Focal Dystonia:
What is it? Who gets it? What can be done about it?

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Although a highly opinionated battle rages over focal dystonia (much like the subject of stage fright, addressed separately), musicians currently concerned with the problem can be assured that while this remains a difficult problem, there are facts to be found about what it is, who gets it and what can be done about it. The challenge (as with stage fright) is finding information that is free of the kind of often heated debate that has little, if any, basis in fact and offers more confusion, guilt and hopelessness than help.

This article is written in support of those experiencing what may be focal dystonia and as beginning reference to anyone wishing to explore and be part of the solution. The writing is dense, for which I apologize, although I did try to make it accessible in useful ways. Hang in there and, I hope, you will find something worth your patience! The fact is, if you or someone you care about has focal dystonia, your patience will be a huge part of its resolution.

PART ONE

What is it?

First, it is *real*. It is not, as has been suggested frequently in Internet fora and back stage conversation, simply something invented as an excuse to cover up more general playing inadequacy or an invention by the medical profession needing a new "disease."

There is tangible, measurable evidence for this being so, not only **behaviorally** (specific, identifiable patterns of what one can and cannot do) but also **neurophysiologically** (identifiable changes in brain activity when this condition is present that are not found when it is not) and **neuroanatomically** (identifiable changes in the physical structures of the brain when this condition is present that are not found when it is not). Although research using brain imaging (to identify neurophysiological and neuroanatomical changes) in focal dystonia is still in its infancy, findings thus far point to tangible and logical underpinnings associated with the problem, thus **challenging the assumption that this disorder does not have a "real" basis**.

In fact, even though brain imaging or neuroimaging as we now know it (CT and PET scans, MRIs, etc.) has been around for only a few decades (MRIs and CT

scans were first developed in the 70's and 80's), **"dystonia" has been recognized and called by this name in neurology for almost a century.** In 1911, Oppenheim (a German neurologist) first used the term "dystonia" to describe the variable tone present in patients with abnormal muscle spasms. And the history of the various forms of this disorder unfold from there.

So, **although it may be a new word for musicians, "dystonia" is not new to medicine--as some people seem to think it is.** Obviously, focal dystonia--and most often in the case of brass players, embouchure dystonia--is a specific form of dystonia. (String, wind players and pianists, for example, more typically and obviously, suffer from "hand dystonia," a famous example of someone afflicted being Leon Fleisher.)

Hopefully (in the case of most readers anyway), we've now gotten past the hurdle of whether or not focal dystonia is real. Next, let's look more closely at what it is, specifically as it turns up in musicians.

Focal Dystonia in Musicians

First, **"focal" dystonia is so named because it is "focal" to a certain location in the body, such as the hand or the embouchure.** Jabusch and Altenmuller (2006), citing various pertinent studies, give a clear (and current) definition of focal dystonia specific to musicians:

"**Focal dystonia in musicians... is a task-specific movement disorder which presents itself as a painless muscular incoordination or loss of voluntary motor control of extensively trained movements while a musician is playing the instrument** (Jankovic & Shale, 1989; Lederman, 1991: Brandfonbrener, 1995; Frucht et al, 2001; Altenmuller, 2003)."

That is to say that focal dystonia in musicians is a neurological disorder, as distinct from, for example, carpal tunnel or "over use syndrome," which is a painful, inflammatory condition. Nonetheless, conditions such as "over use syndrome" or other injury, trauma, stress (including psychological) are risk factors (that is, they put someone at greater than average risk) in focal dystonia.

It is tempting to digress into more of the neurology involved. However, for the sake of brevity and targeted answering of our questions, let's move on from the neurology for now and suffice it to say that **there is an underlying necessary learning that happens (necessary to play an instrument at a proficient level) that takes a maladaptive twist (for possible reasons discussed later) and that this, in turn, creates certain wiring problems in the brain (as well as imbalances in other parts of the person) that then need to be addressed.**

Before proceeding any further, I'd like to introduce a useful and balancing mental tuning for those wishing to consider it:

Focal dystonia is a specific challenge that holds within it unique and powerful opportunities.

PART TWO

Who gets it?

Reportedly, **one per cent of all musicians** are affected (Altenmuller, 2003).

While the **majority are professional musicians** and of those **the large majority are classical musicians, those afflicted also include (contrary to popular report) jazz and pop musicians** (e.g., in the Jabusch & Altenmuller, 2006, study).

The **great majority of musicians presenting with focal dystonia are men**, a consistent finding from research and anecdotal evidence. In the Jabusch & Altenmuller (2006) study, which used 144 musicians with focal dystonia, when they controlled for number of men and women that normally show up in the general population of professional musicians in Germany (meaning, they took measures to find out what the gender difference was independent of how many men compared to women musicians there are), the ratio was 6:1 men to women.

The **average age** of onset (when **it first shows up) is** usually reported as "fourth decade," meaning **in the 30's**. But it needs to be emphasized that this is an average age. In the **Jabusch & Altenmuller (2006) study**, for example, the average age was 33. However, **the range of ages was 17 to 63**! So, there's a lot of individual difference, an important consideration, I believe.

Other predisposing factors include **family history** (which could be a genetic predisposition, an environmental risk factor or a combination of both). Somebody else in the family has something like it, such as musician's dystonia or writer's cramp. Also, those who tend to be **perfectionistic** have a greater than chance liklihood of getting focal dystonia. Another frequent report is that, more often than not, the person tends to be a **"natural" player** (although my personal experience is that this is not as often the case as generally implied). Obviously, though, there are many musicians with focal dystonia that do not have a family history, are not so perfectionistic and/or are not "natural" players. **The absence of any one of these does not preclude a diagnosis of focal dysonia. This is simply a statistical profile of trends.**

PART THREE

Why do people get it?

Already, this question has been touched upon above. But let's explore it further.

STAY TUNED!