

## Who is Affected by Dystonia?

Dystonia affects men, women, and children of all ages and backgrounds. Dystonia is the third most common movement disorder. Conservative estimates suggest dystonia affects no fewer than 250,000 people in the USA and potentially millions worldwide.

## What Causes Dystonia?

There are many causes for dystonia. Dystonia may occur due to an inherited or new genetic mutation. Dystonia may also result from changes in brain activity caused by another health condition such as Parkinson's disease or traumatic brain injury. Certain drugs are known to cause dystonia. However, for many people who develop dystonia, there is no identifiable cause.

## Are There Different Types of Dystonia?

Yes. Dystonia can take many forms. Dystonia may affect a single body area or multiple areas throughout the body. The movement symptoms of dystonia may be chronic or occur periodically. Dystonia may be the only movement symptom a person has, or it can occur with other abnormal movements (for example, tremor). Dystonia may occur by itself or as a symptom of other diseases.

The age at which symptoms begin may influence prognosis and treatment. Dystonia that begins in childhood is more likely to involve multiple body parts and more likely to be associated with additional movement and neurological symptoms. Dystonia that develops during adulthood is more likely to remain focal to a specific body area.



## What is Dystonia?

Dystonia is a neurological disorder that causes involuntary muscle contractions. These muscle contractions result in abnormal movements and postures, making it difficult for individuals to control their body movements.

Dystonia can affect any region of the body including the eyelids, face, jaw, neck, vocal cords, torso, limbs, hands, and feet. Depending on the region of the body affected, dystonia may look quite different from person to person. The movements and postures may be painful.

In addition to abnormal movements, depression and anxiety are common non-motor symptoms of dystonia.

### COMMON SIGNS OF DYSTONIA

- A body part is flexed or twisted into an abnormal position.
- Repetitive and patterned body movements, which may resemble tremor.
- Dystonic symptoms may worsen or occur only with specific tasks. For example, hand dystonia may be present only when writing or playing a musical instrument.
- Attempting a movement task on one side of the body may activate dystonia symptoms on the opposite side.
- Dystonic movements and postures may be temporarily relieved by a gentle touch or specific action called a sensory trick.

## CONTACT US

### Dystonia Medical Research Foundation

One East Wacker Drive, Suite 1730  
Chicago, Illinois 60601-1980

PHONE 312-755-0198 | TOLL FREE 800-377-DYST (3978)

EMAIL [dystonia@dystonia-foundation.org](mailto:dystonia@dystonia-foundation.org)

WEB [www.dystonia-foundation.org](http://www.dystonia-foundation.org)

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# DYSTONIA

## A MOVEMENT DISORDER



Many thanks to past DMRF Clinical Fellow  
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## DYSTONIA VOCABULARY

Your healthcare providers may use unfamiliar language to describe dystonia.

**FOCAL:** Dystonia that affects a single body part, for example, the neck.

**SEGMENTAL:** Dystonia that affects two or more connected body parts, for example, the face, neck, and arm.

**GENERALIZED:** Dystonia that affects the torso and at least two other body areas, frequently the limbs.

**ISOLATED OR PRIMARY:** Dystonia is the only neurological symptom a person appears to have.

**ACQUIRED OR SECONDARY:** Dystonia that appears to have a specific cause such as drug reaction, brain injury, or as a symptom of another neurological or metabolic disorder.

**PAROXYSMAL DYSKINESIAS:** Dystonia may occur in episodes, often with additional movement symptoms.

## What Treatments are Available?

There are many types of dystonia and diverse symptoms, so treatment must be specific to a person's individual needs. Treatment may include a combination of oral medications, botulinum neurotoxin injections, and/or surgical procedures such as deep brain stimulation. Complementary therapies may include occupational therapy, physical therapy, speech/voice therapy, pain management, and other therapies depending on a person's symptoms. Addressing the non-motor symptoms of dystonia, including depression and anxiety, is also essential to relieving disability and improving quality of life.

## What Type of Doctor Treats Dystonia?

Seeking treatment from an appropriately trained medical team, including a movement disorder specialist, is critical to living well with dystonia. A movement disorder specialist is a neurologist with training in the diagnosis and treatment of movement disorders such as dystonia. Physiatrists, otolaryngologists, speech-language pathologists, and neuro-ophthalmologists may treat specific dystonias that fall under their specialties.

## Is Dystonia Fatal?

No, dystonia is almost never fatal. Dystonia does not affect vital organs such as the heart.

In extreme cases, the development of increasingly frequent or continuous episodes of severe dystonia may cause a medical emergency called status dystonicus. If untreated, this rare condition can cause life-threatening complications. Status dystonicus is a treatable condition and, with prompt medical attention, symptoms typically can be brought under control.



## Living with Dystonia

Dystonia is often a chronic disorder that requires ongoing treatment. Individuals from all walks of life are living with dystonia worldwide.

Seeking expert medical care, becoming informed about dystonia and treatment options, and developing a personal support system can greatly benefit daily living.

Researchers all over the world are actively pursuing improved treatment options and a cure. Until a cure is found, the Dystonia Medical Research Foundation (DMRF) is available to make sure no person or family affected by dystonia has to face it alone.

## Where Can I Find Resources & Support?

The Dystonia Medical Research Foundation (DMRF) is a not-for-profit organization available to help individuals and families. The DMRF's mission is to advance research for more effective treatments and ultimately a cure, promote public awareness and patient education, and provide coping support resources.

Contact the DMRF for information, assistance identifying movement disorder centers for diagnosis and treatment, and connection to other people for peer-to-peer support.

Detailed descriptions of specific types of dystonia and treatment options are available at [www.dystonia-foundation.org](http://www.dystonia-foundation.org).

## What Research is Happening?

Investigators are working every day to improve dystonia treatment options and find a cure. To learn more, including how you can make a difference by participating in research, visit [www.dystonia-foundation.org/research](http://www.dystonia-foundation.org/research).

Interviews with dystonia investigators are available for viewing at [www.youtube.com/FacesofDystonia](http://www.youtube.com/FacesofDystonia).

## COMMON MISDIAGNOSES

Dystonia symptoms should not be confused with:

- Orthopedic conditions (for example, scoliosis and congenital torticollis)
- Muscle cramps
- Muscle contractures
- Essential tremor
- Tics

