

FOCAL DYSTONIA and ME

In this article I wish to clarify some questions and myths about Focal Dystonia. For my preference, I do this in the style of a personal letter rather than an academic paper. It is a personal issue for me, and the informality of a personal sharing of thoughts grants me the tranquility to be as transparent as this subject requires me to be.

I resigned my position as Principal Oboe with the Chicago Symphony Orchestra in 2004 due to the consequences of acquiring Musicians' Focal Dystonia. I subsequently re-auditioned successfully for the same position in June, 2016. My return does not mean I have found a cure for Focal Dystonia, nor an escape for its consequences. I now have the advantage of foreknowledge of the situation and what I believe is a viable plan to continue performing. Only time will tell if this strategy will prove consistent enough to warrant my permanence in the orchestra. A solution is not a *cure*, but for all practical purposes it might be just as useful.

Invariably, while discussing diseases, medical experimentation, job loss and other complications, one may acquire a perception of pessimism. Indeed, this article *is* fraught with catastrophic situations, often with the most painful outcomes. Still, the silver lining is felt at every detail, particularly if we consider my return to the Chicago Symphony. Also, Focal Dystonia has permitted - or... forced - a diversification of my human and musical experience to levels I could not imagine back when I mostly played oboe. These two decades of dealing with Dystonia have not been "lost", nor void of life-changing musical moments, particularly for my understanding of what music does to human beings, and how it works.

I am able to perform today by understanding my limitations and working within them, both in the amount of time I play, the position of my hand, adjustments I made to the oboe itself, careful reed making, using sensory tricks, and by relearning how to play and express music within these limitations, technically and expressively, without allowing the old tarnished brain pathway to control my playing.

Focal Dystonia Basics

Dealing with Focal Dystonia has been the greatest challenge in my life, and I am both hurt that it happened to me as I am amazed at the important information and research I came in contact with because of this illness. Ironically, Focal Dystonia has also been one of my greatest mentors.

Dystonia is a neurological condition allowing for the involuntary contraction of muscles. It is a neurological – not muscular – issue located in the brain, outside of our immediate control. "Focal" Dystonia is a narrower version affecting only a particular section of the body. It is a myth to assume that musicians who acquired Dystonia practiced the wrong way, practiced too much or too little, didn't warm up properly, ate the wrong food, or could have done anything to prevent it from setting in. Focal Dystonia comes to professionals and amateurs, cool and stressed people, soloists and orchestra musicians, virtuosos or not, regardless of instrument, age or career length. You will find musicians with Focal Dystonia in professional orchestras just as you will find them in local community ensembles, in students and amateurs.

There is no test or blood exam that can indicate the presence of

Focal Dystonia. The diagnosis is made through a process of elimination by neurologists or performing arts medical experts, at the end of which the only plausible explanation remaining is Focal Dystonia. Musicians affected by this illness should seek second opinions - I reached out to four of them - as well as alternative and independent opinions outside of neurology. We do this not out of distrust for these experts, but because the current Focal Dystonia research available is far too limited for us to pin our hopes solely on neurology. For example, in their professional stature and knowledge neurologists repeatedly alerted me that Focal Dystonia is *incurable* and that I would eventually quit out of frustration for not finding a cure. I did. They were right. But I also took a step back, considering that neurologists are seeing the situation from their point of view, aided by significant but still incomplete research on “how to regain your performance ability after being diagnosed with Focal Dystonia”.

A firm diagnosis may only arrive years later - four or five years in my case - after our conscious and subconscious attempts to compensate for the illness fall short of our objectives and compromise the muscles we use to perform. With Focal Dystonia now being discussed more frequently in musicians’ circles, it is my hope that the diagnosis time may be reduced, as patients will seek the appropriate medical assistance sooner, and rely less on the dismissal of minor symptoms and/or self-made conclusions.

The central issue with Focal Dystonia is the garbled neural message coming from the brain to the affected area, which may leave it void of information and dysfunctional as to the proper movements certain muscles are supposed to do.

