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- \$50 a month     \$25 a month  
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Yes, I want to support DMRF Canada with a one-time gift.

- \$250    \$100    \$50    \$25    \$ \_\_\_\_\_

### Payment method:

- OPTION 1:**  For monthly giving, I am sending 12 postdated cheques made payable to the Dystonia Medical Research Foundation Canada.
- For a one-time gift, I have enclosed my cheque made payable to the Dystonia Medical Research Foundation Canada.

**OPTION 2:**  Make online donations.

You can make a credit card donation or sign up to be a member of our Monthly Giving Team by visiting our website [www.dystoniacanada.org/donateonline](http://www.dystoniacanada.org/donateonline) or scan the QR Code.



You can also call our office at 1.800.361.8061. Your monthly gift can be stopped at any time by contacting DMRF Canada.

Please note: DMRF Canada has removed mailed in credit card information as a payment method to help safeguard donor information.

Charitable #12661 6598 RR0001

## Dystonia Medical Research Foundation (DMRF) Canada

DMRF Canada is a registered non-profit Canadian charity. The mission of DMRF Canada is to advance research for more treatments and ultimately a cure, to promote awareness and education, and to support the needs and well-being of affected individuals and families. DMRF Canada works in partnership with the Dystonia Medical Research Foundation in the United States as well as other Canadian research organization to ensure funding of the best and most relevant dystonia medical research worldwide.

## Contact Us

For more information on dystonia and DMRF Canada, contact us at:

### Dystonia Medical Research Foundation Canada

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*serving all dystonia-affected persons  
d'asservant toutes personnes atteintes de dystonie*

# What is Dystonia?

## What is Dystonia?

Dystonia is a neurological disorder that causes excessive, involuntary muscle contractions. These muscle contractions result in abnormal muscle movements and body postures, making it difficult for individuals to control their movements. The movements and postures may be painful. Dystonic movements are typically patterned and repetitive.

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.

In addition involuntary movements and postures, depression and anxiety are frequent non-motor symptoms of dystonia.

Dystonia affects over 50,000 in Canada, of all ages and backgrounds. Most common forms affect adults but it can also occur in childhood especially if genetic.

For more details and information visit [www.dystoniacanada.org/about-dystonia](http://www.dystoniacanada.org/about-dystonia) or contact us at 1-800-361-8061 or [info@dystoniacanada.org](mailto:info@dystoniacanada.org).

## How many forms of dystonia are there?

There are many forms of dystonia. Dozens of diseases and conditions also include dystonia as a major symptom. Dystonia may affect a single body area (e.g. face, neck, hands, feet) or be generalized throughout multiple muscle groups. Please see inside of brochure for a complete list.

## What are the clinical features?

Clinical features are the signs and symptoms of dystonia, which can vary a great deal from patient to patient. These include age at which symptoms began, body distribution, certain qualities about the symptoms, and the presence of other movement disorder symptoms or other neurological features. Doctors use these factors to guide diagnosis and treatment.

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## What is known about the cause of dystonia?

In many cases, individuals develop dystonia without any obvious cause. However, if a cause can be identified, this may guide treatment. When describing dystonia by the cause, it may be characterized as primary, secondary, or dystonia-plus:

### Primary Dystonia

The word primary describes a case in which the dystonia is the only neurological disorder that the person has. Primary dystonias include some genetic forms (such as DYT1 dystonia in which a gene has been identified) and forms for which a cause is not usually found (such as most focal dystonias).

### Secondary Dystonia

Secondary dystonias result from apparent outside factors and can be attributed to a specific cause such as exposure to certain medications, trauma, toxins, infections, or stroke.

Spinal cord injury, head, and peripheral injury are also recognized contributors to dystonia. Other examples of secondary dystonias include drug-induced dystonias and dystonias associated with cerebral palsy, cerebrovascular disease, cerebral infections and post-infectious states, stroke, encephalitis, brain tumor, and toxins.

### Dystonia-plus

Sometimes dystonia occurs along with symptoms of other neurological disorders or has a particular quality that resembles another disorder. These forms may be put in a category called dystonia-plus.

