Focal Dystonia Guide and Resources

WHAT IS DYSTONIA?

What is dystonia?: “Dystonia is a disorder characterized by involuntary muscle contractions that cause slow repetitive movements or abnormal postures. The movements may be painful, and some individuals with dystonia may have a tremor or other neurologic features.” from the National Institute of Neurologic Disorders.

WHAT CAUSES DYSTONIA?

“Researchers believe that dystonia results from an abnormality in or damage to the basal ganglia or other brain regions that control movement. There may be abnormalities in the brain’s ability to process a group of chemicals called neurotransmitters that help cells in the brain communicate with each other. There also may be abnormalities in the way the brain processes information and generates commands to move.” from the National Institute of Neurologic Disorders. Focal dystonia is specific to a body part or task, whereas there are other forms of dystonia that may affect global aspects of the body and are not task specific.

IS THERE A CURE?

There is no “one size fits all” cure. Some people have found relief and progress with some of the current treatments, such as Botox shots or anticholinergics, whereas others have found no improvement. The side effects to both medicines are numerous and are not for everyone. However, many people have found movement therapies to be extremely helpful, such as sensory re-education. It can be useful to seek the help of a physical therapist or occupational therapist once a diagnosis has been made.

HOW MANY PEOPLE DOES FOCAL DYSTONIA AFFECT?

An estimated 1–2% of musicians are affected by focal dystonia. That means for every orchestra of 70-100 people, there may be one or two people dealing with this diagnosis. Some statistics suggest that men are more likely to have focal dystonia than women.

HOW DO I KNOW IF I HAVE FOCAL DYSTONIA?

The most important thing is to find a doctor and a neurologist who take your symptoms seriously and who are respectful of your music-making. Sometimes, the symptoms can appear to be a result of overuse, aggravated by stress. Yet, the afflicted body part or body parts (fingers, facial muscles) are acting involuntarily and the changes may be gradual or sudden. A neurologist can help rule out other diagnoses such as carpal tunnel, tendinitis, or other neurological conditions. Being your own advocate (or your student’s) is important to make sure they get the care they need. Not all physicians understand how important music is to musicians, and musicians are often told to decrease their playing time and that’s it. While that can be helpful and important, it’s not the only solution.

SOURCES:

The Dystonia Society: www.dystonia.org/uk
www.dystonia.org
Dystonia Research Foundation: https://www.dystonia-foundation.org

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www.MUSICIANHEALTHCOLLECTIVE.COM