

Neck dystonia and pain

Some people with neck dystonia report experiencing pain while others report none.

There are a number of medications that can be helpful in managing pain. Many people also find attending pain management sessions helpful. To learn more about managing pain, you can get our **Dystonia and pain** leaflet through the helpline or from the website.

Dystonia and mental health

Mental health is a sensitive topic for many people with dystonia as many cases of dystonia are initially mistaken for 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 also increasingly understood, that although mental health conditions do not normally cause dystonia, there can be an important relationship in some cases between dystonia and mental health 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 problem, 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.

Occupational therapy

Occupational therapists can advise on equipment which assists posture & movement such as neck supports, high-backed chairs and other seating adaptations.

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

0845 458 6322

Website

www.dystonia.org.uk

2nd Floor, 89 Albert Embankment, London SE1 7TP

Office no: 0845 458 6211

email: info@dystonia.org.uk

www.dystonia.org.uk

Registered Charity No: 1062595 and SC042127

Neck dystonia

The
dystonia
society

Neck 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. Neck dystonia usually does not spread, 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.

How is the condition treated?

To date, no cure has been found but there are a number of helpful treatments that can substantially mitigate symptoms for most 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 an electromyographic (EMG) or ultrasound machine is used to identify the appropriate muscles to inject.

A number of different **oral medications** have also 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. Our leaflet **Drugs used for dystonia** has more information.

Many patients report **physiotherapy** as being helpful. The objective is to correct the postures and movements affected by dystonia through a set of targeted exercises. This type of therapy requires commitment as the process will involve daily exercises. To ensure the exercises are appropriate, they need to be prescribed by a neurophysiotherapist familiar with the condition.

In the small minority of cases where other treatments are not effective, **deep brain stimulation (DBS)** may be an appropriate alternative. In this procedure, electrodes are planted into the brain to help 'rebalance' movement and to control posture. The electrodes are powered by a battery implanted in the chest.