## How is dystonia treated?

Because each case of dystonia is unique, treatments must be highly customized to the needs of individuals. Physicians may combine approaches, including the following:

- Botulinum neurotoxin, a biological product, is injected into specific muscles where it acts to relax the muscles and reduce excessive muscle contractions. Botulinum toxin injections are most common for focal dystonia.

- Oral medications: There are many medications that have been shown to improve dystonia.
- No single drug works for every individual, and several trials of medications may be necessary to determine which is most appropriate for you. Working with your physician to determine the drugs best suited for your case may be challenging, but finding the right drug(s) can result in a dramatic improvement in symptoms.
- In severe cases, several surgical techniques including deep brain stimulation (DBS) may be offered.
- Complementary therapies such as daily relaxation and breathing techniques may also be beneficial. It is best to consult your doctor to discuss the best treatment options for your unique circumstances.

## Is dystonia life-threatening?

For the overwhelming majority, dystonia does not shorten life expectancy and is not fatal. In severe generalized dystonia that affects many body areas, problems can arise that are secondary to the dystonia and require emergency care. These circumstances can be life-threatening if not treated, for example if breathing or heart function is compromised. However, these instances are quite rare and usually treatable. Dystonia does occur as a symptom of many degenerative disease, some of which do impact mortality, but the dystonia itself does not shorten life span.

## Forms of dystonia

Doctors use these classifications to guide diagnosis and treatment. Forms of dystonia include:

**Focal dystonias** affect a specific group of muscles or body parts, including:

- **Blepharospasm** affects the muscles of the eyelids and brow.
- **Cervical dystonia** affects the neck and sometimes the shoulders.
- **Oromandibular dystonia** (cranial dystonia) includes forceful contractions of the face, jaw, and/or tongue.

- **Spasmodic dysphonia** (laryngeal dystonia) affects the vocal cords.
- **Hand dystonia** (writer's cramp) affects the fingers, hand, and/or forearm.
- **Lower limb dystonia** affects the leg, foot, and/or toes.

**Musicians' dystonias** are task-specific dystonias sometimes given this name because constant use of various muscles and movements can contribute to dystonia among musicians related to their performance.

**Early-onset generalized dystonia (DYT1 and non-DYT1)** is characterized by twisting of the limbs and torso.

**Dopa-responsive dystonia** refers to a group of dystonias that respond to a medication called levodopa.

**Myoclonus dystonia** is a hereditary form that includes prominent jerk-like movements called myoclonus.

**Paroxysmal dystonias and dyskinesias** involve episodic abnormal movements which occur only during attacks.

**X-linked dystonia-parkinsonism** is a hereditary form of dystonia (also called Lubag disease) that includes symptoms of parkinsonism.

**Rapid-onset dystonia-parkinsonism** is a hereditary form of dystonia that includes symptoms of parkinsonism.

**Secondary dystonias** are forms triggered by factors such as trauma, medication exposure and toxins.

- **Trauma:** Dystonia may follow trauma to the head and/or to a specific area of the body.
- **Drug-induced** (Tardive dystonia & dyskinesias): Specific drugs can cause dystonia.
- **Neurological and metabolic disorders:** Dystonia can occur as a symptom of multiple disorders such as stroke and Parkinson's disease.

**Functional dystonia** is secondary to psychological/psychiatric causes or an underlying pain syndrome.

## How do I explain dystonia to someone else?

Dystonia can be a very difficult thing to explain to others, but it is very important. Having the support of loved ones is a critical part of living well with dystonia. Providing your family and friends with the information included in this brochure may help them understand what dystonia is and how it can be treated. Talking about dystonia is an inherently personal choice, and one only you can make for yourself.

## Support is available

You are not alone. Across Canada there are many resources—including DMRF Canada. Contact us and we will help you get connected to the appropriate point of contact. One of the most enriching resources for a patient and for their family members are support groups—this allows individuals to grow in confidence, knowledge, and helps them deal with the difficulties of dystonia while being amongst their peers.

Here are some other ways for you to get support and stay connected:

 [dystoniacanada.org/support](https://dystoniacanada.org/support)

Find us on social media:  
[dystoniacanada.org/social-media](https://dystoniacanada.org/social-media)

**Yes, I want to sign-up for the newsletter.**

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