



# Dystonia: Essential Facts for Patients

## WHAT IS IT?

Patients with dystonia experience involuntary muscle spasms or contractions. This leads to twisting or jerking movements, and unusual body positions. Dystonia can affect almost any part of the body. Most commonly, only one area is affected. Here are some common dystonias:

- Neck muscle contractions lead to abnormal head turning, tilting or twisting, often combined with shaking or jerking movements. This condition is known as *cervical dystonia*, or *torticollis*.
- Face muscle contractions lead to excessive blinking or eye spasms, known as *blepharospasm*. This may occur with lower face spasms and is known as *Meige syndrome*. When jaw and/or tongue are affected, it is known as *oromandibular dystonia*.
- In *spasmodic dysphonia*, patients experience strained or breathy voice.
- Other commonly affected areas include the hand or foot. When the hand is involved, it often occurs with specific activities, such as writing or playing a musical instrument. These are known as *task-specific dystonias*.
- In some cases, several areas of the body are affected. In rare cases, usually when dystonia starts in childhood, many regions are affected, known as *generalized dystonia*.

## WHAT IS THE CAUSE?

There are many different causes for dystonias. Some people get dystonia because they inherited a gene that causes it. Other people get dystonia because of a life event like a brain injury or infection, or exposure to a drug or chemical. Some people may get dystonia after many years of a very repetitive activity such as writing (*writer's cramp*) or playing a musical instrument (*musician's dystonia*). However, most cases of dystonia have no clear cause.

## HOW IS DYSTONIA DIAGNOSED?

A doctor, often an expert in movement disorders, makes the diagnosis by performing an examination. For some people, blood tests or brain scanning may be recommended. The doctor will use information including:

- The age dystonia started
- The area of the body affected
- Whether the dystonia started suddenly or appears to be getting worse
- Whether there are any other associated clinical problems

However, it may not be possible for your doctor to find an exact cause and many patients go undiagnosed or misdiagnosed initially. Also patients with mild dystonia may not seek expert medical advice and remain undiagnosed.

## IS THERE A TREATMENT?

There may be treatment for dystonia. If your doctor finds a cause then he/she may recommend a specific treatment for that cause. Otherwise, there are medications that may provide at least some relief. The most commonly used medications include:

- Anti-cholinergics
- Benzodiazepines
- Baclofen
- Muscle relaxants

Medications often must be given on a trial-and-error basis, balancing the benefits against potential side effects. Other people with dystonia may benefit from botulinum toxin injections. These injections should be provided by medical experts. Botulinum toxin injections temporarily weaken muscles to relieve the contractions/spasms and usually need to be injected three to four times per year. When medications and toxin injections don't provide enough relief, there may be surgical treatment options. You should speak to your doctor about options.

## WHAT CAN I EXPECT AS I LIVE WITH DYSTONIA?

For most people, dystonia develops over a period of a few months, or sometimes a few years. It does not usually continue to get worse. In some people, dystonia may spread from one body area to another, or other problems may develop.