



WHAT IS DYSTONIA?

Life impact and chronic pain treatment perspectives

A patient and health coach discusses a painful neurological movement disorder that may affect more people than we realize

BY TOM SEAMAN

WHEN WE HEAR the terms “Parkinson’s disease” or “essential tremor,” we can usually form a picture in our mind because we have heard of these conditions before. The term “dystonia,” however, usually leaves people scratching their head. It sounds more like a small European country than it does a health condition. However, it is actually the third most common neurological movement disorder.

Dystonia is characterized by uncontrollable, involuntary muscle spasms and contractions, repetitive movements,

twisting, and/or abnormal postures. Muscle contractions can be sustained or intermittent and sometimes include a tremor. Dystonia can affect any part of the body, causing varying degrees of disability and pain from mild to severe.

In some cases of dystonia, people have muscles that involuntarily contract with no change in physical appearance. However, pain is almost always present regardless of physical presentation. People often describe their muscles as feeling like tightropes.

A good way of looking at dystonia is in terms of muscle pairs. During normal movement, when one muscle contracts, its opposing muscle relaxes. For example, when we contract/flex our bicep, our tricep coordinates by relaxing. When we extend our arm, our tricep contracts and our bicep relaxes. Quadriceps and hamstrings are examples of other muscle pairs that work in the same fashion. In dystonia, opposing muscles involuntarily contract simultaneously, which is what causes awkward

movements, abnormal postures, and pain. The affected muscles can feel like a charley horse that never goes away.

Dystonia does not impact cognition or shorten a person’s life span. However, given the severity of symptoms that some people experience, quality of life can greatly diminish. There is currently no cure available, so treatments are limited to minimizing symptoms.

Approximately 500,000 people are estimated to have dystonia in North America and over 1 million worldwide. These figures may be low when considering those yet to be diagnosed and those who have been misdiagnosed. Surprisingly, dystonia is more common than Huntington’s disease, muscular dystrophy, and ALS (Lou Gehrig’s disease) combined, yet many are unfamiliar with it, as education and awareness are limited.

DYSTONIA CLASSIFICATIONS

There are multiple forms of dystonia and symptoms are highly variable. It may affect a single area of the body or



“Over a period of ten months, my pain increased exponentially to the point that I could barely function. It felt like there was a power drill in the base of my skull that radiated down my neck.”

multiple muscle groups. Symptoms may include a cramp or a tendency for the affected part of the body to tighten and/or tilt or turn to one side, as in the neck for example. In the case of dystonia in a lower limb, a foot may curl and/or leg may drag, and coordination problems with the upper and lower torso may be evident. In the face and head, eyes may blink rapidly and uncontrollably, or close entirely. Symptoms may also include a tremor or difficulty speaking.

Forms of dystonia are based on the body regions affected. Focal dystonia is localized to a specific part of the body. The most common focal dystonias are cervical dystonia, blepharospasm, cranio-facial dystonia, and task specific dystonia, all described below.

- **CERVICAL DYSTONIA** is where the muscles in the neck that control the position of the head are affected, causing the head to turn or pull to one side,

forward, or backward. Many people have a combination of these head/neck positions.

- **BLEPHAROSPASM** involves involuntary contraction of the muscles controlling eye blinks. Usually both eyes are affected. Symptoms include increased blinking, and spasms may cause the eyelids to stay open or closed.

- **CRANIO-FACIAL DYSTONIAS** are forms of focal dystonia that affect the muscles of the head, face, and neck. Oromandibular dystonia affects the muscles of the jaw, lips, and tongue. This may cause difficulty opening and closing the mouth; speech and swallowing may also be affected. Meige syndrome is a term used to describe oromandibular dystonia accompanied by blepharospasm. Spasmodic dysphonia, also called laryngeal dystonia, involves the muscles that control the vocal cords, resulting in strained or breathy speech.

- **TASK-SPECIFIC DYSTONIA** is a focal dystonia that occurs when undertaking a repetitive activity. An example is writer's cramp, which affects the muscles of the hand and sometimes the forearm, and only occurs during handwriting. Musician's dystonia is a term used for dystonia affecting one's ability to play an instrument or perform. It can involve the hand in keyboard or string players, the mouth and lips in wind players, or the voice in singers.

