

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.

Myoclonus dystonia

Myoclonus dystonia is a rare condition where myoclonus (sudden 'electric-shock'-like jerks of the muscles) and dystonia occur in combination. This type of dystonia typically starts in childhood, and usually affects the neck, trunk and arms. Like most types of dystonia, the condition can be very variable in severity, but after the initial development of the condition it does not usually spread any further.

It does not affect the mind or the senses, although some people with the condition do describe feeling anxious. The jerking movements and the dystonia may improve when alcohol is taken.

Myoclonus Dystonia can run in families, and a specific gene abnormality has been identified that causes the condition in about 25% of people. This gene test is a research test, and so testing is not generally available. The condition can often skip generations, and is very variable in severity between people, even those within the same family.

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.

"I am learning that whatever dystonia throws at me in my life, there is another path I can take"

How can myoclonus dystonia be treated?

Most people with myoclonus dystonia are treated with tablet medication. Treatment is not essential, however, and starting treatment depends on how severe the symptoms are. If people decide to take treatment, then usually a combination of drugs are used to treat the myoclonus and the dystonia.

Although these drugs can be very helpful, they are not effective in everyone, and can cause side effects.

Botulinum toxin injections can also be used to treat the dystonia, particularly if it affects the neck. These injections can sometimes also reduce the severity of the myoclonus too. Botulinum toxin injections temporarily weaken the muscles they are injected into. Injections have to be repeated every three months or so.

These injections can be a very successful treatment, and side effects are generally mild and rare. For more information on this treatment please see our separate leaflet: [Botulinum toxin treatment](#).

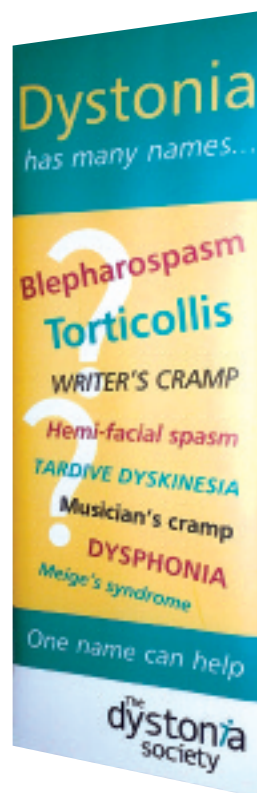
Myoclonus dystonia

How do I live with myoclonus dystonia?

Myoclonus dystonia can be a challenging condition to live with. Most people find that the symptoms can be made worse by anxiety, and therefore can find social situations quite difficult. Because the condition can be a genetic one, many people find it helpful to speak to a genetic counsellor about the genetic issues and to understand what implications the condition may have for one's family.

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.

a condition where myoclonus (jerking movements) and dystonia occur together

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