What is Dystonia?
Dystonia is a neurological movement disorder. Improper signaling in the brain causes the muscles to contract and twist involuntarily. These muscle spasms may force areas of the body into awkward positions or movements. Dystonia may interfere with daily activities, and some forms of dystonia may be painful. Dystonia is not a psychological or psychiatric disorder.

Dystonia affects men, women, and children of all ages and backgrounds. Dystonia is the third most common movement disorder after essential tremor and Parkinson’s disease, affecting an estimated 300,000 people in the United States and Canada.

What Causes Dystonia?
Some forms of dystonia are attributed to a specific cause or trigger, and for other forms the cause is not yet identified. Dystonia may be genetic or caused by physical trauma, exposure to certain medications, and other neurological/metabolic conditions. However, the biochemical process in the body that generates symptoms remains unknown. This is often referred to as the “mechanism” of dystonia. Scientists are actively trying to uncover how symptoms occur and suspect that the mechanism is common to all forms of dystonia.

Classifying Dystonia
Dystonia is not a single disorder. There are many forms of dystonia, and dystonia can be a symptom of several disorders and conditions. Physicians have developed a system to classify dystonia to help guide the treatment process.

The term primary dystonia is used to describe a case in which the dystonia is the predominant symptom, and the person is not affected by other neurological conditions. Secondary dystonia refers to dystonia that is associated with a known outside factor or condition (such as trauma, drug exposure, stroke, cerebral palsy, and others).

What is the DMRF?
The Dystonia Medical Research Foundation (DMRF) is a 501c3 non-profit organization that has served the dystonia community since 1976. The DMRF funds medical research toward improved treatments and a cure, promotes awareness and education, and provides support resources for affected individuals and families.

Contact Us
For more information on dystonia and the DMRF, contact us at:

Dystonia Medical Research Foundation
One East Wacker Drive, Suite 2810
Chicago, Illinois 60601-1905

Phone: 312-755-0198
Toll-free: 800-377-DYST (3978)
Fax: 312-803-0138
Email: dystonia@dystonia-foundation.org
Web: www.dystonia-foundation.org

Look for the DMRF on Facebook and Twitter!
What Can I Expect?

Although dystonia can significantly impact an individual’s life, with effective treatment people with all forms are able to pursue an education, work, travel, and live fulfilling lives. Having dystonia does not define who you are. The Dystonia Medical Research Foundation (DMRF) can provide support resources to help individuals adjust to life with dystonia.

At this time, there is no way to predict the prognosis, but the age at which symptoms begin often affects if and how the dystonia will spread to other body areas. When dystonia symptoms occur in childhood, they typically (but not always) begin in the limbs and become generalized. When dystonia occurs in adulthood, the symptoms generally remain focal. Adults may develop more than one focal dystonia. Hemidystonia is almost always caused by secondary factors. Secondary dystonias can occur at any age.

Seeking treatment from an appropriately trained and experienced doctor is an important part of coping with dystonia symptoms. Local support groups and online social media forums provide connection to others in the dystonia community for sharing information and support.

How Does Dystonia Affect the Body?

Some forms of dystonia affect a specific body area such as the neck, face, jaw, eyes, limbs, or vocal cords. When dystonia affects a single body area, it is called focal dystonia. Segmental dystonia affects two or more connected body areas. Generalized dystonia refers to dystonia that affects the limbs, trunk, and other major body areas simultaneously. When dystonia only affects muscles on one side of the body, it is called hemidystonia.

Movement symptoms that occur in episodes may be referred to as paroxysmal dyskinesias.

Is Dystonia Fatal?

Dystonia is almost never fatal. In rare cases, a person with very severe generalized dystonia may experience secondary effects that require prompt or emergency medical attention. Such circumstances are treatable and most people recover fully. Dystonia may occur as a symptom of several degenerative diseases, and these conditions may affect life span.

How is Dystonia Treated?

Because each person with dystonia is unique, treatment must be highly customized to the needs of the individual. Physicians may use a combination of the following treatments: occupational therapy, physical therapy, oral medications, botulinum neurotoxin injections, and surgical procedures. Complementary therapies such as daily relaxation and breathing techniques may also be beneficial.

In most cases, the type of doctor who is typically trained to diagnose and treat dystonia is a movement disorder neurologist. Otolaryngologists, neuro-ophthalmologists, and ophthalmologists may also treat focal dystonias that fall under their specialties.

How Can I Learn More About My Diagnosis and Treatment Options?

Your doctor and local DMRF support group are important sources of information about dystonia and treatments. Also, visit www.dystonia-foundation.org to learn about these forms of the disorder and more:

- Blepharospasm
- Cervical dystonia/Spasmodic torticollis
- Dopa-responsive dystonia
- Early-onset generalized dystonia (DYT1 and non-DYT1 forms)
- Oromandibular dystonia/Meige’s syndrome
- Spasmodic dysphonia/Laryngeal dystonia
- Musician’s dystonia
- Myoclonus dystonia
- Paroxysmal dystonia and dyskinesias
- Rapid-onset dystonia-parkinsonism
- Secondary dystonia
- Tardive (drug-induced) dystonia
- Writer’s cramp/Focal hand dystonia
- X-linked dystonia-parkinsonism (Lubag)
- Other genetic forms of dystonia