Focal Dystonia is "silent", with no apparent sign of the condition

setting in. There is no pain, no "click", no dizziness or rash or any identifiable mark that a change has occurred in the way our brain works in the affected area. After one acquires Focal Dystonia our body will make adjustments to the area naturally, automatically. It is beautiful, a bit scary, and curious to see this process at work. Eventually some localized symptoms begin to appear as *consequences* of the original Focal Dystonia event in the brain, such as curled fingers, spasms and certain difficulties with tasks usually done with greater precision, or when the natural adjustments no longer provide sufficient relief. The question remains to me if these are consequences "of Focal Dystonia" or "of the body's efforts in making up for the presence of Focal Dystonia". The latter is a mending attitude, and the former is a direct damage caused by the affected neuron(s).

At this point it is important to understand how the body's supportive systems come to play. Picture, if you will, what appears to be a plastic lawn chair, weighing only a few pounds, and which you can probably lift with just a finger or two and little effort. Upon attempting to lift it, however, you realize it must be made out of iron or lead, or be bolted to the ground. Even without your conscious demand for more muscle power, your body immediately summons support for your fingers, coming from the *flexor*, biceps and even the larger trapeze or pectoral muscles in order to bring your task to completion and lift the chair. Before you know it, your entire body is vested in the task of lifting, without the need for you to consciously call these muscle groups into action.

One of the traits of Focal Dystonia which for me always appeared bizarre is that it is *task-specific*: it will affect only a specific pathway or activity, leaving the arms and fingers free to exercise other similar functions, depending of course on the severity of the condition on

the affected area which in some cases may render fingers or an entire hand clenched, apparently atrophied or otherwise compromised. On practical terms it means that Focal Dystonia affects my *oboe* playing, but has negligible influence in my English Horn, oboe d'amore, or baroque oboe playing. What we call "playing the oboe" is actually the result of a complex line of synapses between neurons in the brain, bringing together sounds, feelings, touch, past experiences, movements of fingers, memory, precise positioning of dozens of muscles, comparative auditory perception, visual input and just about everything you might think would be remembered as part of the task of "playing an instrument", including fears, joys and other emotions we choose to associate with playing and add to the mix while practicing, repeated over and over through decades of practicing and performing. All of this information forms a *pathway* through the brain, connecting it to the fingers, lungs, muscles through the nerves, which then recall what "oboe playing" is as a neurological task and inform the body what it needs to accomplish. This is how come the oboe seems familiar every time we play it. " The strategy of "re-wiring", therefore, or the re-training of the brain to create a new oboe pathway is prone to failure or only limited success, because the brain seems to gravitate towards information it already knows, in pathways already established, even if one of them is faulty.

My particular situation

This natural support system also applies to our playing musical instruments. Although Focal Dystonia affected the usage and position of my near-hand muscles, unbeknownst to me the result of years of subconscious compensation for that silent and still undiscovered brain issue left the entire left side of my body affected and tensed, as one muscle group after another attempted to

compensate and complete the task of assisting my fingers to move up and down as my playing required. It was not the *weight* of the fingers that was an issue, nor was the repetitiveness of their action, but their *lack of information* and *new finger placement* given by the garbled message coming from the brain which impaired my playing. This flawed information created a new balance between the *extensor*, *flexor* and *pronator* muscles, which is now different than it was when I did my original oboe training. The *pronator* has permanently altered what I consider to be the natural and normal playing for my wrist counterclockwise about 45 degrees, the *flexor* is pulling harder, bringing the affected fingers into the palm of my hand, and the *extensor* had no choice but to accommodate the *flexor*'s pull. In doing so, the *extensor* became overly stretched, resulting in inflamed tendons. While the *pronator quadratus* muscle is located around the wrist and thus closer to the oboe action, the *pronator teres* runs further back, next to the *flexor*, and it could be questioned whether the closeness of these two muscles might be of significant interest in understanding the changes in my arm. I could also argue, perhaps, that the *extensor* might not even be part of the Focal Dystonia package, but merely an innocent by-stander who was adversely affected by what was going on with the *flexor* and *pronator teres*.

Focal Dystonia affects two fingers of my left hand with involuntary tension of the *flexor* and *pronator* muscles (the 3rd and 4th fingers, or "A" and "G" on the oboe). The 5th finger is affected only due to its proximity and attachment to the 4th and by being at the edge of the *pronator*'s 45-degree shift, but it is not affected directly by Focal Dystonia, even if at first we suspected it might. The two affected fingers have curled and clenched into the palm of my hand, but the strength of this clenching varies. On some days it is strongly

clenched, but on others not so much, and I observed how this has nothing to do with nerves, temperature, over-playing, repertory or other routines.

