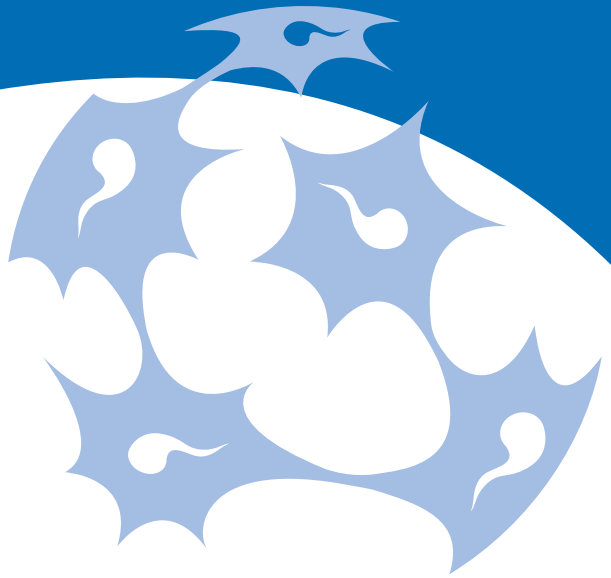


What is Dystonia?

Information for patients



Dystonia is a neurological movement disorder affecting around 70,000 people in the UK.

It is a term used to describe involuntary muscle contractions in one or various parts of the body that can cause certain postures, tremors, and pain. Dystonia can be present in any part of your body. In some people the postures and movements can cause embarrassment.

There is no treatment that completely resolves the symptoms that are associated with dystonia, but there are different treatment options that could positively improve your quality of life.

Areas that can be affected include:

- **Cervical dystonia (neck)** causes the head to twist, turn, pull in one direction, or shake. This is the most common type of dystonia.
- **Blepharospasm (eyes)** cause the eyes to blink more frequently or close involuntarily, interfering with vision.
- **Hand/foot dystonia.** Hand dystonia affects the ability to write and do tasks using the hands such as using a knife and fork, holding a cup, or using tools. Foot dystonia can affect wearing shoes or walking.
- **Laryngeal dystonia (voice)** affects the muscles of the vocal cords, causing the voice to be altered, often sounding strangled or breathy.
- **Oromandibular dystonia** affects the muscles of the mouth, jaw, or tongue. This can lead to difficulties opening/closing of the mouth or cause biting down or teeth grinding.

Sialorrhea (excessive drooling) - although not a type of dystonia, it is also treated in our clinics at Leeds. Botulinum toxin is injected into the salivary glands, which reduces the production of saliva. Like with all Botulinum toxin injections, the effect wears off over time and so injections usually need to be repeated.

Treatment options

Botulinum toxin injections

Botulinum toxin injections are the first-line treatment for dystonia that is in one or two areas of the body. The injections are usually administered every three months and can be very effective in reducing the intensity and impact of the symptoms by weakening the overactive muscles.

The toxin is produced by a bacterium called *Clostridium Botulinum*; it is purified and used in tiny, controlled doses, then injected directly into the affected muscle. The biological effect of the toxin takes three to five days to start taking effect. Maximum benefit occurs after about two weeks and the benefit lasts for eight to 12 weeks in total. However, the practical benefits could occur sooner and /or last longer. The injections need to be repeated at regular intervals.

We will assess the outcome of the injections, looking at the agreed goals and your response, during each clinic appointment. Your symptoms will be assessed to ensure we are delivering the best treatment for you, looking at the muscle activity, posture, and the Live Chart to ensure we deliver the best treatment outcome.

Before we start the injections for the first time, we will explain your treatment plan, provide you with information leaflets about your condition and ask you to sign a consent form. We will give you time to ask any questions you may have about your condition. You can decide to stop the treatment at any point.

We need to know if you have had any injections with Botulinum toxin for any reason within the last three months, as this increases the possibility of developing side effects or other complications.

It is important that you inform your injector if you are pregnant. Pregnant patients are only injected after a multidisciplinary team (MDT) meeting, weighing up the risks and benefits of the treatment goals.

Guided injections

Some patients require guided injections, these are used if the previous injections without guidance are not working. Using guidance enables a greater accuracy of muscle selection when injecting. Each patient is assessed individually as to whether guided injections would be beneficial.

