

What the Dystonia 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.

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

// Our **helpline** offers an opportunity to discuss your concerns and our **advocacy service** can offer support if you are having difficulties getting access to the treatment or other support you need.

// Our **regional support groups** run by volunteers provide an opportunity to share experiences and meet others with dystonia. We also run regular **Living with Dystonia** and **Dystonia Management** events across the country.

// Our website has information on dystonia and practical ideas on how to cope with dystonia. The address is www.dystonia.org.uk. You can also sign up on the website for our free e-newsletter.

Helpline

0845 458 6322*

Website

www.dystonia.org.uk

*Calls cost 3p per minute plus your phone company's access charge

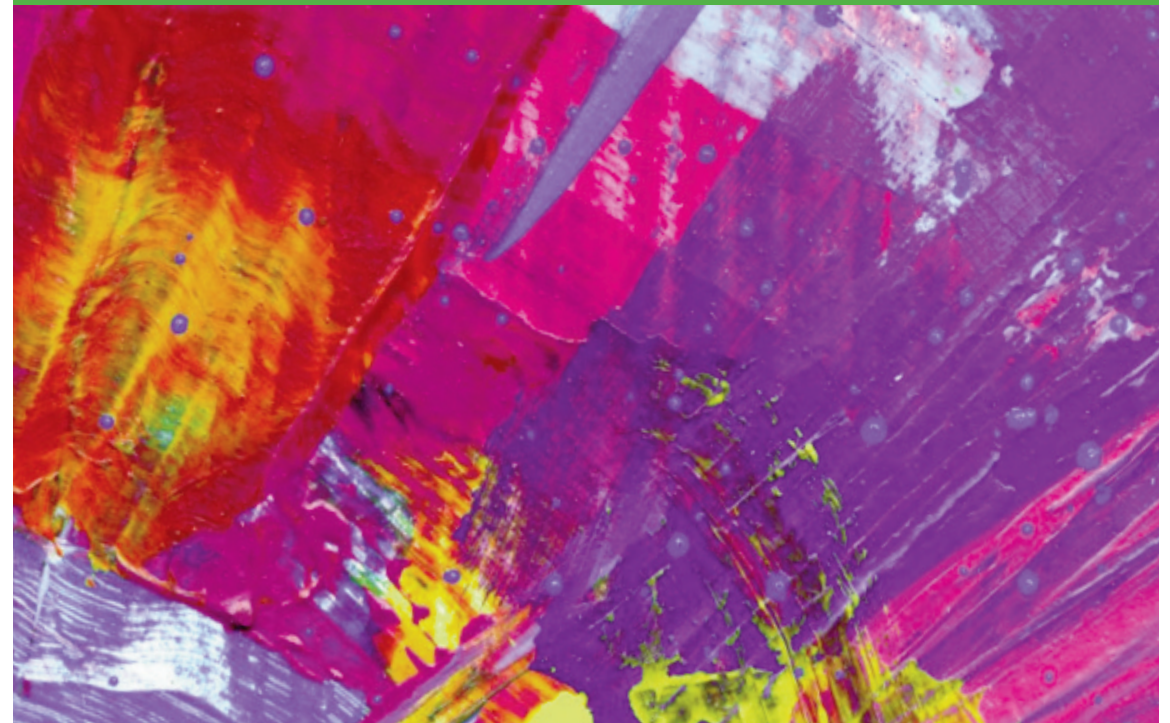
August 2015

The Dystonia Society, 2nd Floor,
89 Albert Embankment, London SE1 7TP
Office no: 020 7793 3651
email: info@dystonia.org.uk
www.dystonia.org.uk
Registered Charity No: 1062595 and SC042127

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Dystonia explained



What is dystonia?

Dystonia is a neurological movement disorder caused by faulty signals from the brain. It causes painful twisting, repetitive movements or abnormal postures. It is estimated to affect at least 70,000 people in the UK. Currently there is no known cure but effective treatments, coping strategies and support are available. Symptoms do sometimes disappear but this is rare – it occurs in around 5-10% of cases. In most cases dystonia does not shorten a person's life span.