I probably acquired Focal Dystonia during my first or second year in the Chicago Symphony (1995-1997), and spent practically my entire 9-year initial tenure with that ensemble coping with this disease, including the Grammy-winning Strauss Concerto recording, the works recorded for Wayne Rapiere and Boston Records (Schubert, Bach, Telemann) and those recorded for Cedille Records (Yano, Sydor, Martinu, Moscheles, Molique, Krommer and Hummel). The first sign that something odd was happening to my health came during my third season - 1998 - when I visited my family physician complaining of a searing pain in my chest, thinking it could be some kind of heart issue. None was found, but years later I would come to understand how the pectoral muscle was already being stressed towards my left arm, causing this searing sensation on the *sternum* bone, in an attempt to compensate for the effects of Focal Dystonia. This compensation action by then had already involved the *extensor, flexor, biceps, triceps* and *delta* muscles. All of them were tenser than normal, but I felt little difference because the end result was being taken care of: I could play, normally. If I felt any tension around my arms it was easy to dismiss as part of a myriad of other explanations, from playing too hard with the kids on the day before, or reacting to Chicago's notorious cold winters. Never in my wildest nightmares would I suspect that a neurological condition was already brewing within me.

The tipping point appeared late in the year 2000, when the Chicago Symphony presented Prokofiev's Peter and the Wolf in the Family Series I adored so much. As part of the performance, I was asked to "walk like a duck" while I played the oboe lines. As a result, I pulled

a muscle in the tail bone area. What appeared to be an independent issue soon fixed with steroids created a cascade effect in all the muscle groups between the lower back and my left hand, causing my fingers to curl into the palm of my hand. One month later I began having difficulty performing works that I've known all my life, such as the Mozart Oboe Quartet, and it would take me unusual amounts of time to learn new music. By March, 2001 I performed Mozart's Concerto with Gerry Schwarz conducting in São Paulo, and needed to practice a full hour of scales before a rehearsal or performance. I realized something was terribly wrong and upon my return to Chicago consulted with our symphony physician, followed by two general neurologists at Chicago's Rush Memorial Hospital and by performing artists specialists Dr. Alice Branfonbrenner at Northwestern Memorial Hospital and Dr. Richard Lederman at the Cleveland Clinic. All four neurologists confirmed I had acquired Focal Dystonia.

Immediately after the diagnosis was confirmed I alerted the orchestra's management of these findings. My Chicago Symphony colleagues and staff were wonderful and supportive to me even as I gradually entered this period of experimentation, looking aimlessly for solutions and finding none. I will always be grateful to our Assistant Principal Oboe Michael Hensch for rushing to the hall countless times as a last minute substitute when I was in pain or otherwise incapable of playing, to Personnel Manager Carol Lee Iott, and to the Vice-President of Production Vanessa Moss for being by my side as I needed more time off to try different treatments. I could not have asked for more supportive colleagues in a tight moment.

In the months that followed my diagnosis I must have spent nearly 150 hours in physical therapy of various kinds. As an oboist and

reed maker used to looking at a complex situation and finding creative solutions, from testy gouging machine measurements to off-beat oboe adjustments which Carlos Coelho often complains to me about, I went about this problem with the same strategy: looking at the whole body and trying to fix anything that might possibly be wrong from a point of view of *balance*, hoping to find a link to whatever it was that led to Focal Dystonia. The comparison with reed-making here is that often the solution is found not by focusing on a small part of it, but in looking at the whole item as a complete working machine. If the neurologists have not *yet* found a solution, then the solution must still exist somewhere. Or so I thought.

Searching for a solution

Focal Dystonia tends to vary in strength and intensity during the first few years, making tendon tension feel like a moving target. It is difficult to understand exactly how far we can push the muscles in a compensation strategy before the tendons inflame. It leads me to hopes that the illness may not be all that serious, but then again it is. In time, however, Focal Dystonia settles and that limitation becomes a known factor, allowing for better precision in determining how much playing I can do. Using soft treatments such as placing warm towels in the arm prior to playing and cold ones afterwards, and also making regular use of a tens machine to reduce tension in the muscles granted me some extra months of regular performance. It was a price I was willing to pay in order to continue playing, finishing projects that were important to me, and also learning about the limitations I was dealing with. If Focal Dystonia now had a predictable limit, I could also predict how much playing I can do before I acquired tendinitis as a result of my compensation efforts. This is a limited way of playing, yes, but it is *some* way I can continue to play.

