## Embouchure dystonia: the journey towards recovery and exploring new career perspectives

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Thank you for giving me the opportunity to speak here today. I am Mark Weinel and I am a professional trombone player. I trained at the Royal Academy of Music in London and after some years of freelance playing with the City of Birmingham Symphony Orchestra in the UK and then the Noord Nederlands Orkest in Holland, I took up the permanent post, here in Antwerp, of Principal Trombone with the orchestra of the Kunsthuis Opera Ballet Vlaanderen; a position I hold to the present day.

Learning and playing an instrument begins long before auditioning to get into a music conservatoire. Having started at the age of ten, I already knew at 15 that playing professionally was my vocation and like all other hopeful young musicians, I dedicated everything to obtaining the academic and performance levels needed to achieve this goal. Entry into the music profession is notoriously difficult and competitive, and of those players who successfully enter a music conservatoire, only a small number will go on to find a full time position in a professional orchestra. I have been fortunate enough to have played professionally throughout my working life, so you can imagine my horror when in 2009 at the age of 46 and at the height of my career, I was struck by a debilitating condition causing a breakdown of control over the lip and surrounding facial muscles that are vital in producing notes on a trombone: a form of Task-Specific Focal Dystonia known as Embouchure Dystonia. To make a sound on a trombone, the lips connect with the mouthpiece. The tongue releases the air and the lips form a shape that causes them to vibrate as the air is blown through the instrument. This shape is called the embouchure. This flexible embouchure uses groups of many small muscles in and around the lips making minute and often rapid movements against the air stream, enabling the player to change the note, the volume and the tone quality. It is therefore central to playing the trombone.

In the beginning, the symptoms of dystonia were not obvious. Small things started to go wrong. When things are not going well, the brass player's thoughts are that the embouchure is tired or out of condition. However, neither rest nor additional practice produced any improvement; the lips were just not responding as they should and it was taking more effort to produce notes of the right quality. This steadily got worse until even the simplest notes were not coming out. The increased physical effort of playing was causing the lips to spasm even after playing had stopped, and I had to consider that there might be something medically wrong.

I had first encountered dystonia when a trombone-playing colleague in the orchestra with similar playing problems was diagnosed with it. At that time the internet was only in its infancy and information was hard to come by. He had to rely on what was best practice then, which included such treatments as beta-blockers, physio-therapy on the jaw and neck and botox injections, which he turned down. After some years of fruitless experimentation he decided to stop. Suspecting that I might have the same problem, I went to a neurologist to be sure that what I had was not the onset of something serious or life-threatening. After various tests and an MRI scan I got the official diagnosis. When the neurologist broke the news he admitted that there was not much known about dystonia and that it was for the moment regarded as incurable. He went on to suggest that I might play another instrument in the orchestra. While this was well meant, it was rather like suggesting a dentist become a gynaecologist.

Knowing the experiences of my colleague, I decided to research alternative methods of recovery to the conventional medicine route. Indeed, later I was to find out that in a 2005 study made by Professor Eckart Altenmueller at the University of Hannover, Germany where 144 professional musicians were put through various therapy trials, none of the chemical treatment strategies, including botox treatment, had had any effect on those with embouchure dystonia.

Research on the internet led me to Professor Joaquin Fabra, a Spanish trombonist, who had managed to rehabilitate himself completely from embouchure dystonia and who had been treating other musicians for the last twenty years without the use of any medication. I went to study with him for a week in Madrid, followed up by a number of Skype sessions over a period of months. Fabra was the first person to give me what I felt was a logical explanation of what dystonia might be, and, more importantly, he gave me hope that recovery was possible. He believed that if there was no indication of any neurological disease and if the lips functioned normally away from the instrument, then dystonia was an emotional, mental and physical problem and not a neurological one and the action to be taken should be in regard to these factors.

According to him, the physical symptoms are caused by involuntary malformations in the embouchure, a situation built up gradually over many years and leading to too much tension in the embouchure muscles. Mentally, the problem is exacerbated by 'overtrying'; when the required note or quality of note is not produced, more physical effort is used leading to more tension. Emotionally, there is too much attachment placed on the result, and when it is not forthcoming, tension increases still further. Gradually, the thought 'I want to play this note' becomes 'I mustn't miss this note', which invariably leads to actually missing the note. In the orchestra of course, there is a very big focus on the result; the trombone is a very exposed instrument and you are part of a live performance.

