

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.

Paroxysmal dystonias

Paroxysmal dystonias are a group of rare conditions where attacks of dystonia occur, in between which people are usually completely normal. Sometimes there are triggers to these attacks such as sudden movement, fatigue, coffee and alcohol. In some types of paroxysmal dystonia the attacks are very brief (seconds to minutes), whereas in others the attacks can be much longer (minutes to hours).

Some people have many attacks per day, whereas others have very infrequent attacks.

During an attack, people do not lose consciousness, and are completely aware of their surroundings. Paroxysmal dystonias do not affect the mind or the senses. Paroxysmal dystonias are not the same as epilepsy, and therefore do not necessarily disqualify one from driving (although advice should be sought from the driving licence authority (DVLA)).

In most people the condition has no known cause and usually starts in teenage years. Sometimes the condition can be caused by damage to the brain, for example following a head injury. The condition can occasionally run in families.

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 paroxysmal dystonias be treated?

To date, no cure exists for people with paroxysmal dystonias, although a great deal of research is being undertaken around the world, with significant progress. The condition is not life-threatening but treatment is essential and usually available using drugs.

Although paroxysmal dystonia is not the same as epilepsy, many people can be very successfully treated using small doses of the same drugs used to treat epilepsy. In some people these drugs can stop attacks completely. Drugs are not universally effective, and some people do experience side effects.

“Knowing there are others who understand what it’s like to live with dystonia, who I can talk to and meet up with, really helps me cope”

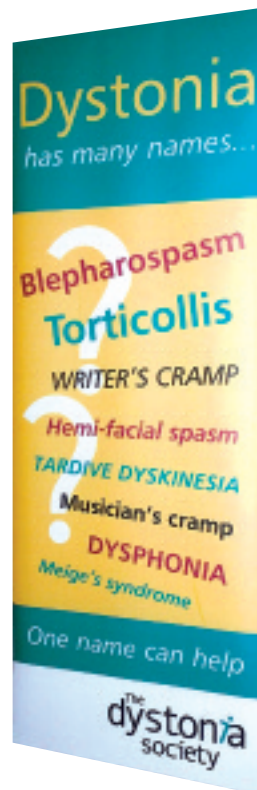
Paroxysmal dystonia

How do I live with paroxysmal dystonia?

Paroxysmal dystonia can be a challenging condition to live with. The attacks can be quite unpredictable, and this can interrupt normal life. Paroxysmal dystonia is quite a rare condition, and therefore most people, including some doctors, will not have heard of it. People can become confused between paroxysmal dystonia and epilepsy.

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 group of rare conditions where dystonia affects the whole or part of the body in brief episodes, in between which people are not affected by dystonia.

1st Floor, Camelford House
89 Albert Embankment
London SE1 7TP
Office no: 0845 458 6211
Helpline: 0845 458 6322
www.dystonia.org.uk
Reg charity no: 1062595

The
dystonia
society

The
dystonia
society