The faulty information coming from the brain often spurts fingers into action without any advance notice, as if it was a sudden reflex. When this happens, the fingers snap into action with far greater intensity, like a muscle *spasm*. I have found that applying greater tension to the muscles of the hand - such as what we oboists normally do when we play with a leaky key - tends to minimize these occurrences, but then again, extra tension while playing may cause tendon inflammations.

Besides being overly tensed, the *flexor* muscle also pulls each of these two affected fingers down at different strengths and directions - and this is where the *pronator* muscle contributes as I explained earlier with the different positions for the “G” and “A” fingers. Because of that counterclockwise 45-degree deviation of the *pronator*, the “G” finger – the one closer to the edge of that *pronator* turn – received an extra pressure downward. The finger thus searches for the g-key somewhere inside the bore, it sticks to the actual key and becomes difficult to lift. It is as if I tell the finger to lift of the key and it would respond that it has already done so from its point of reference, even the key as not lifted. This is because the point of reference tied to the oboe pathway in my brain is set according to the *previous* position of my *pronator* and *extensor* muscles. It is not as simple as just telling the “G” finger to adjust up a bit, because what we refer to as “G” finger action is in fact a complex code of neurological information built and strengthened over decades of playing. I can’t simply change that pathway without incurring a domino effect of other doubts somewhere else in my overall playing because the “G” finger is not alone in the act of oboe playing or in the “oboe neural pathway”, but is part of a complex set of interactive and interdependent actions and reactions involving all 10 fingers, arms, face, breathing, if not the entire body, intellect,

emotional input and everything else that is actively in us being a musician.

The “A” finger, on the other hand, by being more central in the hand, is less affected by what the *pronator* and *extensor* did, and thus is now set on a more distant plain than the “G” finger. I explain: as our *pronator* turns our wrist and hand, the fingers at the edge of that motion (4th and 5th fingers) become more distant from their neighbors, like the 3rd finger. This causes a separation which in “normal” oboe playing does not exist. We all learned how to put our fingers in line, and proper technique teaches us to move them equally and in small amounts. The 2nd, 3rd and 4th fingers thus move in similar amounts, direction and downward pressure. Not so when the *pronator* turns our hand to the side by 45 degrees. The 4th and 5th fingers are taken out of line, and in my case the 3rd/middle finger gets stretched away. The fingers which used to be in-line with ease now settle into a comfortable position that looks as if I am holding a small baseball. This means the “A” finger now searches for the a-key somewhere around 5-10mm *above* the actual key and has the opposite action to what I described above with the “G” finger. Because of its tendency to rapidly fly off the key, the “A” finger is the most affected by the spasms common to musicians with Focal Dystonia, being responsible for my giving a “B” to the Chicago Symphony one on occasion.

Regardless of what Focal Dystonia did to my fingers, my concentration was now aimed at going around its effects, and it is precisely this work in opposition to the new finger placements that caused tension, tendinitis, pain and time off playing. To make it clear: Focal Dystonia does not bring tendinitis. It is *the work I do to compensate for it* that does. Focal Dystonia changed the placement of my fingers, so as to make it impossible for them to “find” the

oboe and act properly in accordance to the instructions acquired and strengthened over a lifetime of oboe performances. In order to rewire, relocate, reposition the fingers and continue playing I endure some collateral damage, in a way, which permit me to play but needs to be constantly checked to make sure I don't overdo the tension. Neither Focal Dystonia nor tendinitis permit me to play comfortably, but between the two there is a delicate balance, managed by careful choices and monitoring. If I play too much I may develop tendinitis, and if I play too little, then, well...what is the point of fighting the disease?

Sensory tricks and the “prepared” oboe

It is wrong to assume that fast playing would induce more tension than slow playing. I noticed how playing a Mozart Symphony would leave me with tendon tension much quicker than, say, the Mozart Oboe Concerto. This is because during a long note or slow passage I become more vulnerable to experiencing a spasm. In order to avoid that spasm I apply more pressure on both sides of the arm - *extensor* and *flexor* (the leaky key strategy). When I play faster passages, however, even if I still use some extra tension to make sure the fingers are working properly, their up and down work involves relaxation and blood flow at levels sufficient to overcome some of the extra tension brought by the fast passages. In this context, playing fast does add tension, but not as much as playing a long note or slow passage, even if this does seem odd. The trick is that in order to play any of these pieces – slow or fast – I need to practice as little as it is absolutely necessary, or else I may accrue more tension than can be released during down time, and thus risk the onset of tendinitis as the tension adds up every time I play.

