

BURDEN OF DYSTONIA IS MORE THAN A MOVEMENT DISORDER

AT A GLANCE

- Individuals with dystonia may experience anxiety, depression, pain, and impaired sleep.
- Non-motor symptoms associated with dystonia can be as disabling as the involuntary movements and postures.
- Treating non-motor symptoms can have a dramatic positive impact on quality of life

Dystonia is a neurological disorder that affects the physical body, but the impact goes far deeper. The hallmark signs of dystonia are excessive, involuntary muscle contractions that cause abnormal postures and/or repetitive movements. Individuals diagnosed with dystonia also commonly experience symptoms that affect more than how the body moves.

Besides the movements and postures of dystonia, individuals may experience additional symptoms such as anxiety, depression, persistent pain, and impaired sleep. These non-motor symptoms are a significant burden for many patients. Studies have shown that the non-motor symptoms can be as detrimental to quality of life as the dystonic symptoms.

Movement disorder neurologists are increasingly recommending that addressing these non-motor aspects of dystonia are essential to help patients feel and function as well as possible. Consider

consulting your movement disorder specialist if you believe you may be experiencing non-motor symptoms related to dystonia.

Anxiety & Depression

Research has demonstrated that individuals with dystonia are prone to certain mental health disorders, including anxiety and depression. Individuals with dystonia are more likely to experience anxiety and depression than the general population, and at higher rates than individuals with other chronic disorders.

The presence of anxiety and/or depression in individuals with dystonia is among the most reliable predictors of diminished quality of life. Because untreated mental health disorders can have serious and lasting health consequences, several research groups have recommended more routine evaluation of individuals diagnosed with dystonia for co-existing anxiety and mood disorders.

Social anxiety is the most common anxiety disorder among individuals with dystonia. Specific types of dystonia are associated with increased rates of obsessive compulsive disorder and alcohol abuse.

Sleep Difficulty

Problems with sleep are among the most common and problematic non-motor symptoms associated with dystonia. Sleep disturbances can occur even in cases when the dystonia symptoms are reduced or absent during sleep, and in cases in which the dystonia is well-controlled with treatment.

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Persistent Pain

Depending on the type of dystonia, pain can be a pervasive and disabling symptom. In many cases, alleviating the dystonic movements and postures will reduce pain. However, alleviating the dystonia symptoms may not alleviate all pain. Researchers continue to explore the relationship between dystonia and pain. There may be neurological changes in how the body perceives and processes pain. Depression and sleep disturbance—which are common among dystonia patients—may worsen pain. Dystonia can also cause or worsen painful orthopedic conditions such as arthritis.

Treating Non-Motor Symptoms

Living well with dystonia often requires addressing more than the physical movement symptoms. A team of healthcare professionals from multiple disciplines may be necessary, including a movement disorder neurologist, psychiatrist, clinical psychologist, and others depending on the needs of the individual. Appropriate complementary therapies may provide valuable underlying support to the treatment process and dramatically improve quality of life.

This content is adapted from “It Stacks on Our Shoulders like Bricks: Burden of Dystonia is More than a Movement Disorder,” an article published in the Spring 2018 issue of the Dystonia Dialogue newsletter.



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ANXIETY

An anxiety disorder differs from simple worry in the following ways:

- It is more intense
- It is long-lasting
- It interferes with work, activities, or relationships

Social anxiety disorder is the intense fear of any situation where public scrutiny may occur, usually with the fear of embarrassment or humiliation.

Obsessive-compulsive disorder (OCD) is an anxiety disorder marked by uncontrollable, reoccurring thoughts (obsessions) and/or behaviors (compulsions) that an individual feels compelled to repeat over and over.

DEPRESSION

Clinical depression includes at least one of these two symptoms, nearly every day, for more than two weeks:

- An unusually sad mood
- Loss of enjoyment and interest in activities that were once enjoyable

Additional symptoms of clinical depression can include:

- Lack of energy and tiredness
- Feeling worthless or feeling guilty
- Thinking about death or wishing to be dead
- Difficulty concentrating or making decisions
- Moving more slowly, or becoming agitated and unable to settle
- Sleeping difficulties, or sleeping too much
- Loss of interest in food, or eating too much; weight loss or weight gain

If you believe you may be experiencing symptoms of a mental health disorder, talk to your doctor about evaluation and treatment options.