

### Why the Word 'Psychogenic'?

Functional dystonia is sometimes called *psychogenic dystonia*, which refers to the observation that many cases have psychological or psychiatric factors that contribute to the physical symptoms. Treating underlying emotional and mental disorders can reduce the movement symptoms, though researchers do not yet fully understand why this is the case.

The human brain is a spectacularly complicated and interconnected system. Areas of the brain associated with movement are also involved in cognition, emotion, memory, and other mental functions.

Researchers are actively studying functional dystonia and functional movement disorders to better understand the underlying neurology and improve treatment.

### What is Functional Dystonia?

*Dystonia* is a neurological disorder that causes intense, involuntary muscle contractions. These muscle spasms make it difficult for patients to move their bodies freely and control their body movements. There are many types of dystonia and numerous causes.

In *functional dystonia*, there is abnormal, unintended movement or positioning of the body due to the nervous system not working properly. Functional dystonia can cause movement symptoms in the face, neck, shoulder, torso, and/or limbs.

Functional dystonia is often seen in individuals with psychiatric disorders and/or exposure to psychological stressors. The start of symptoms is often preceded by an injury, illness, or emotionally stressful event.

### What is the DMRF Canada?

The Dystonia Medical Research Foundation (DMRF) Canada is a charitable organization that funds medical research toward a cure, promotes awareness and education, and supports the well being of affected individuals and families.

### To learn more about dystonia and the DMRF Canada, contact:

#### DMRF Canada

#209 - 550 St. Clair Ave. West

Toronto, Ontario M6C 1A5

Phone: 416.488.6974

Toll free: 800.361.8061

[www.dystoniacanada.org](http://www.dystoniacanada.org)

Email: [info@dystoniacanada.org](mailto:info@dystoniacanada.org)

Connect with the DMRF Canada on  
[Facebook](#), [Twitter](#) and [YouTube](#).

For more in-depth information, visit  
[dystoniacanada.org/functionaldystonia](http://dystoniacanada.org/functionaldystonia)

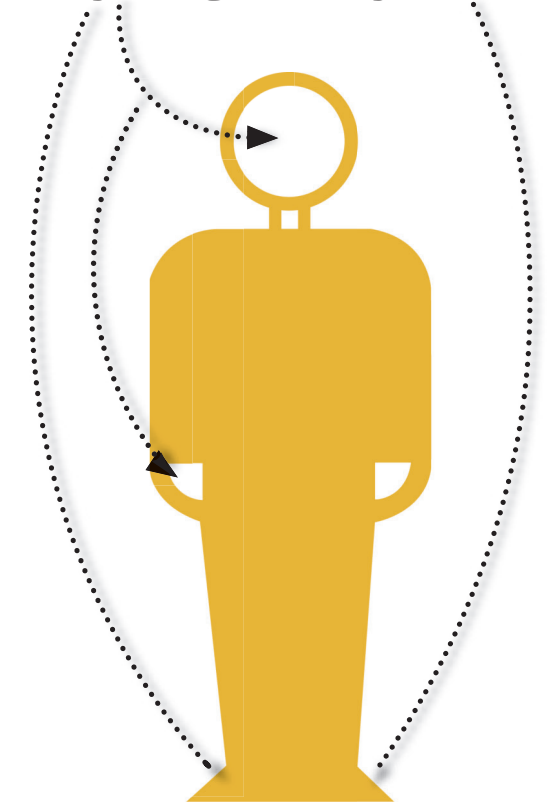
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## Functional Dystonia (Psychogenic Dystonia)



serving all dystonia-affected persons  
déservant toutes personnes atteintes de dystonie

## Are there Different Types?

There are several genetic subtypes of generalized dystonia. For example:

### *Early Onset Generalized Dystonia*

**(DYT1/TOR1):** DYT1 dystonia typically begins around age 10 years with the twisting of a foot or arm. Symptoms tend to progress to involve additional limbs and the torso, but usually not the face or neck. In rare cases, the vocal cord muscles are affected. The symptoms tend to be less severe the later in life they start and if they start in a hand or arm. About 30% of individuals who have the DYT1 genetic mutation will develop dystonia. If a person does not manifest symptoms before the age of 28 years, they will usually remain symptom free for life—even if they have the DYT1 mutation. The DYT1 mutation is responsible for about 90% of early onset generalized dystonia in individuals of Ashkenazi Jewish ancestry and up to about 50% of early onset generalized dystonia in other ethnicities.

### *Adolescent Onset Generalized Dystonia*

**(DYT6/THAP):** DYT6 may occur as generalized dystonia or remain focal to a specific part of the body. Although the symptoms may resemble DYT1 dystonia, onset of DYT6 is usually in the late teens and symptoms are more likely to occur above the neck. Symptoms typically affect the muscles of the tongue, vocal cords, and face. Patients often have difficulty speaking. About 40% of individuals who have the mutation will develop dystonia.

Testing for DYT1, DYT6, and other known dystonia genes is available. A genetic counselor can help families understand what genetic testing may be appropriate.

## What Kind of Doctor Treats Dystonia?

Individuals with dystonia are encouraged to seek treatment from a neurologist (or child neurologist) with special training in movement disorders. A multidisciplinary team of medical professionals may be appropriate to tailor treatment to the needs of the patient.

## What Treatments are Available?

Treatment to lessen dystonia symptoms may include oral medications such as anticholinergics, baclofen, and benzodiazepines combined with botulinum neurotoxin injections, and/or surgical procedures such as deep brain stimulation (DBS).

Specific treatment may be needed to prevent loss of motion in the joints and/or curvature of the spine due to the dystonic postures. Complementary therapies to support overall functioning and wellness may include occupational therapy, physical therapy, speech/voice therapy, and other interventions depending on a person's symptoms. Individuals with childhood onset generalized dystonia may have increased risk for depression so monitoring and addressing emotional and mental health is often an important part of the treatment strategy.

## Is Dystonia Fatal?

No, dystonia is almost never fatal. In extreme cases, the development of increasingly frequent or continuous episodes of severe generalized dystonia causes 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

Living well with generalized dystonia is possible. The early stages of symptom onset, diagnosis, and seeking effective treatment are often the most challenging. In some cases, treatment can dramatically reduce or suppress symptoms.

Individuals and families living with dystonia are strongly encouraged to:

- Seek treatment from a neurologist who specializes in movement disorders.
- Learn about dystonia and treatment options.
- Develop a multi-layered support system of support groups, online resources, friends, family, and mental health professionals, if needed.
- Investigate complementary therapies that support overall functioning and wellness.
- Get active within the dystonia community.

## Dystonia can occur with other movement symptoms:

*Dopa-responsive dystonia* includes symptoms of dystonia and parkinsonism (slow movement, muscle rigidity, tremor, balance instability). Symptoms typically respond to a drug called levodopa.

*Myoclonus-dystonia* is characterized by rapid jerking movements (myoclonus) alone or with dystonia. Additional features may include obsessive compulsive disorder, depression, anxiety disorders, and alcohol abuse.

*Paroxysmal dyskinesias* are episodic movement disorders. The involuntary movements may include dystonia, chorea (uncoordinated jerking), ballism (rapid, flinging movements), and/or athetosis (writhing).

*Rapid-onset dystonia-parkinsonism* is characterized by abrupt onset of dystonia with parkinsonism. Additional features may include anxiety, depression, and seizures.

*X-linked dystonia-parkinsonism* is characterized by parkinsonism, often followed by dystonia later in life. Affects individuals of Filipino descent almost exclusively.