I also sought ideas in the experiences of other musicians with Focal

Dystonia, who spoke to me of "*sensory tricks*" and other means of coping with the limitations at hand. Sensory tricks are attempts to convey a misleading message to the brain, making it search for solutions away from the damaged pathway. As such, as far as my brain is concerned, I no longer finger the "oboe", but something akin to a saxophone, as my fingers no longer reach the oboe in a straight line, but slightly curved outward. After some experimentation I added a large coin glued to the G-key providing an extension for my fourth finger. With sensory tricks and alterations to the oboe I can bypass the pathway in the brain that tells me how to "play oboe" and simply create a different one - albeit similar in many ways.

During the initial six months after the diagnosis I tried various therapies, experimented with finger weights, taking small amounts of time off from playing, added intense stretching exercises and warm-ups, visited chiropractors, massage therapy, posture work, acupuncture, performed selected repertory, limited or cancelled teaching and other professional engagements, and began experimenting with alterations to the oboe itself, pegging extensions to the keys which would assist my fingers in reaching them. To no avail. I visited dentists who proposed that the mercury contained in dental fillings could have affected my neurological system, and considered replacing all my fillings with new mercury-free units (I didn't). I tried medicine for Parkinson's disease, calculating that Focal Dystonia could be a result of some level of paralysis (it isn't). Another doctor injected the common dental anesthetic Novocain into my fingers, hoping to nullify any kind of localized agent which could be affecting the fingers' response (that didn't work either). And of course I experimented with the common drug Botulinum Toxin - Botox - used by many Dystonia patients, though it had no effect due to my particular situation - Focal Dystonia affected only

two of my fingers, and a potential leakage of Botox into the muscles affecting the entire hand could compromise the other, healthy three fingers. At some point I developed *double tendinitis*, feeling the pain of inflammation simultaneously on both ends of the *extensor* muscle: wrist/hand and elbow, as a result of that muscle encountering uncommon stress. Also, one of my neurologists suggested that a brain tumor could be pressing against neurons related to the oboe pathway. To my relief a Magnetic Resonance Imaging – MRI showed no such presence. This period was characterized by experimentation in all forms possible. As the saying goes, when all plausible solutions have been attempted, the only option left must be the correct one, so my strategy was to reach that point where every stone was turned and a solution would be revealed. At stake was my career, the sustenance of my family, the education of my children, and as I soon came to find out, my sense of self-worth and personal identity.

In November of 2001 came my worst fear. I was unable to play, at all. I sat in rehearsal, taking notes, watching my colleagues play, feeling useless. I requested a longer medical leave from the Chicago Symphony. I stopped playing altogether for two months, hoping to restart as a beginner, little by little, and establish a new finger technique that would prove successful, even if my neurologists warned me it wouldn't change the condition at all. They were right, it didn't. Of all the attempts to find physical solutions, one stood out as truly remarkable, and that was the deep tissue massage with therapist Sonia Broglin, similar to Rolfing and also referred to as “soft tissue” massage. It took two years of weekly or bi-weekly work, returning always as soon as I rested from the previous session. This work allowed more blood flow and cleaning into the muscles that I had been using to compensate for Dystonia, and thus - as the theory goes - also permitted a better flow and usage of whatever

neurological information passed through the nerves in that region.