Fabra's outline for recovery was to encourage the embouchure to relax, to focus entirely on the process of producing the note and not the result and to allow any dystonic symptoms to occur without trying to stop them. After a few months of work on this there seemed to be some improvement and with pressure to get back to playing in the orchestra, not least from myself, I returned on a part-time basis to continue my recovery within the orchestra. At the time this seemed like a good idea, but dystonia is not a problem of stamina whereby you can only play half a concert season, nor is it an issue of technical inability to play the more difficult pieces. It is the lack of consistent control of the lips, regardless of the length or difficulty of the music. So with hindsight, my return was premature because the process of playing the notes was not consistent enough and the confidence in the process was not developed enough. It needs to be developed first outside and then tested within the orchestra. In practice what happened was that I chose the pieces where I was least exposed, so that minimal damage could be caused to the performance if there was a mishap, and this made it less obvious that I was still struggling. But in the end, it became too risky for the orchestra to have me there when the results of my playing were still so uncertain, so it was decided that I would continue my rehabilitation outside the orchestra.

I became intrigued by the idea that my sub-conscious could be preventing my lips from carrying out a specific physical task. The simple physical exercise Fabra had given me was not yielding results, and the cost of the sessions was high, so I decided that I needed more help with the mental and emotional side in order to enable the physical side to work. Firstly, I went to see a psychotherapist, but after some time it became apparent that the sessions were more about general counselling rather than a way of directly dealing with my specific problem. I then went to a UK-based hypnotherapist who said he had had success with musicians' dystonia. I felt that this could be a way of somehow reprogramming or resetting my subconscious thought processes and I followed a 6 month course with him. I was given specific relaxation techniques and personally scripted recordings to influence the subconscious. I also followed a masterclass online from a world-renowned trombonist about his view on the operation of the embouchure in an effort to make an improvement on the physical side, but his approach was the same standard textbook way that I had been originally taught and it differed from Fabra's idea of what constituted a well-formed embouchure.

At first the hypnotherapy seemed to bring some small improvements, but there came a point when improvement stopped. What was wrong? Why weren't these things working for me if they had apparently worked for others?

At this time, by chance I met socially a doctor who was a specialist in stomatology and maxillo-facial surgery. He told me he was interested in embouchure dystonia and was working privately on an experimental but time-consuming method of processing MRI scans, from which he could reconstruct images of the lip muscles in 3D and which he believed could show modifications in the muscles in dystonia sufferers. After a consultation with him I had the specified MRI scan he required, hoping that the results might show something that could be medically treated. However, no result was forthcoming and eventually there was no reply to my emails. I had been aware of the work of Canadian-based Dr Joaquin Farias with dystonia sufferers for some time, but my initial research had indicated that he was concerned with dystonia of the fingers in musicians. But when I found out that he was holding personal workshops at Utrecht University, I discovered he was also working with embouchure dystonia, so I applied to study with him there for a week. His view of dystonia was it is a malfunction of the whole face and that it is a physical, neurological, psychological and emotional symptom of an imbalance of the body and mind as a whole. The goal of his training is to facilitate a process of reorganization of the body's coordination known as neuroplasticity. The whole body approach was not one I had considered yet, and he gave me some helpful suggestions regarding embouchure, breathing and body posture but continuing study with him was not an option. However, I was interested in pursuing this more physiological approach further.

Some of my previous researches had found that some dystonia sufferers had rehabilitated themselves with the help of Alexander Technique, a method that highlights and works to change inefficient habits of movement and patterns of accumulated tension in the body. I found a UK-based trombone teacher who was also an Alexander teacher. It was an experiment that I thought was worth trying, and the teacher was willing to work with me, although he had no direct experience with dystonia. After five days intensive lessons both in Alexander Technique and trombone work I felt that there had been some improvement, but once again this did not last. So in subsequent meetings we started to experiment with 'free buzzing', or vibrating the lips away from the instrument. However, we found that this required extra muscular support because there was no mouthpiece, thus causing more tension, so it was not a solution.

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At this point I would like to mention the people in the background on this journey, without whom there would be no journey. The understanding and support of the management and doctor at the Opera, of my GP and doctors at the mutuality, and of the Fonds Voor De Beroepsziekten who have recognized my dystonia as a workrelated illness.

All we know about recovery is that it takes a comparatively long time. With no specific medical path and no scientific measures of progress or recovery, it can become difficult to explain things to the various institutions, who understandably need some kind of written evidence and justification to support what you are doing. Coming out of the orchestra was seen by the mutuality as a backward step, although there had in fact been no deterioration in my condition, I had simply tried to go back into the orchestra too soon, so I had to seek an authority on dystonia to provide justification as to why they should continue to support me.