Types of dystonia

EARLY-ONSET DYSTONIAS

These types of dystonia usually start in childhood or early adulthood and include:

// GENERALISED DYSTONIA

Affects most of the body, frequently involving the legs and / or arms and back (trunk).

// DOPA-RESPONSIVE DYSTONIA

Inherited dystonia responsive to treatment with dopamine.

// PAROXYSMAL DYSTONIA

Affects the whole or part of the body in brief episodes.

// MYOCLONUS DYSTONIA

Where sudden involuntary “electric-shock” type jerking movements occur with dystonia.

ADULT-ONSET DYSTONIAS

These types of dystonia normally appear between the ages of 30 and 70 although this can vary. They usually only affect one area but in a minority of cases the dystonia can spread to another area. If this happens, then it usually only spreads to one other area.

Forms of adult-onset dystonia include:

// NECK DYSTONIA (Cervical dystonia or spasmodic torticollis)

Causes the head to twist, pull in one direction, or shake.



// EYE DYSTONIA (Blepharospasm)

Affects the muscles around the eyes causing involuntary eye closure, twitching or blinking.

// VOICE DYSTONIA (Laryngeal dystonia)

Affects vocal cords causing the voice to be breathy or strangled.

// HAND DYSTONIA (Writer's or musician's cramp)

Affects the ability to write and sometimes other hand-based tasks.

// OROMANDIBULAR DYSTONIA

Affects muscles of the jaw, tongue and mouth.

In the minority of cases where adult-onset dystonia spreads the condition can be described as:

// CRANIAL DYSTONIA (Meige syndrome)

A combination of oromandibular dystonia and eye dystonia. Sometimes also affects voice and/or lips.

// MULTIFOCAL DYSTONIA

Affects two or more parts of the body.

// SEGMENTAL DYSTONIA

Affects two adjoining parts of the body.

ACQUIRED DYSTONIAS

These dystonias are caused by damage to or degeneration of the brain or abnormal response to certain medications. These causes can occur at any age. There are more than 50 types which include:

// CEREBRAL PALSY WITH DYSTONIA

Caused by damage to the developing foetal or infant brain.

// HEMIDYSTONIA

Affects one side of the body.

// TARDIVE DYSTONIA

Caused by an adverse reaction to certain medications.

Causes of dystonia

The cause of dystonia in most cases is not known although a minority of cases have an identifiable cause. One possible cause is faulty genes – these types of dystonia are called **inherited** and generally appear in childhood.

Some forms of dystonia have a known cause other than genes. These are called **acquired** dystonias. Causes can include an injury to the brain at birth or due to a stroke; other causes include medical conditions, accidents or a side effect of some drugs - primarily those used to treat psychiatric conditions. If the dystonia has no known cause, this is called an **idiopathic** dystonia.

Is dystonia inherited?

Some types of dystonia have been linked to a gene and so can be inherited. Dystonia that develops during childhood without an environmental cause is often inherited through one or more affected genes.

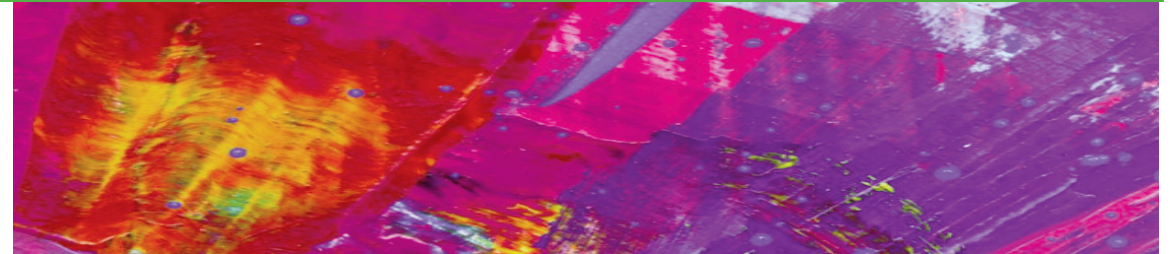
Most genetic dystonia is inherited in a dominant manner, which means that, if a parent has this type of dystonia, there is a 50% chance of passing the dystonia gene to each child.

