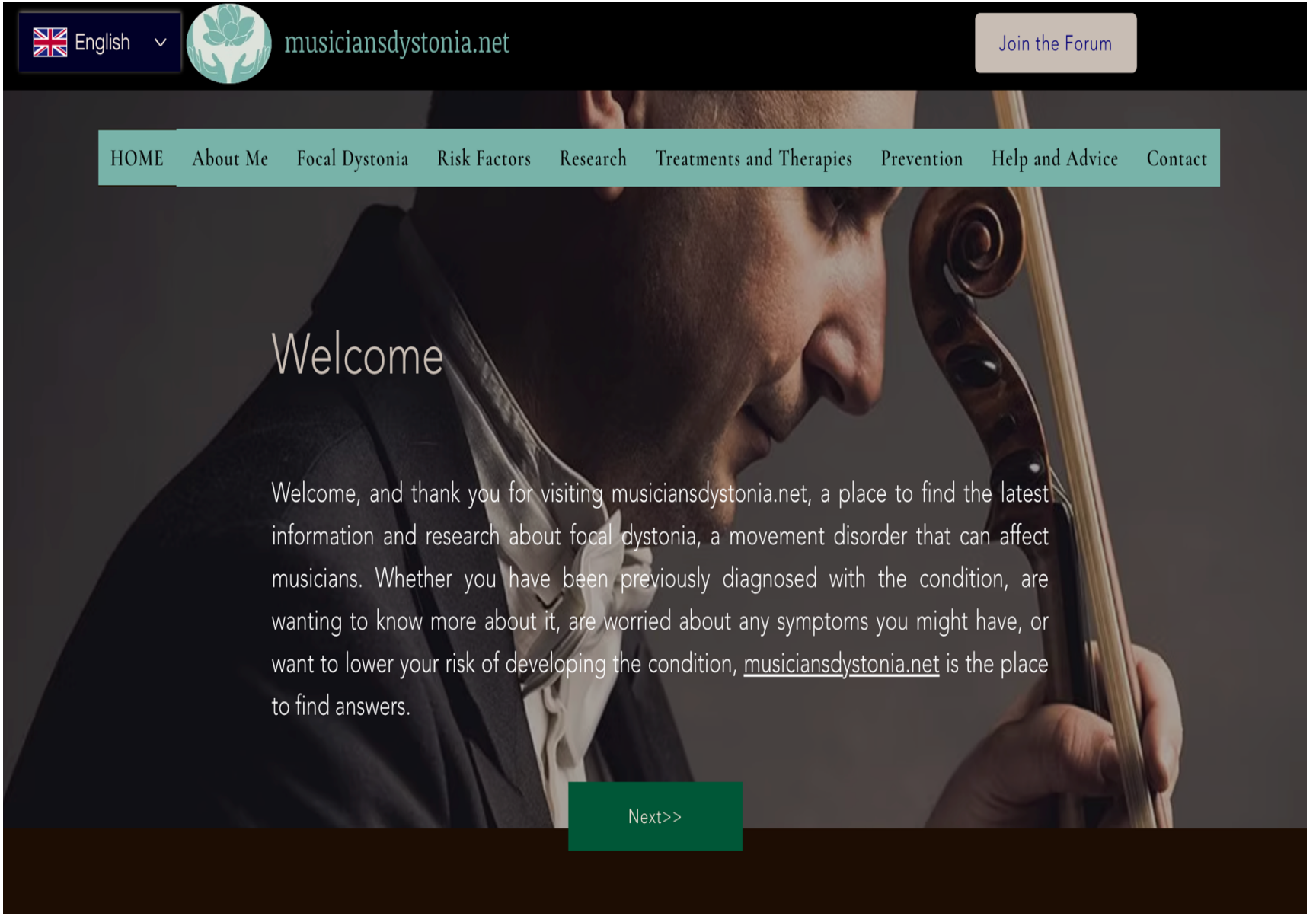
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Appendix P: Website Screenshot - musiciansdystonia.net


English
musiciansdystonia.net
Join the Forum
HOME
About Me
Focal Dystonia
Risk Factors
Research
Treatments and Therapies
Prevention
Help and Advice
Contact
Welcome
Welcome, and thank you for visiting musiciansdystonia.net, a place to find the latest information and research about focal dystonia, a movement disorder that can affect musicians. Whether you have been previously diagnosed with the condition, are wanting to know more about it, are worried about any symptoms you might have, or want to lower your risk of developing the condition, musiciansdystonia.net is the place to find answers.
Next>>

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