

## What is the Cause?

The cause of dystonia is not known at this time. Scientists believe dystonia symptoms result from improper signals in the nervous system that cause muscles to contract involuntarily. Researchers and doctors do not yet fully understand the neurological mechanisms that cause this abnormal muscle contraction.

Most cases of hand dystonia represent isolated (primary) dystonia, meaning that there are no identifiable causes for the dystonic symptoms. Hand dystonia may occur in conjunction with early onset generalized dystonia also called DYT1 dystonia. Isolated hand dystonia occurs mainly in patients with no family history of the disorder. Only 5-25% of individuals have a family history of dystonia.

Hand dystonia may be acquired (secondary) as a consequence of injury, peripheral nerve damage, or spinal cord lesions. Symptoms of acquired hand dystonia may persist even when the hand is at rest, there may be a greater frequency of pain, and there may be additional symptoms beyond those affecting the hand.

## What is Hand Dystonia?

*Dystonia* is a neurological movement disorder characterized by persistent or periodic muscle contractions that cause abnormal, often repetitive, body movements, postures, or both. The movements are usually patterned and twisting, and may resemble a tremor.

*Focal hand dystonia* is a specific form characterized by excessive, involuntary muscle contractions in the fingers, hand, forearm, and sometimes shoulder. Symptoms usually appear when a person is doing a task that requires fine motor coordination of hand and arm muscles.

Hand dystonia includes a group of disorders called *occupational hand dystonias* that affect musicians, golfers, or typists. The symptoms often occur only during a specific activity requiring use of the hand, such as playing an instrument, golfing, or typing. *Writer's cramp* is a dystonia that is present when a person is writing. Hand dystonia may occur as an isolated focal dystonia or be a part of generalized dystonia.

## Focal Hand Dystonia (Writer's Cramp) DYSTONIA OF THE HAND AND FINGERS



To learn more about dystonia  
and the DMRF, contact:

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### **Are There Different Forms or Varieties?**

Some cases of hand dystonia are *task-specific*, meaning that the dystonic symptoms occur only in the context of a specific activity such as writing or playing a musical instrument. When the hand is not being used for that particular task, the symptoms are not apparent.

For example, common manifestations of writer's cramp include excessive gripping of a pen, flexion or extension of the wrist, elevation of the elbow, and occasional extension of a finger or fingers causing the pen to fall from the hand while writing. Sometimes the disorder progresses to include the elevation of shoulders or the retraction of the arm while writing.

Some cases of hand dystonia cause a sustained posture of the hand such as a bend in the wrist, a clenched fist, and/or contractions in the fingers.

Pain is typically more frequent in hand dystonia acquired from secondary causes. Isolated (primary) hand dystonia may include mild discomfort (cramping, aching) in the fingers, wrist, or forearm, especially while performing a specific task.

### **What Treatments are Available?**

No single strategy is appropriate for every case of hand dystonia. One of the most effective methods is to adapt tasks to diminish or avoid triggering the dystonic movements. This may involve occupational therapy or using assistive/ adapted devices.

A multitude of drugs has been studied to determine benefit for people with writer's cramp, but none appear to be uniformly effective. About 5% of people's symptoms improve with the use of anti-cholinergic drugs, such as Artane® (trihexyphenidyl) and Cogentin® (benztropine).

Botulinum neurotoxin injections into selected muscles may be helpful in treating focal hand dystonia. The injections are often given with electromyography (EMG) or ultrasound guidance, and must be repeated every three to six months.

Although a medication with the word "toxin" in the name may seem confusing, botulinum neurotoxin injections have decades of research and clinical experience demonstrating that they are a safe and effective medical therapy. Botulinum neurotoxin has been approved for use in the United States since 1989.

Treatment with botulinum neurotoxin may cause muscle weakness, causing limitations in fine motor control. Although this treatment is not effective for all people, significant improvement of dystonic posture and reduction of pain have been reported in up to two-thirds of those persons treated.

### **How is This Likely to Change or Progress Over Time?**

Hand dystonia typically begins subtly and slowly, with gradual progression. Symptoms then plateau and remain relatively stable. A little less than half of individuals with hand dystonia develop a tremor. When hand dystonia develops in children, the possibility exists that it marks the beginning of early onset generalized dystonia (also called DYT1 dystonia). Primary hand dystonia in adults typically begins between the ages of 30 and 50 years old and affects both men and women.

### **How is This Going to Affect My Daily Life?**

Living well with hand dystonia is possible. The early stages of onset, diagnosis, and seeking effective treatment are often the most challenging. The symptoms may vary from mild to severe, and fluctuate from day to day. Individuals may have to learn new ways to accomplish daily tasks, particularly those using fine motor movements.

Individuals living with dystonia are strongly encouraged to:

- Seek out the best medical care.
- Educate yourself about dystonia and treatment options.
- Develop a multi-layered support system of support groups, online resources, friends, family, and mental health professionals, if needed.
- Investigate complementary therapies.
- Get active within the dystonia community.

### **How Do I Find the Best Doctor?**

The kind of physician who is typically qualified to treat hand dystonia is a neurologist who specializes in movement disorders. Occupational therapy with a professional who understands dystonia can be extremely helpful.

### **What Support is Available?**

The Dystonia Medical Research Foundation ([www.dystonia-foundation.org](http://www.dystonia-foundation.org)) can provide educational resources, self-help opportunities, contact with others living with hand dystonia, 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 has served the dystonia community since 1976. The DMRF funds medical research toward a cure, promotes awareness and education, and supports the well being of affected individuals and families.

The DMRF can put you in touch with others with dystonia for networking and support.