

# Neck dystonia

Learning about neck dystonia 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 neck dystonia to others may not only help them to understand your condition, but also, in turn, help you to cope with it.

“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”

## What the Society offers

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.

The Society is also committed to ensuring that everyone with dystonia has access to the treatments they need.

**Helpline: 0845 458 6322**

Our services include the following:

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

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- **Our regional support groups** run by volunteers 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](http://www.dystonia.org.uk). You can also sign up on the website for our free e-newsletter.
- **The organisation** supports research into potential treatments and ways of coping.
- **Join us** – become a member and receive our quarterly newsletter. Call: 0845 458 6211 or email [info@dystonia.org.uk](mailto:info@dystonia.org.uk).

(also known as cervical dystonia and spasmodic torticollis)

dystonia affecting the muscles of the neck

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# What is dystonia?

Dystonia is uncontrollable and sometimes painful muscle spasms caused by incorrect signals from the brain. It affects at least 70,000 in the UK. Dystonia is a neurological movement disorder that results in abnormal postures or movements, 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.

## What is neck dystonia?

**Neck dystonia**, also known as **cervical dystonia** and sometimes **spasmodic torticollis**, is a focal dystonia of the neck and symptoms usually appear between the ages of 30 and 50. By causing neck muscles to contract involuntarily, it produces abnormal movements and postures of the neck and head.

The movements can lead to the head and neck twisting (torticollis) or being pulled

forwards (antecollis), backwards (retrocollis), or sideways (laterocollis).

Symptoms may vary from mild to severe and the muscular spasms may result in pain and discomfort. Sometimes, the condition may be partially relieved by touching the chin, other parts of the face, or the back of the head.

Though neck dystonia may progress, it is not life-threatening and does not affect other brain functions. Neck dystonia is unlikely to become generalised, although occasionally another part of the body may be affected. The condition varies from one individual to another. In some cases it may progress for about five years and then get no worse. In other cases it hardly progresses at all.

Occasionally, symptoms may disappear, but may return at a later date. Because every case of neck dystonia is different, it is difficult to predict accurately how it may change in the future.

## What causes neck dystonia?

Neck dystonia is believed to be the result of abnormal functioning of the basal ganglia, an area deep within the brain involved in the control of movement. Much research is currently ongoing and progress made towards a better understanding of the condition.

## How is the condition treated?

To date, no cure has been found. Many drugs have been tried but while some of these may provide benefit for some individuals, none is universally effective. These drugs may also produce side effects in some people.

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. Sometimes electromyography (EMG) is used to identify the appropriate muscles to inject.

## How do I live with neck dystonia?

Neck dystonia can be a challenging condition to live with. Engaging socially or carrying out certain activities, such as driving or walking can sometimes become more difficult.

Sensory tricks (e.g. touching a part of the head with a finger), relaxation techniques, and pacing your self where possible may be among a number of coping strategies you may wish to pursue.