Electromyography (EMG) guided injections

EMG is currently used in the nurse and consultant clinics. The EMG machine is connected to stickers attached to your skin and to a very thin needle, like the ones used without the guidance. This records the electrical activity of the dystonic muscles. The same needle is used to inject the toxin into the intended muscle.

Sometimes, we use the needle without injecting any toxin. We do this to build up a picture of which muscles are active (i.e.,

are dystonic) and contributing to symptoms. We can then use this information to develop a pattern of injections.

Ultrasound (US) guided injections

Ultrasound guided injections are used to identify specific muscles in areas of the body where there are several muscles that cannot be easily identified in any other way, or where there is a risk of injecting the toxin to an unwanted muscle, or there are arteries or nerves that we need to avoid.

Measuring your symptoms before and after receiving treatment

The Live Chart is one tool we use to see how well your treatment is working. It is very difficult to make a true assessment without this. We ask that you complete it each week and bring it with you to clinic. We can then clearly see when the treatment started to work, when your symptoms were well controlled and when your symptoms started to return. There is a section for any side effects that you may have experienced and an open box for any additional comments you would like to share with us. We request you fill the chart in before your treatment begins to give us a baseline, so we can see the true benefit of the injections. The chart is only helpful if it is completed on a weekly basis throughout your injection cycle.

There are other tools that may be used in special circumstances, in addition to the Live Chart or instead of the Live Chart. These will be explained at your clinic appointment.

You may be asked to record your movements after the injections and email them to the team (email addresses on the

back page). This will help us to better understand the pattern of your movements and can influence your future treatment.

Therapies

Physiotherapy can be used together with Botulinum toxin injections. A specially trained physiotherapist will give you a bespoke exercise programme, working closely with you to manage your symptoms.

Occupational therapists can sometimes help to make everyday activities easier.

Lifestyle

Many people living with dystonia find mindfulness and relaxation techniques can be helpful with dealing with the anxiety of living with dystonia. There are support groups available both online and in person and can be found on the Dystonia UK website (see the back page).

Medication

Medication can be helpful for some patients. Every patient responds differently in terms of benefit and tolerance to medication.

GABAergic medication - medication such as diazepam, lorazepam, clonazepam and baclofen, help relax the muscles, reducing the muscle spasms and movements. The main side effects of these drugs are drowsiness, tiredness, and dependency.

Anticholinergic medication – medication such as trihexyphenidyl work by blocking a chemical called acetylcholine, which can cause muscle spasms in some people.

Dopaminergic medication – The drug levodopa can help patients with dopa-responsive dystonia.

All the drugs for dystonia need to be taken regularly and not suddenly stopped unless advised to do so by a healthcare professional.

Neurosurgical procedures

If Botulinum toxin injections are not beneficial or if the dystonia is generalised (in multiple areas of the body), surgery may be an option.

DBS (Deep Brain Stimulation) is the main type of surgery for dystonia. Electrodes are implanted into the brain with a battery device, like a pacemaker. It is implanted just under the skin around the chest or stomach area. The electrodes and battery are connected internally with an insulated wire. The DBS system provides electrical impulses that control the abnormal muscle activity. After surgery, frequent visits to the DBS clinic are required to have the settings of the DBS system adjusted in order to optimise benefit. Sometimes, a range of settings are given to the patient to enable them to change the DBS system without having to visit the hospital. DBS is currently not available at Leeds Teaching Hospitals; however, a referral can be made to a hospital that offers this service.

Multidisciplinary Team MDT

The dystonia team runs a regular meeting to discuss individual patients. At this meeting different professionals who are involved in your care are invited to attend to try and establish the best treatment for you.

The Team

The dystonia team at Leeds Teaching Hospitals Trust includes consultants, specialist nurses, specialist physiotherapists and occupational therapists. We work closely together to provide you with the best possible treatment outcomes.

Useful contacts:

Dystonia nurse email – leedsth-tr.dystonianurse@nhs.net

Dystonia nurse mobile - **07798 617 663**

Consultants' secretary's phone number **0113 392 3339**

Dystonia UK website - dystonia.org.uk

Seacroft Hospital switchboard - **0113 264 8164**

Leeds General Infirmary switchboard - **0113 243 2799**



What did you think of your care?

Scan the QR code or visit bit.ly/nhsleedsfft

Your views matter



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