

# What is dystonia?

Dystonia is a neurological movement disorder. It causes involuntary muscle contractions which lead the affected parts of the body to develop abnormal movements or postures, with or without tremor. Dystonia can affect just one part of the body or several different areas. However, when it first develops in adulthood, it usually confines itself to one part of the body.

## Oromandibular dystonia

In oromandibular dystonia the muscles that move the mouth and jaw are affected by involuntary spasm. This unwanted muscle contraction can pull the mouth into different positions. This often happens when people are using their mouths e.g. talking or eating, but can happen at rest as well. Like most types of dystonia it can be made worse when people are anxious or tired.

In most people the condition has no known cause and usually starts in mid-life. Typically the mouth is the only part of the body affected, although some people can experience dystonia around the eyes

(*blepharospasm*) and/or neck (*cervical dystonia* /*torticollis*) in association with oromandibular dystonia. An old name for the condition when eyes, neck and mouth are affected together by dystonia is *Meige's syndrome*. Usually if the condition comes on in mid-life with no obvious cause, it does not spread further, nor does it affect the mind or the senses.

In some people, previous treatment with medicines that work by blocking the chemical dopamine in the brain (which can be used to treat a variety of conditions including nausea, vertigo or anxiety as well as psychiatric conditions such as schizophrenia and depression) can be the cause of oromandibular dystonia. Such people may also be affected by dystonia elsewhere in the body, and the condition typically comes on after long-term treatment with such drugs. Another name for dystonia caused in this way is *tardive dystonia*.

## What causes dystonia?

Dystonia is thought to be due to a problem in a part of the brain called the basal ganglia, structures deep in the brain that control movement. Although the precise way in which these structures malfunction is not fully understood, much research is ongoing and is progressing towards a greater understanding of the condition.

## How can oromandibular dystonia be treated?

To date, no cure exists for oromandibular dystonia, although a great deal of research is being undertaken around the world. If you decide that you want treatment, then the two main choices are tablets or botulinum toxin injections. Sometimes both can be used together.

A few different drugs can help reduce the severity of symptoms in people with oromandibular dystonia. Although some people get great benefit from such drugs, they are not effective in everyone, and some people experience side effects.

Injections of botulinum toxin can be a very effective treatment for oromandibular dystonia. The botulinum toxin temporarily weakens the muscles it is injected into. Injections will need to be repeated every three months or so. Injections into the muscles that move the mouth can be difficult, as a very precise dose needs to be given to avoid weakening the muscle too much and some muscles can be difficult to inject. Any excessive weakness of the injected muscles is always temporary. Because of these difficulties muscles are usually injected using electromyography (EMG) – a tool

that helps identify which muscles are affected most by the dystonia.

*For more information on this treatment please see our separate leaflet, 'Botulinum toxin treatment'.*



# Oromandibular dystonia

## How do I live with oromandibular dystonia?

Oromandibular dystonia can be a challenging condition to live with. The movements around the mouth can sometimes lead to people feeling self-conscious in social situations. Sensory tricks, such as chewing gum, may help control the spasms for some.

Learning about oromandibular dystonia and talking about it to others who have the condition may help you come to terms with it and find the best way to manage your specific condition. A brief explanation of oromandibular dystonia to others may not only help them to understand your condition, but also, in turn, help you to cope with it.

## What the Society can offer

- **The Dystonia Society** is dedicated to providing information and support to everyone affected by dystonia in the UK and to raising awareness of the condition and the needs of everyone affected.

The Society is also committed to ensuring that everyone with dystonia has access to the treatments they need.

- **Our Helpline** is open Mondays – Fridays between 10am – 4pm and offers an opportunity to discuss concerns in confidence, and to obtain information on dystonia and its various treatments, including ways of making living with dystonia easier.

**Helpline: 0845 458 6322**



- **Local support** is provided via the Society's regional support groups run by the Society's team of volunteers.
- **The organisation** encourages and supports research into potential treatments and practical ways of coping with the condition.
- **Join us** – become a member and receive our quarterly newsletter. Call: 0845 458 6211.

*dystonia affecting the muscles that move the mouth, tongue and jaw*

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