

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, it usually confines itself to one part of the body and is known as a focal dystonia.

Blepharospasm

Blepharospasm is a focal dystonia of the muscles around the eyes and typically affects people aged between 50 and 70. It can cause uncontrollable blinking and closure of the eyelids. In extreme cases, someone with blepharospasm may be unable to prevent their eyes from clamping shut, so that, at times, they are effectively 'blind'.

Blepharospasm usually develops gradually. First symptoms may include eye irritation and discomfort, sensitivity to light and increased blinking. The severity of symptoms may vary at different times of the day or from day to day. People with blepharospasm may be symptom-free when they first wake or after resting, and may find that the condition worsens when they are tired, under stress or reading.

The variability of symptoms can sometimes lead to delays in diagnosis, since the symptoms may not be apparent when patients visit their GP. Bright or flickering light (even from a television), smoke or wind can all irritate the condition. Physical activity such as walking can also cause spasms.

The frequency and severity of the muscle spasms can increase over a period of one to two years and can sometimes extend into the muscles of the lower face, jaw and neck. When blepharospasm is associated with spasm of the jaw and mouth (*oromandibular dystonia*) it is referred to as cranial dystonia (or *Meige's syndrome*).

What causes blepharospasm?

Blepharospasm is believed to be the result of abnormal functioning of the basal ganglia,

a small area deep within the brain which is involved in the control of movement. It normally develops in those over the age of 50, and in most cases does not spread to involve other muscle groups.

How is the condition treated?

To date, no cure has been found, although a great deal of research is being carried out around the world, with significant progress. Many drugs have been tried in the treatment of blepharospasm, but while some of these may provide benefit for some individuals, none is universally effective.

Botulinum toxin injections, which weaken the muscles affected by spasm, are the most effective treatment. Injections need to be repeated every three months or so. In cases where little improvement results from the injections, it may be because they have not been accurately targeted, or the dose needs adjusting, or a different type of botulinum toxin is required.

Occasionally, electromyography (EMG) is used to identify the appropriate muscles. The muscles requiring injections will vary from one individual to another, and may vary from one occasion to another.



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Blepharospasm

*dystonia of the muscles
around the eye*

How do I live with blepharospasm?

Having the symptoms of blepharospasm may, for some, cause uncomfortable feelings of being very self-conscious about the condition, social embarrassment, or even loss of confidence. Certain devices, such as ptosis props, tinted lenses, or sunglasses, can be helpful in both keeping the eyelids open, and helping with sensitivity to light. Learning about blepharospasm and talking to others who have the condition may help you come to terms with it and find the best way to manage your condition. A brief explanation of blepharospasm 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.



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your questions answered