



# Dystonia

## Symptoms or Behaviors

- Spooning of fingers
- Elbow & wrist flexion
- Foot in-turning
- Inversion at ankle
- Upward extension of big toe
- Turning of neck or “torticollis”
- Jaw or facial contortions
- Unexplained muscle pain
- Unexplained muscle weakness

## About the Disorder

Dystonia is a neurological movement disorder characterized by involuntary muscle contractions which force certain parts of the body into abnormal, sometimes painful, movements or postures. Dystonia is highly variable in its manifestations. Anyone can manifest symptoms of dystonia; it is the third most common neurological disorder affecting approximately 200,000 people in North America. Medical researchers believe that dystonia results from an abnormality in the basal ganglia where messages that initiate muscle contractions are processed. Researchers suspect a defect in the body’s ability to process neurotransmitters which help cells in the brain communicate with each other.

Dystonia is described according to the part or parts of the body that are affected. If only one body part is involved, such as a hand, foot or the neck, the form is termed a “focal dystonia”. If two contiguous parts are involved, such as the face and neck, then it is termed a “segmental dystonia”. If two noncontiguous parts of the body are involved, such as the face and one leg, it is termed a “multifocal dystonia”. If one half of the body is involved, it is called a “hemidystonia”, and if both legs, as well as one additional body part are involved, then it is termed, “generalized dystonia”. A focal dystonia that progresses to become generalized, or generalized dystonia itself, are the most common parts observed in children. When dystonia is due to another identified disease, then it is called secondary dystonia. When dystonia is not caused by another disease or condition, it is called primary dystonia.

Primary dystonias includes the genetic dystonias and some adult-onset, focal dystonias. Secondary dystonias may be due to a wide variety of causes including cerebral palsy, metabolic diseases, head trauma, and others. Dystonia may occur at rest or with action. A feature of dystonia that distinguishes it from most other movement disorders is that a dystonic movement of one limb may be triggered by an attempted movement of a different limb. For example, a dystonic posture of the right hand may occur while the left hand is performing a rapid movement, or a dystonic posture of the foot may occur during walking. It is important to know that there is no abnormal muscle tone in children with dystonia. A dystonic limb may or may not have increased resistance to movement, presenting as either stiff or floppy, or changes with time.

Symptoms of dystonia in childhood appear between the approximate ages of 5 to 16, and are usually in the foot or in the hand. In generalized dystonia, the involuntary dystonic movements may progress quickly through the body and involve all limbs and the torso. When symptoms emerge during early childhood or in late adolescence, they often begin in the upper body parts with symptoms progressing slowly.

# Educational Implications

Dystonia can affect many different parts of the body. Early symptoms may include deterioration in handwriting after writing several lines. Also foot cramps and/or a tendency of one foot to pull up or drag which may occur suddenly or after running or walking long distances. The neck may turn or pull involuntarily, especially when the individual is tired or stressed. One or both eyes may blink uncontrollably and rapidly, rendering a person functionally blind. Other possible symptoms are tremors and voice/speech concerns. Over periods of time symptoms may be noticeable, widespread and unrelenting. At other times, there can be little or no progression. The constant movement of dystonia can be compared to working out 18 hours/day. For individuals whose sleep is disrupted by constant movement, dystonia can interfere with the ability to sustain effort, concentrate and complete educational tasks throughout the school day. Students with dystonia may have difficulty breathing or swallowing due to muscle involvement in the areas of the jaw or tongue. Students with dystonia may also experience severe pain or headaches which can affect the quality of school work. Associated stress and depression can aggravate and or increase the symptoms of dystonia.

## Resources

**Dystonia Medical Research**  
One East Wacker Dr., Suite 2430  
Chicago, IL 60601-1905  
Phone: 312-755-0198  
Fax: 312-803-0138  
[www.dystonia-foundation.org](http://www.dystonia-foundation.org)

**WE MOVE**  
204 W. 84<sup>th</sup> St.  
New York, NY 10024  
Phone: 215-875-8312  
Fax: 212- 875-8389  
[www.wemove.org](http://www.wemove.org)

**Spasmodic Torticollis Dystonia**  
PO Box 28  
Mukwonago, WI 53149  
[www.spasmodictorticollis.org](http://www.spasmodictorticollis.org)  
Phone: 262-56-9534  
888-445-4588