Involuntary, sustained muscle contractions that often causes a twisting or turning movement. Difficulty in daily tasks due to muscle contractions. These common symptoms of dystonia undermine people’s ability to work, go about daily life and maintain interpersonal relationships.

About Dystonia

Dystonia is a movement disorder characterized by involuntary, sustained muscle contraction that can cause repetitive or twisting movements and abnormal postures. Depending on its type, dystonia can affect a specific part of the body, such as the neck, limb or face, or it can affect larger areas.

While the cause of dystonia remains unknown, changes in nerve cell communication in the brain likely play a role. Dystonia can also be secondary to other conditions, including Parkinson’s and Huntington’s disease.

More than 300,000 people of all ages, genders and backgrounds are estimated to live with dystonia today. The actual number is likely higher, however, as many cases remain misdiagnosed or undiagnosed.

Treatment

While there is no cure for dystonia, various treatments are available to help people manage their symptoms.

Botulinum neurotoxin injections, the first-line treatment for some forms of dystonia, treat affected muscle groups. Ongoing research and innovation continue to expand this class of treatments. One botulinum neurotoxin recently approved by the FDA, for example, reduces how often patients must visit their health care provider’s office for treatment injections.
Dystonia poses significant health care challenges. Research to find more effective treatments and potential cures is critical, as is access to existing treatments.

Injections are not the only form of treatment. Oral medications, deep-brain stimulation and other surgical procedures are also options. People may also benefit from non-pharmacologic treatment, such as physical and occupational therapy, which can improve quality of life.

**The Need for Access**

Treatments like botulinum neurotoxin injections are not always easy to access. People with dystonia may face challenges such as health plan prior authorization and reauthorization requirements. Other insurance barriers like non-medical switching can introduce more complications. Insurers can sometimes favor one type of neurotoxin over others, but the available neurotoxins are deemed non-interchangeable by the FDA. Switches should occur only on a case-by-case basis at the discretion of the patient and his or her health care provider.

**The Need for Innovation**

Dystonia’s impact underscores the urgent need for innovative treatments. While current treatments can relieve symptoms, they do not address the root cause of the disorder. Emerging areas of research, like gene therapy and transcranial magnetic stimulation, offer hope, but they are in early stages and require further investment.