

Who is Affected by Lower Limb Dystonia?

Dystonia affects men, women, and children of all ages and backgrounds. In children, lower limb dystonia may be an early symptom of an inherited dystonia. In these cases, the dystonia may eventually generalize to affect additional areas of the body. Children with cerebral palsy may have limb dystonia, often with spasticity (muscle tightness and rigidity). Lower limb dystonia in children may be misdiagnosed as club foot, leading to unnecessary orthopedic procedures that can worsen dystonia.

When seen in adults, lower limb dystonia seems to affect women more often than men. Age of onset is typically in the mid-40s. Symptoms may develop after periods of prolonged exercise, for example long-distance running or long-distance walking. Symptoms are often triggered by running, walking, or standing but may be absent at rest. Electrolyte disturbances and disorders of energy metabolism must be ruled out if symptoms occur only with exertion and fatigue.

What is Lower Limb 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. The movements and postures may be painful. Dystonic movements are typically patterned and repetitive.

Lower limb dystonia refers to dystonic movements and postures in the leg, foot, and/or toes. It may also be referred to as *focal dystonia* of the foot or leg. Individuals often have to adapt their gait while walking or running to compensate for the dystonic symptoms, and/or may require the assistance of mobility devices such as crutches, walkers, or wheelchairs.

Ironically, symptoms of lower limb dystonia may occur while walking forwards, but improve or disappear when walking backwards. Some individuals may be able to temporarily lessen symptoms with a 'sensory trick' to another part of the body, such as gently touching the face or head.

Lower limb dystonia is frequently misdiagnosed, sometimes mistaken for other gait disorders, orthopedic and structural conditions, and psychiatric disturbance.

What Support is Available?

The Dystonia Medical Research Foundation (DMRF) can provide educational resources, self-help opportunities, contact with others, volunteer opportunities, and connection to the greater dystonia community.

What is the DMRF?

The Dystonia Medical Research Foundation (DMRF) is a 501(c)3 non-profit 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, contact:

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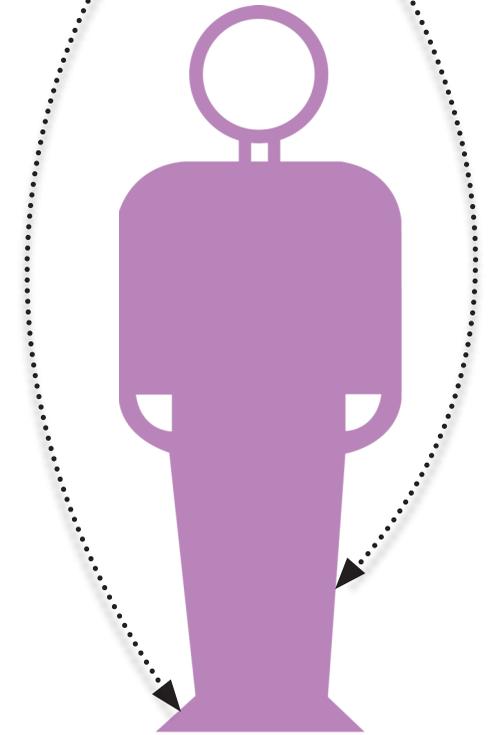
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*Connect with the DMRF on Facebook,
Twitter, and YouTube.*

Lower Limb Dystonia



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Common Symptoms of Lower Limb Dystonia

- Foot rolls outward so that the sole faces inward
- Foot or leg turns inward
- Foot points downward
- Extension of big toe
- Toe curling
- A sense of tightness or stiffness in the limb
- Changes in walking or running gait

What is the Cause?

For many adults who develop lower limb dystonia, there is no identifiable cause and it is not associated with additional neurological disease.

However, there are a number of conditions that are known to cause lower limb dystonia. These include brain injury, stroke, or injury to the limb. A fixed position of the foot may suggest that the dystonia was acquired from an injury or underlying cause. Fixed foot dystonia may also be associated with a pain syndrome following an injury called complex regional pain syndrome or reflex sympathetic dystrophy. In some of these cases, the dystonia occurs before the onset of the pain syndrome.

In some individuals, fixed foot dystonia is a symptom of a functional (psychogenic)

movement disorder or functional neurological symptom disorder (conversion disorder). Many people with functional movement disorders experience a mix of motor symptoms including dystonia, tremor, gait disorders, and tics. They may also experience weakness, sensory symptoms, non-epileptic seizures, and other functional neurological symptoms.

Dystonia is not a typical early symptom of Parkinson's disease but, in rare cases, lower limb dystonia appears to be an early sign of certain parkinsonian conditions. For example, toe pointing or curling triggered by exercise has been documented in individuals ultimately diagnosed with young-onset Parkinson's disease, which is seen in individuals under the age of 50.

Lower limb dystonia may also occur as part of generalized dystonia, for example inherited disorders such as early-onset (DYT1) dystonia and dopa-responsive dystonia.

What Kind of Doctor Treats Dystonia?

Individuals with dystonia are encouraged to seek treatment from a neurologist with special training in movement disorders. A movement disorder specialist can diagnose—or rule out—lower limb dystonia and assess any possible underlying causes. A team of medical professionals with various specialties may be appropriate to tailor treatment to the specific needs of the individual.

What Treatments are Available?

Treatment to lessen dystonia symptoms may require a combination of approaches. The goal of treatment is to improve a person's ability to function and move more freely. Regular botulinum neurotoxin injections administered by a qualified medical expert are among the most effective therapies to help relax dystonic muscles and alleviate the abnormal movements and postures. Oral medications such as anticholinergics, baclofen, and/or benzodiazepines may also be used for this purpose. Deep brain stimulation surgery may be an option for select patients, especially for inherited dystonia which can progress to generalized dystonia.

Physical therapy and/or occupational therapy may improve overall daily functioning. Part of the treatment plan may involve using orthotics (wearable medical products or devices) to help lessen symptoms and make it easier or more comfortable to walk. Case reports have demonstrated success with using computer-assisted gait analysis to customize an orthotic specific to a patient's needs. Orthotic options may include ankle brace, toe spreaders, rocker bottom shoes, platform or raised heels, or a combination of these. A light weight ankle foot orthotic may worsen dystonia in some and improve walking in others.

Physicians and rehabilitation therapists are beginning to explore the use of wearable stimulation devices to reduce lower limb

dystonia with some success. Functional electrical stimulation devices were originally developed for use in other gait disorders, but may be helpful for select individuals with lower limb dystonia.

Individuals with dystonia frequently experience depression and anxiety disorders. Evaluation and treatment for mental health disorders may be an important part of a beneficial treatment plan.

Living with Dystonia

Adjusting to life with lower limb dystonia can be challenging and require significant changes to a person's activities and lifestyle, but living well is possible. The early stages of symptom onset, diagnosis, and seeking effective treatment are often the most challenging. Once a treatment plan is established, individuals can find new and innovative ways to stay active and engaged in daily living.

Individuals and families living with dystonia are strongly encouraged to:

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