During my last season with the Chicago Symphony I confronted tendinitis on a monthly basis, generally after about 3 or 4 weeks of playing. I derived from that experience that if I limit my playing to an average of one hour of playing per day I could allow the muscles and tendons to relax enough to avoid falling prey to tendinitis again. That limitation is hardly enough to maintain an orchestral position, and as I forced the muscles and tendons to meet orchestra demands I developed inflammations/tendinitis regularly and was forced to stop playing. I felt myself being a bad colleague to be so dependent on others to fill in for me at the last minute so many times, and being unable to predict when I would be available to provide adequate performance commensurate with the expectations laid on me or my position. Truth be told, the writing was on the wall, and I was no longer qualified to be sitting in the Chicago Symphony. I was disabled, handicapped, damaged goods, unable to perform my duties. Beaten by the one-hour-a-day limitation, relying on the words of neurologists regarding the incurability of Dystonia, and finding no solution after years of trial and error with alternative treatments, I decided it would be best if I accepted the loss and left the orchestra altogether. I cared too much for the high standards of performance and accountability in the Chicago Symphony to permit that I would become a focal point of lesser achievement, a weak link, so to speak. I also feared the domino effect my instability could create in my colleagues, as my insecurity would cause other musicians to lose concentration. In a tightly knit, high functioning orchestra, such small perceptions often make the difference between an excellent concert and a life-changing artistic event. In Chicago we pride ourselves in diving for the latter, as we should.

Orchestra contracts are unprepared for Focal Dystonia

Departing from a major orchestra due to an illness should be less of a personal burden, after all such orchestras boast formidable contracts, with health insurance, disability and a host of benefits for departing musicians needing care. Not so with regards to Focal Dystonia. The insurance company of choice with the Chicago Symphony did not recognize Focal Dystonia as a disability. I was thus *denied* disability insurance and left the orchestra without any income whatsoever. This is an apparent flaw in the CSO Musicians' Contract, as it failed to properly protect its members as they undergo a career-based illness. I literally returned to live in a couch in my parent's living room. In fact, given the statistics of orchestra musicians acquiring Focal Dystonia, my suggestion to the CSO's musicians as well as to all other professional orchestras and Unions is to add the words "Focal Dystonia" and specific language to that effect on their disability insurance policies, so their insurers will not disregard the needs of one of their musicians again in the future. Musicians who acquire Focal Dystonia are disabled *as far as their continuing orchestra work is concerned*, even if they may still be able to play *something* or exert their playing capacity to *some extent*. This is particularly important because more often than not musicians have dedicated an entire life to playing their instruments, having no other training. We are entitled to a second chance, with our instrument at hand, trying and trying again until we hopefully succeed, without the suspicion that such trials are undeserving of disability insurance support. Understanding and making sense of this is up to the Insurance Companies, but leave no doubt that *Focal Dystonia is a disability capable of impeding the continuation of employment*, and *no* musician should be denied disability insurance as a result of this illness. Also, due to the emotional impact carried by any of a fair list of job-threatening and career-ending illnesses, musicians may incur depression and even life-ending thoughts as a

result of their loss, and thus be unable to devote time and energy to taking insurance companies to Court or sifting through hundreds of pages of insurance information looking for their rights. Orchestra committees and unions would serve their musicians better if they *each* assign a representative to accompany all critically ill colleagues through all their rights and benefits during their convalescence, where these protections are found in orchestra contracts, union guidelines or state and federal law.

It is wrong to minimize Focal Dystonia as a mere neurological condition. These medical "conditions" come with consequences that affect not only the muscles that we push hard to compensate for, but they also have a devastating effect on the psyche, emotional well-being, self-worth, self-esteem, and on the all-important *identity* of the patient. Focal Dystonia itself - that is, an interrupted neurological pathway somewhere in the brain - is of little conscious concern to me, when facing the myriad of *consequences* arising from it. These *consequences* to our emotional well-being cannot be easily discarded as being as bad or worse than the condition itself, because musicians learn from a young age to build a life around music and that instrument. Take the instrument away and their personal security and identity may collapse.

Family and law on Focal Dystonia

Focal Dystonia affects more than the actual person diagnosed with it. As can be expected, an illness capable of causing such disorientation for years on end prior to a diagnosis, and of such chaotic emotional, professional and financial roller-coaster afterwards is bound to affect those who live *with* the patient just as much as the patient. Sadly, it is not uncommon for people who suffer from major illnesses and disability to also encounter difficulties with

