

Frequently Asked Questions about Dystonia

What is dystonia?

Dystonia is a movement disorder that causes the muscles to contract and spasm involuntarily.

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. Dystonia affects men, women, and children of all ages and backgrounds. Please refer to the section entitled “Forms of Dystonia” and visit:

www.dystoniacanada.org/formsofdystonia.

How do I know if I have dystonia?

The type of doctor with the training and expertise to diagnose and treat dystonia is a movement disorder specialist—a neurologist with special training in movement disorders. Dystonia is a clinical diagnosis, which means the physician must observe and recognize the physical symptoms and rule out other possibilities. Testing may include blood and urine analysis, and brain scans. There is no single test to definitively diagnose dystonia. There are several genes that cause or are associated with dystonia and your doctor may order genetic tests.

To find your local movement disorder clinic, visit: **<http://www.dystoniacanada.org/support>** and select the location closest to you.

What can I ask my doctor to ensure I get the best care?

There are a several questions you will likely have upon being diagnosed with dystonia. Remember to have questions ready before visiting your doctor. Come with pen and paper (or a voice recorder if writing is difficult) so you can take notes and record answers. The following are common questions

- What type of dystonia do I have?
- What can you tell me about what may have caused the dystonia?
- How will my daily life be impacted by my dystonia?
- Will my symptoms worsen?
- Can I pass dystonia on to my children?
- Will I develop other illnesses as a result of dystonia?
- How can I explain dystonia to my family, friends and employer?
- Is there anyone my family or employer can talk to about this?
- How can I help raise awareness of dystonia?
- Are there any groups or associations I can join for people who are coping with dystonia?
(Note: Please get in touch with the Dystonia Medical Research Foundation Canada! Email us at: **info@dystoniacanada.org**)

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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.

Will I have this forever, or will it go away? Is there a cure?

Unfortunately, there is not yet a cure for dystonia. However, there are a number of treatments.

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.

Are these treatments covered?

This is a difficult question to answer, as coverage is dependant upon the type of dystonia you have, and the type of treatment you need. We recommend you consult with your doctor, and refer to our financial support section available at: www.dystoniacanada.org/financialsupport

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Does dystonia travel throughout the body? Will it affect my heart?

Dystonia affects muscles that can be controlled voluntarily, mostly the skeletal muscles. Dystonia does not affect smooth muscles, such as the heart. However, dystonia can affect breathing in several ways. Severe neck dystonia can cause difficulty breathing when the upper airway is impacted. Dystonia involving the vocal cords can potentially cause shortness of breath when the vocal cord muscles contract excessively, but in general the muscle contractions occur when speaking. Dystonia can cause stiffness in the muscles between the ribs and can cause a sensation of shortness of breath. Occasionally, dystonia can affect the diaphragm. Finally, when a person with dystonia has involvement of the spine, twisting of the torso can limit how much the lungs can expand when breathing, and this can potentially cause shortness of breath.

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 resources included in this package 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.

How do I find a doctor who specializes in Dystonia?

The DMRF Canada recommends that individuals with dystonia speak to a movement disorder neurologist about their specific needs. If you are looking for an appropriate contact, please contact us as we can help you to find someone in your area. You can also visit www.dystoniacanada.org/support to find an appropriate professional in your area.

Is there support out there for me and my family?

There are various resources available to dystonia patients. One of the most enriching supports offered are support groups, provided by the DMRF Canada – this allows patients to get together, share their stories, build some personal networks and gain confidence knowing that they are not alone through this journey. Contact the DMRF Canada to find out about the supports that are available in your community.

Our thanks to the Dystonia Medical Research Foundation for providing information online via: <https://www.dystonia-foundation.org/>