Other forms of dystonia include

- **GENERALIZED DYSTONIA**, which affects most of the body;

- **MULTIFOCAL DYSTONIA**, which involves two or more unrelated body parts;

- **SEGMENTAL DYSTONIA**, which affects two or more adjoining parts of the body such as the face and neck, neck and upper arm, and trunk and leg muscles; and

- **HEMIDYSTONIA**, which involves the arm and leg on the same side of the body.

Although dystonia is not considered a progressive disorder, over time, symptoms may become more severe in some

<Years of sedentary living suffering from dystonia, chronic pain, and depression resulted in massive weight gain. After making major lifestyle changes, Tom lost 150 pounds. While he shrunk, his nephew grew!

people. My initial symptoms progressed over a period of ten months, from a minor annoyance to severe disability with forceful, involuntary muscle contractions and pain unlike anything I had ever experienced. Conversely, some people have symptoms that manifest but never progress, and sometimes improve. I attribute my steep and rapid decline to improper treatments prior to a diagnosis, but I can't say for sure if my symptoms would have worsened otherwise.

WHAT CAUSES DYSTONIA?

In most cases, the specific cause of dystonia is not known, but it is thought to be due to a chemical imbalance in the brain involving acetylcholine, norepinephrine, serotonin, GABA (gamma-aminobutyric acid), and dopamine. When these neurotransmitters are malfunctioning, it can affect how the brain generates commands to move certain body parts. In most cases, no brain abnormalities are visible using magnetic resonance imaging (MRI) or other diagnostic testing. A proper diagnosis is made by an experienced physician; typically, a neurologist specializing in movement disorders.

Dystonia is divided into three groups: idiopathic, genetic, and acquired. Idiopathic dystonia refers to dystonia that does not have a clear cause. Genetic dystonia refers to people who carry a defective gene from one or more parents. However, it does not follow that if one inherits a defective gene they will develop dystonia. Acquired dystonia results from environmental or other damage to the central nervous system. Some causes of acquired dystonia include birth injury, such as hypoxia and neonatal brain hemorrhage, infections, reactions to certain recreational and prescription drugs, heavy metal

or carbon monoxide poisoning, and physical or emotional trauma.

LIFE IMPACT OF DYSTONIA AND CHRONIC PAIN

People with dystonia and chronic pain not only suffer with unrelenting agony, they have difficulty sleeping, working, socializing, driving, and performing basic everyday tasks. They are also more prone to anxiety and depression. Researchers have reported that brain activity in patients with chronic pain is different from those who do not have chronic pain. In a healthy brain, all regions are in a state of equilibrium. When one region is active, the others quiet down. In people with chronic pain, the prefrontal cortex, the location for cognitive, emotional, and behavioral functioning, is always active.

Daily coping strategies

- **TREAT PROBLEMS as challenges to overcome.**
- **TAKE PRIDE in your achievements.**
- **LEARN about your condition and take responsibility for it.**
- **DEFINE SUCCESS as taking good care of yourself.**
- **ACCEPT the illness and reject "why me?" questioning.**
- **BE WILLING to use all available resources for help.**
- **LIVE for today, one day at a time—not in the past or the future.**
- **KNOW that you are not defined by what you can or cannot do.**
- **ENJOY small pleasures when you recognize them.**
- **KNOW that your value and worth have not decreased due to your condition.**

When this region is stuck in full throttle, neurons can change their connections with other neurons, or die prematurely.

It was hypothesized that these changes make it difficult for people to concentrate, solve problems, make decisions, or be in a good mood. A person in chronic pain is impaired in a similar manner to those who are multi-tasking without ever getting a break. With so much overstimulation, it is difficult for the brain to rest and function optimally.

A symptom frequently experienced is anxiety. Researchers observed that patients in chronic pain have reduced brain activity in the areas that control the response to pain. They believe that reduced control over pain signals causes the brain to become extremely vigilant in anticipating future pain. This helps explain the heightened levels of anxiety frequently experienced by those living with chronic pain. In my work as a health coach, many of my chronic pain clients are hypervigilant. In other words, they are often stuck in fight, flight, or freeze mode, which prevents healing.

Researchers also believe that reduced control over pain signals contributes to depression. It causes increased emotional reaction to future experiences of pain, which contributes to a sense of hopelessness in being able to overcome pain. This is consistent with other research that has found that people who are depressed have reduced ability to control their emotional state.

