How do I live with blepharospasm?

Having the symptoms of blepharospasm may, for some, cause uncomfortable feelings of self-consciousness about the condition, social embarrassment, or even loss of confidence. Certain devices, such as ptosis props, polarised 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 to 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.

Dystonia and mental wellbeing

Mental (emotional) wellbeing is a sensitive topic for many people with dystonia as many cases of dystonia are initially misdiagnosed as a mental health (or psychological) condition. In the vast majority of cases, dystonia is a neurological illness and does not have a mental health cause.

However, it is increasingly understood, that although mental health conditions do not normally cause dystonia, there can be a relationship in some cases between dystonia and conditions such as stress, depression and anxiety. This relationship can be two way - the symptoms of dystonia can cause anxiety or depression but also anxiety and stress can make the physical symptoms of dystonia worse.

If you are affected by a mental health condition, it is important to get treatment. To learn more, you can get our Dystonia and mental health leaflet through the helpline or from the website.

The Dystonia Society

The Dystonia Society is dedicated to providing information and support to everyone affected by dystonia in the UK. Our services include a helpline, advocacy, regional support groups and events about dystonia across the UK.

You can find out more and sign up for our free e-newsletter on our website. Alternatively you can email or call the Society.

Helpline
020 7793 3650

Website
www.dystonia.org.uk

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Blepharospasm

Blepharospasm is a form of dystonia affecting the muscles around the eyes. Dystonia is a neurological movement disorder characterised by continuous or intermittent muscle contractions which cause abnormal, often painful, repetitive, movements, postures, or both, which can occur with or without tremor. It can affect just one part of the body or several different areas. However, when it develops in adults, in the majority of cases it confines itself to one part of the body.

What is blepharospasm

Blepharospasm is a form of focal dystonia affecting the muscles around the eye 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 unable to see at all.

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, reading or exposed to sunlight.

The variability of symptoms can sometimes lead to delays in diagnosis, since the symptoms may not be apparent when people 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 initiate spasms for some people.

The frequency and severity of the muscle spasms can increase over a period of one to two years and can occasionally occur alongside other dystonic symptoms in 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 within the basal ganglia, a small area deep within the brain, 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 research is being carried out around the world on better understanding and treating dystonia. Many medications have been tried in the treatment of blepharospasm, some of these may provide benefit for some individuals, but none has been found 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.

Botulinum toxin injections into the muscles around the eye can cause side effects such as droopy eyelids, blurred vision or over-production of tears. Usually these effects are mild and wear off relatively quickly. If the side-effects are a problem they should be discussed with a doctor.

A large text version of this leaflet is available. Please call 020 7793 3651