

## For More Information about Dystonia:

### Care for Dystonia

[care4dystonia.org](http://care4dystonia.org)

### Dystonia Medical Research Foundation

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

### DRD Central

[www.drdcentral.com](http://www.drdcentral.com)

### We Move

[wemove.org/dys](http://wemove.org/dys)

### National Institute of Health

[health.nih.gov/topic/Dystonia](http://health.nih.gov/topic/Dystonia)

### Chat rooms & Bulletin Boards:

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

[community.wegohealth.com/group/dystonia](http://community.wegohealth.com/group/dystonia)

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

Hi, My name is \_\_\_\_\_

Contact me: \_\_\_\_\_

Those living with Dystonia can enjoy a complete,  
empowered and happy life.

We at Dystonia Living Magazine encourage you to  
reach out. Don't know where to start?

Contact DLM or the Dystonia Awareness Advocate  
listed above!



Dystonia Living Magazine is a  
grassroots lifestyle publication by  
and for those living with Dystonia  
and other movement disorders.

<http://dystonialiving.com>  
[info@dystonialiving.com](mailto:info@dystonialiving.com)  
Twitter: @DystoTwit  
FB: Dystonia Living Magazine  
Podcast: [dystonia.podbean.com](http://dystonia.podbean.com)

**Twitching?  
Feeling stiff?  
Sustained or Repetitive,  
Unexplained Muscle  
Movements or Spasms?**

# »»» Dystonia



*Ever heard of it?*

**This is a patient publication made available to you by a  
Dystonia Awareness Advocate in your area and Dystonia  
Living Magazine.**

## What is Dystonia?

Dystonia is a neurological movement disorder. Something goes wrong in a part of the brain called the Basal Ganglia, causing the body's system of movement to malfunction.

When this happens, the muscles contract and spasm at the wrong times and in exaggerated ways. The muscles become disobedient.



Abnormal postures, involuntary, repetitive movements specific to the muscle group affected

are familiar to one living with Dystonia. This activity may become more intense during periods of stress or fatigue, but generally disappear when the body is fully supported or at rest.

Dystonia may be progressive, but is usually not life-threatening.

Dystonia can be connected to gene malformations or may manifest as a result of some other injury or illness. Very often, the cause of Dystonia is unknown.

Dystonic spasms and contractions, when sustained, may cause various types of pain,

including 'deep pain', a type of pain which may be hard for a patient to define.

Patients with Dystonia have complained of fatigue and pain in affected areas. They may only have problems when attempting to use a specific muscle group.

Dystonia may be diagnosed under other names, such as Spasmodic Torticollis, Blepharospasm or Writer's Cramp.

## Who Does Dystonia Affect?

Dystonia is an equal opportunity disorder, impacting the lives of people from every part of the world and at every age.

Many are born with the gene mutations already known to be associated with the disorder, but not all of those who have the mutation actually develop Dystonia.

**Dystonia is found in patients of all ages, from every demographic.**



## Diagnosis & Treatment

Dystonia is a rare disorder which is not always easily recognized and is usually diagnosed after a patient has been to see more than one doctor over a period of time, including a Neurologist.



A complete history is taken. Tests (excluding gene tests) such as blood panel, SED rate and MRIs, will most often be given to rule out other conditions with similar symptoms. The patient's movements and motor responses are observed.

After diagnosis, follow-up by a Movement Disorder Specialist is recommended. Seeing a speech-language pathologist, physical, &/or occupational therapist is sometimes indicated. Treatment may also include pain management, adaptive technology, off-label medications & sometimes surgery.

Secondary issues, such as arthritis, Dysphagia, functional blindness, social, communication, breathing & bladder control difficulties should be properly addressed and a plan for pro-active palliative care put in place.