This led me to contact Eckhart Altenmueller to ask for his opinion and support, which he provided. He also suggested that I could benefit from a specialist brass re-trainer and recommended someone to me in Dusseldorf, Germany. I could see this might be a more practical and affordable way to progress on an ongoing basis. It turned out eventually that the person he recommended had moved away, but the idea was good and I continued in my search for a suitable retrainer. Around this time another player who had been having embouchure problems told me he had been having some breakthroughs thanks to David Vining, an American professional trombone player, now fully rehabilitated, whose own journey took him to study with specialists in Alexander Technique, Feldenkrais Technique and Body-Mapping. He has written and published exercises that helped him to recover and a book that takes into account the physiology of playing the trombone, with a particular focus on the breathing. I thought this was very interesting, especially given his more physiological approach, so I bought the materials. After working through the books, music and you-tube videos for some time, I was not getting any consistent improvement so I had a personal consultation with him, via Skype. He gave me some of his basic exercises to practise that focused exclusively on just blowing air through the instrument and only gradually forming an embouchure to make a sound. To him, the embouchure was secondary to the airstream because the embouchure did not exist until it had been caused to vibrate by the airstream. Vining's own experience was that he had to find his own way to recovery through a cocktail of therapies, not just one magic bullet. He recommended that these were the basic exercises I needed to master, which could take a day, a week or a year, and suggested that if I went back over exercises and ideas from all my previous experiences and focused on the parts that had made some positive difference I could put it all together to find the key to my own rehabilitation. He advised me not to practise other things, because this just reinforces the old way of playing, which was different from the advice I had received from Fabra who advocates that if symptoms appear, just accept them and carry on.

I was very disappointed not to make more progress with this. The material had seemed to be the best and most specific and appropriate approach I had found so far. It made sense, so why wasn't it working? Again, I found myself frustrated and demoralized.

Meanwhile, I came across a new web site, by Ko de Rooij, a Dutch trumpet player and brass teacher who suffered from dystonia while he was still a student. Ko felt that his eventual recovery was due very largely to using a method called The Balanced Embouchure, written by American trumpet player Jeff Smiley, and he now specialises in teaching it himself. While not designed to cure dystonia specifically, the simple exercises are relatively straightforward to learn, and they are radical in that the method questions and contradicts in some areas the generally accepted view of how an efficient brass embouchure should operate. I have been having regular personal lessons with Ko since June of this year; although it is still fairly early days I am optimistic as to how things are progressing. In this short space of time, I can feel a positive movement and change in the embouchure, introducing more stability in my playing. When I was a student, the general plan amongst the trombonists was to allow two to three years after graduating to see if there was any prospect of succeeding in the profession, with a vague idea of doing 'something else' as a Plan B, which is reasonable when you are young. But for musicians who have already established their playing careers, perhaps over decades, a more considered approach is required. There is a need to formulate a practical plan, ideally together with an experienced mentor, which takes into account the often overlooked transferable competencies of the musician, and perhaps more importantly, unlocks what is hidden within the person behind the musician. Some time ago, the Opera suggested this to me and are financing a careers programme. At first, accepting this as a musician is a difficult step. Every success to date has been because you have been focused on your music and now it feels that you are being asked to dilute that focus. However, I decided that in parallel to working on my rehabilitation it is necessary to formulate a more structured plan B. Tom will elaborate later on the details of how the programme works.

Dystonia has always been a taboo subject in the musicians' world; it was hidden away and explained as a player just losing their lip or their nerve. With information now more freely available than ever before, it is astonishing how many musicians from all levels are affected. In recent years young top professionals such as the Bass Trombonist of the London Symphony Orchestra, and the Prinicipal Trombonist of the Halle Orchestra have had their careers brought to an early end because of dystonia. Most recently the world-renowned Phil Smith, the long-standing Principal Trumpet with the New York Philharmonic Orchestra retired because of dystonia. And there are many more lesser-known professionals and amateurs who struggle on, some of whom I know personally. There can also be grave mental and emotional consequences for a musician with dystonia. One rehabilitated player I consulted admitted to me that in the darkest days of his dystonia he became clinically depressed and was close to suicide. So dystonia is by no means trivial. Understandably, musicians do not want to think about an illness with no known medical cure and affected musicians are afraid of losing work. But at least musicians' dystonia is becoming more widely recognized now and there is information available about different people's ideas and experiences of rehabilitation.

In conclusion, I have found that it is possible for people to make a recovery from dystonia, which is the first ray of hope. I continue to focus on rehabilitation and recovery, while at the same time following the careers programme, and I would now like to hand over to Tom, who will explain more about that.

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