

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 with 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.

- **Our helpline** offers an opportunity to discuss concerns in confidence and to get information about dystonia.

Helpline: 0845 458 6322

- **Written support.** If you would prefer to receive support and information in writing you can email our support team or send us a letter.

support@dystonia.org.uk

- **Our regional support groups and events** provide an opportunity to share experiences and meet others.
- **Our website** has information on dystonia and a lively forum. The address is www.dystonia.org.uk. You can also sign up on the website for our free **e-newsletter**.
- **Our helpcards** can help you to explain your condition to people you meet.
- **Join us** – become a member and receive our quarterly newsletter. Call: 0845 458 6211 or email info@dystonia.org.uk or go to the Membership page on our website

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Oromandibular dystonia

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

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 develops in adults, in the majority of cases it stays focal to one part of the body.

If the dystonia does spread it is usually only to one other part of the body. For instance, sometimes dystonia around the eyes (blepharospasm) and/or neck (cervical dystonia /torticollis) can spread into the mouth and/or jaw area. This is the most common cause of **oromandibular dystonia**.

When the eyes, neck and mouth are affected together by dystonia, this is called **Meige's syndrome**.

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 and/or tongue

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. It does not affect the mind or senses.

Although oromandibular dystonia most commonly develops following spread of dystonia from the neck or eyes, it can also appear in isolation. Where the condition comes on in mid-life without obvious cause, it will not usually spread further.

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 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.

How can oromandibular dystonia be treated?

Unfortunately, to date no cure exists for oromandibular dystonia, although there are treatment options that can reduce the impact of the symptoms usually using tablets and/or botulinum toxin injections.

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 very effective. The toxin temporarily weakens the muscles and injections need to be repeated around every three months. 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 the over-active muscles.

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