partners who don't fully grasp or accept the seriousness of the health-related adjustments and sacrifices that need to be made to maintain a family structure together through these conditions. Many partners become angry at their ill spouse as a diversion from their actual feelings towards the illness, which has no physical presence to receive such emotions. In November, 2001, a few days after I began my medical leave from the Chicago Symphony and roughly 6 months after my diagnosis I was served with divorce papers, ironically claiming all the consequences of the disease as an impediment for proper matrimonial continuation, such as my focus on my personal issues and the immense amount of time being devoted to finding a cure, plus the signs of depression which accompanied the entire process. So much for "in sickness and in health", one might think, but consider that the average spouse may have an even harder time understanding that which not even the patient could understand at the time. Add to that the idea of *identity*, the fact that it takes a lot of strength for a Focal Dystonia musician to *accept* their fate, the end of all they have worked for in their lives, many times since before middle school. In this scenario, denial is a friend, a momentary insane thought that helps keep ourselves focused on an elusive cure, if that even exists. I understand other musicians affected by Focal Dystonia also encountered changes in their relationships, which either ended or became stronger as the couple worked together (or not) to overcome the consequences of this condition and to the overall family stability.

The loss of family and the closeness of my children through an aggressive litigious process did not help my work against the consequences of Focal Dystonia. I was always - and still am - very close to my children, and the prospect of being taken away from regular involvement in their lives was devastating to me. The catastrophic nature of this family situation is a separate saga, but it

intertwines with my Focal Dystonia issues enough to make me include it in this article as a consequence of the illness, not only in the arguments made in favor of the separation, but in the effects of such a monumental life change in a person already burdened with an incurable illness. It also became clear how Focal Dystonia is such a mystery to legal authorities when dealing with loss of employment and disability.

As I searched for medical solutions, the divorce issue took proportions for which I could not have been prepared for. My doctors were barred from testifying on my behalf, and none of my medical information was introduced into Court hearings. I was levied support payments calculated on the basis of my *pre-disability income*, that is, it was as if I never acquired Focal Dystonia at all. I was found to be financially responsible for acquiring a disability, and granted no relief for continuous treatments and medical support whatsoever, even if I no longer had income to provide for my own support, let alone for others'. This conclusion is irresponsible and discriminatory, and reached absurd consequences for my children, ironically the ones who were supposed to be protected by a Family Court. The list of reprehensible actions taken against my children's best interests due directly or indirectly to my acquiring Focal Dystonia is shameful, and kept me returning to US Courts, at great personal expense, in the futile attempts to establish my civil rights as a person of handicap.



Figure 1: the 3rd and 4th fingers have curled and now clench into the palm of the hand.



Figure 2: the “new” balance between the fingers positions the “G” finger lower than key level, and the “A” finger higher.

Corrosion from within

Depression is a common aggregate to Focal Dystonia. It can be argued that an extra artistic sensitivity leads us towards an artistic career, but in moments like this the sentiments are a self-aimed weapon, as the down feelings in many cases lead our colleagues to catastrophic personal decisions. I remember seeing in a website for musicians with Dystonia that "those considering suicide should contact a crisis center immediately".

Focal Dystonia takes away more than our playing. It also takes our dreams and life plans. Our emotional balance is shaken when our instrument and lifelong musical companion is taken away. Music performance saved my life before, and gave it meaning. I was almost expelled from school in third grade, but that soon led to my visit to a symphony orchestra concert where I heard the great oboist Lido Guarneri play. I fell in love with the oboe, and my life changed. All my most important life moments were surrounded by great music and an oboe...but all of a sudden I am being told I will not be able to do that anymore. I began to question the simplest actions in my life, for lack of reference.

Fighting the loss of my job and career, while simultaneously fighting the loss of my family proved too much to handle. People don't *choose* to become handicapped, and no disabled person should go through humiliations and oppression in order to remain close to my children. The trouble with discrimination is that it comes attached to preconceived notions about a person's positive contributions to others, or lack thereof. The emotional impact of both fronts proved unrealistic for me. I was unable to cope with either loss. Society does not consider it proper for a person to take one's own life or even consider such an option. That option, however, needs to be

understood from the point of view of the person who finds him/herself without a light at the end of the tunnel. Like some patients with Focal Dystonia, I too considered that option, for one simple reason: it would stop the pain. To my benefit, and that of my loved ones, a close friend happened to call me during my worst moment, during the process of writing my final letter explaining why I came to the conclusion that this was the best solution under the circumstances. A crisis center was called to save the day.

After leaving Chicago I spent months in a state of perplexity, unable to sleep more than two hours per night or take any action towards recovery. I would occasionally practice, but would be reminded a few days later that tendinitis was always a consequence of forcing my hand to do what it no longer could. For mere financial survival and thanks to friends willing to help, I participated in a few sporadic musical events, always with the façade of optimism hiding the chasm I felt inside. After all, a revelation of my true feelings at the time would hardly be a professional calling card, and would render my rare visits with my children completely obsolete.

