



Dystonia Fact Sheet

Dystonia Defined

- Dystonia is a movement disorder that causes the muscles in the body to contract or spasm involuntarily. These muscle contractions force the body into twisting, repetitive movements and abnormal postures.
 - Multiple parts of the body can be affected or just one such as legs, arms, neck, face, eyes, and vocal cords.
 - Symptoms are usually chronic
 - Causes varying degrees of disability and pain, from mild to severe
 - Dystonia can be genetic or caused by trauma, medications, or other medical conditions

Dystonia Diagnosed

- Dystonia is estimated to affect 300,000 individuals in North America—100,000 of them children. However, awareness and proper diagnosis is extremely limited.
- It is common for a patient to undergo numerous physician visits over the course of *years* to achieve correct diagnosis.
- There is no singular diagnostic test for dystonia. A neurologist who specializes in movement disorders can diagnose dystonia by observing symptoms.

Dystonia Treatment

- There is no cure for dystonia.
- There is no single treatment or therapy that is appropriate for all cases of dystonia. Treatment may include:
 - Oral medications
 - Botulinum toxin injections (BOTOX)
 - Brain surgery
- Medical therapies attempt to suppress or reduce muscle contractions, but do not diminish or eradicate the underlying disease.

Dystonia Impacts Quality of Life

- Dystonia can interfere with nearly all aspects of a person's life including daily functions such as walking, sitting, sleeping, eating and talking.
- Appearance of awkward body postures and uncontrollable movements often make patients reluctant to go out in public or withdraw from family and friends for fear of being misunderstood or mistreated.
- Dystonia can have an enormous impact on families, spouses, and caregivers who support severely disabled patients.