It is clear to see how dystonia and chronic pain can dramatically impact quality of life, contributing to the loss of one's identity, abilities, and choices that many take for granted. You are almost always being tested to the limits, yet have firm boundaries due to limitations these conditions place upon you.

When my cervical dystonia symptoms began, I had little to no pain in my neck or back, and was able to live a normal life. Over a period of ten months, my pain increased exponentially to the point that I could barely function. It felt like there was a power drill in the base of my skull that radiated down my neck into my shoulders. I had great difficulty

Neutral or positive sensory sensations travel through the nervous system faster than painful messages. This means that if soothing sensations and painful sensations reach the “pain gate” at the same time, the pleasant sensations will prevail.

sitting or standing for more than ten minutes at a time. I lived on the floor in writhing pain for years, unable to do much of anything without assistance. It was a miserable existence and life as I knew it was over.

When numerous doctors could not provide an explanation for my bizarre, painful neck postures and extreme muscle spasms, I researched the internet like crazy and diagnosed myself with dystonia, which was later confirmed by a neurologist. After many ineffective treatments and years of physical and mental suffering, I finally learned a variety of symptom management protocols that greatly improved my life. I also lost 150 pounds that I gained due to my sedentary lifestyle from chronic pain, anxiety, and depression. It is with years of perseverance, patience, acceptance, an assortment of treatments and therapies, a positive attitude, and enthusiasm for what I am still able to do, that I am living a fulfilling life again.

TREATMENTS AND TREATMENT PERSPECTIVE

As with chronic pain, there is no cookie cutter approach to treating dystonia, which includes physical therapy, oral medications, botulinum toxin, brain surgery, and literally everything in between. The challenge for many is that there is little uniformity in how dystonia manifests, making it difficult to diagnose and treat. I have utilized

many treatments over the years and it is always changing based on my needs at the time.

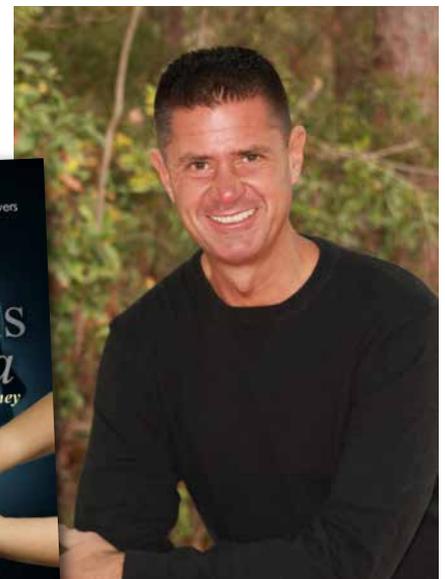
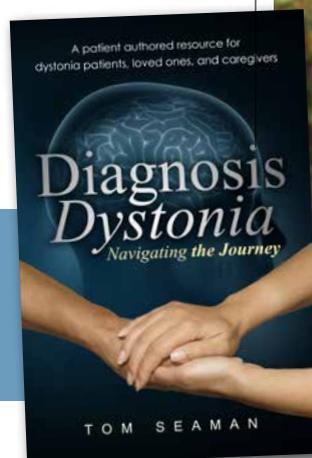
Regardless of one’s treatment approach, an important component of self-care and symptom management involves regulating our daily schedule so that we have the right balance of physical activity, rest, and social interaction. An interesting and helpful fact to remember is that neutral or positive sensory messages travel through the nervous system faster than painful messages. This means that if soothing sensations and painful sensations reach the “pain gate” at the same time, the pleasant sensations will prevail, blocking the slower, painful ones.

With this in mind, one way of reversing the course of pain is to find things that create consistently reliable pleasant experiences that compete successfully with pain. This might include massage, acupuncture, a good movie or book, quality time with family and friends, sex, meditation, prayer, exercise, and music; whatever you find to be a pleasant experience.

No one is immune to the challenges of life. At some time or another we all endure tough experiences. When adversity comes, how we respond to it determines what happens next. Life experiences become tragedies if we

make the conscious decision to make tragedies out of them. We can either resist or we can accept challenges. If we choose to view challenges as opportunities for personal growth, this can be a driving force for positive changes and healing. ■

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