Recovery

What did I have at my disposal which I could still count on? I eventually began my recovery and gradually learned how to work within the limitations of the illness and optimize my playing. Eventually this effort led to an increase in the amount of playing I could do. I added conducting to my musical activities, as it provided a return to the stage and a challenging music making. But what Brazil really needed from my experience were more cultural institutions based on a win-win strategy, befitting students, professionals, patrons and public, opening a managerial point of view more common among American and European institutions. I

also deeply missed my time in the Chicago Symphony and wished to implement in Brazil some of the principles I appreciated so much during the 25 years I lived in the United States.

In 2006 I created the Santa Catarina Music Festival - FEMUSC, where we established what is essentially an American-inspired institution with latin-american spirit: a private Institute with a Board of Trustees, tuition-free and room-and-board provided for all students, with top-notch faculty members/friends from so many great orchestras and conservatories. We soon attracted a large legion of students and today, going into its 12th season, have served over 8000 of them, from 40 countries. FEMUSC is divided into 10 separate but simultaneous workshops, each catering to a different stage in a students' development, from a children's festival all the way to a Marlboro-inspired Professional Program, and each with a separate set of pre-requisites and admissions priorities. We offer over 200 public performances during the 2-week program, in 25 concert series in 7 cities, to over 60,000 people. It transformed the beach-flight, sleepy month of January of the industrial city of Jaragua do Sul (population 130,000) into a bustling commerce town, creating 450 jobs, filling hotels, restaurants and shopping, and moving the economy at approximately three times the amount of the festival's budget. A win-win-win situation, no doubt.

I also created PRIMA - Program of Social Inclusion through Music and the Arts, in one of Brazil's poorest states, Paraiba, with similarly poor ratings in crime, drugs, and social risk. It was a life-changing experience to see how such a "sistema"-inspired program works and evolves people and communities. The plan we implemented was to analyze orchestral playing from the point of view of citizenship, using the orchestra as an example of a well-balanced society, where music can demand from all musicians an embrace of tolerance,

respect, teamwork, personal responsibility, discipline and other character premiums we would like to see in a new generation of residents in the communities served. PRIMA grew strong, reaching thousands of students during the four years I remained at its helm, in 11 music centers distributed through an entire state. I left PRIMA in order to return to Chicago.

While I am happy to continue playing, and overwhelmed by the exciting return to the Chicago Symphony Orchestra, I am also happy to have acquired skills, experiences and appreciation of other forms of musical engagement, namely management and social action. Also, I would not have made it through these difficulties without the close attention of a number of friends who were angels in my time of need. Fortunately for me, they are too numerous for me to mention here, but Charles Stegeman and Frances Debroff deserved a special place in my heart for their unfailing guidance and humanity. Above all, my thanks go to my wife Catalina Guevara for her unfailing love and support during the past 12 years, and to my children Stephan, Ani, Alexandre and Nina Aura for their patience as their father reorganized his life during a period when they needed a strength and security which at times was difficult to provide.

My advice to those who are confronting Focal Dystonia for the first time now, is to "take the curve" on the road, and accept it. The plans, dreams and expectations you had for the previous direction on the road are now lost, forever. Accept it. Open your hearts to the new challenges, which promise to be every bit as interesting as the older ones, if not more. It might just happen that by accepting the unacceptable you will place your mind at ease enough to find solutions you would never have considered had you maintained your mind set on your past. And it might just be that some of that past

will return to you on a silver platter, as a new beginning.

Links of interest:

Musician's With Dystonia

<http://www.dystonia.org.uk/index.php/about-dystonia/types-of-dystonia/focal-hand-dystonia/musicians-dystonia-musicians-cramp>

Dystonia Medical Research Foundation

<https://www.dystonia-foundation.org/what-is-dystonia/forms-of-dystonia/musicians-dystonias>

Leon Fleischer interview, 2007

http://www.nytimes.com/2007/06/12/arts/12iht-pianist.1.6104272.html?_r=0

Leon Fleischer interview, 2010

<http://www.independent.co.uk/arts-entertainment/music/features/leon-fleisher-my-life-fell-apart-1984408.html>