However, not everyone who inherits the gene develops dystonia, a phenomenon known as reduced **penetrance**. For instance, one gene which can cause dystonia, DYT1, causes symptoms in only around a third of cases in which it is present.

It is likely that some forms of dystonia which develop in adults will also have a genetic cause. However, the gene(s) responsible have proved difficult to identify. This is probably because the genes involved have very low penetrance.

What should I do if I think I have dystonia?

If you think you may have dystonia and it has not yet been diagnosed, you should see your doctor and ask to be referred to a



neurologist specialising in movement disorders. If you are diagnosed as having blepharospasm, you may be treated by an ophthalmologist. If you have laryngeal dystonia, you may see an ear, nose and throat (ENT) specialist.

Will my dystonia improve?

In many cases, if dystonia develops in childhood, particularly if it starts in the legs, it may spread to other parts of the body, and can become generalised. However, when it develops in adults, it usually confines itself to one part of the body (focal dystonia). If it spreads – which does occur in a minority of cases – it will usually affect only one other area.

The progress of dystonia is unpredictable. The severity of symptoms can vary from day to day, and while there is often an element of overall progression, it is difficult to estimate how long this will last. Typically, a focal dystonia will progress very gradually over a five year period, and then progress no further. Symptoms in all dystonic conditions can vary.

For some people, their dystonia may sometimes improve or disappear altogether for no apparent reason. The likelihood of a total remission of symptoms has been estimated as somewhere between one-in-ten and one-in-twenty. In some cases, the dystonia may eventually return, but in others it will disappear completely.

Is there a cure for dystonia?

Unfortunately, there is not yet a cure for dystonia. Nowadays, however, many dystonic conditions can be very successfully managed.

How do I live with dystonia?

As with the onset of any long-term medical condition, some people who develop dystonia may go through an initial period of depression, embarrassment and outrage – or relief that there is an explanation for their symptoms.

Most people do manage to develop effective strategies for coping with the challenges that their condition brings. Successful treatments to lessen their symptoms, effective pain control and the acquisition of sensory ‘tricks’ all help to make social situations easier.

Dystonia and pain

Some people with dystonia report experiencing pain while others report none. Pain is most commonly experienced by those with neck dystonia and/or generalised dystonia although some people with other types also report experiencing pain.

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 inter-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.

What forms of treatment are available?

Various treatments are available for dystonia. These will be determined by the type and severity of the particular condition. The main options are:

DRUGS

Drugs are effective for some patients. Some work by interfering with neurotransmitters, the chemical substances that carry messages within the brain. Others are designed to relax the muscles, reduce shaking and control muscle spasms. To be effective, they have to be taken continuously. Drugs can cause side effects. A leaflet on “Drugs used for dystonia” is available from the Dystonia Society.

BOTULINUM TOXIN

Botulinum toxin injections are generally the most effective treatment for most cases of focal dystonia. The injections are usually administered every three months. These injections are also sometimes used in more generalised dystonias as part of a wider treatment regime.

SURGERY

Surgery may be an option where patients have never been or are no longer receptive to other treatments. Surgical treatments include deep brain stimulation (DBS) where 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. There are a number of other surgical treatments that are occasionally used as a last resort when all other treatments have failed.

OTHER SUPPORT

Physiotherapy can be effective in treating neck or generalised dystonia as long as it is used appropriately. It needs to be provided by a specialist physiotherapist who understands dystonia as inappropriate exercises may make symptoms worse.

Depending on the symptoms of dystonia, a number of other types of support can also be helpful including speech and language therapy, dietary advice, pain management support, psychological support and occupational therapy.