



Dystonia

An Advice Guide
for Usdaw Reps

What is Dystonia?

Dystonia is an uncontrollable, and sometimes painful, neurological movement disorder. This means that the condition is caused by the brain sending the wrong signals to muscles in various parts of the body. This makes the muscles contract and spasm, which can cause the person affected to make repetitive movements, twitch, or in some cases have their whole body twist into uncomfortable positions. The spasms can be sustained, so that the person is affected for long periods, or can happen on and off.

What Effect Can This Have?

Each person who has Dystonia is different and will be affected in different ways, and as there are also many types of Dystonia, the possible effects are wide ranging.

Day-to-day, it is likely that people with Dystonia will have techniques and treatments that help them to manage their symptoms.

However, as Dystonia can cause issues with co-ordination, tremors and cramps, people may find holding objects or performing delicate movements difficult. Tasks that involve holding items such as money or operating a till can actually make symptoms worse.

Dystonia can be made worse by stress, and if a person's face or neck is affected, interacting with customers or colleagues may make the person feel under added pressure. This may mean that they feel unable to perform their usual job role, or may require time away from it to practice stress management techniques.

Some people with Dystonia do experience very serious pain, and this can mean that they are unable to perform regular duties or may need additional time and support in order to do so, or may require time away from their work to perform their pain management treatments.

What Support Can Be Offered?

It is important to remember that Dystonia is uncontrollable and the movements the affected person makes are involuntary. This means that the person affected is not able to stop or control the spasms while they are happening. Some ways to support people with Dystonia might include:

- Recognising that medication can play an important role in managing Dystonia, and we can support members by ensuring they have the facilities and time to stick to their regime.

Help and Support

The Dystonia Society provide support, advocacy and information for anyone affected by the condition.

Web: www.dystonia.org.uk

- Awareness of secondary symptoms and the effects they can have on a person with Dystonia, meaning that they can feel comfortable in being honest about any issues they are experiencing.
- Recognising that the symptoms of Dystonia can be intermittent, and that just because a person is not always visibly affected, the condition does still affect them.
- Mobility issues may require amended duties or regular breaks, as tiredness can cause the symptoms to become worse.
- Physical relaxation, regular breaks and keeping stress levels low are all very important to keep the symptoms of Dystonia under control.

Dystonia and The Equality Act

Most members with Dystonia will not think of themselves as disabled. However it may be in the interests of members to show they are disabled because then they would be protected under the Equality Act (Disability Discrimination Act in Northern Ireland).

A person is disabled if they "have a physical or a mental impairment which has a substantial, long term, adverse effect on their ability to carry out day-to-day activities."

Very few disabilities are automatically covered by the Equality Act with the exception of HIV, Cancer, Multiple Sclerosis, severe disfigurement, and being registered blind or partially sighted. Everyone else will have to show that they fit the above definition.

If you can show that the member meets this definition you will have a much stronger case in arguing that the employer should support the member and make reasonable adjustments.

When deciding if a member is covered by the Equality Act, you need to consider the following five questions:

1. Does the member have a physical or mental impairment?

Dystonia is a neurological movement disorder and therefore clearly physical.

2. Is it more than a trivial condition?

The severity of the condition differs between individuals, for some it can be a twitch, or repetitive movements, for others their whole body can twist into uncomfortable positions. The spasms can be for long periods or they can happen on and off. Reps would have to show that the impact on the member's life is more than trivial or minor.

3. Has the condition lasted or will the condition last for more than 12 months?

The member needs to show that the condition has, or will, last for more than 12 months. The member does not have to be constantly suffering and fluctuating conditions such as Dystonia can be counted.

Continued on reverse...

4. What would happen if they stopped taking their medication?

Employers sometimes argue that the member is not disabled because their condition is controlled by medication. However, in deciding whether or not someone is disabled, they must be assessed as if they were not taking their medication. This is because medication only controls the symptoms but does not cure the condition.

5. Does the condition affect their day-to-day life?

If you can show that the member's Dystonia has a substantial effect on how they carry out normal day-to-day life then they may be covered. It helps to assess this by working through a typical day with a member, from getting out of bed, washing and bathing, to travelling, cooking or cleaning.

If you can show that the member meets all of the criteria listed, then they will be entitled to the protection of the Equality Act. The employer would then have a duty to make reasonable adjustments to take account of the member's Dystonia to help them stay in, or get back, to work.

The member will be the best judge of what adjustments they need but examples of reasonable adjustments could include:

- Awareness training for managers and colleagues.
- Additional support for standing/sitting where there are mobility issues.
- Amending duties to minimise stressful situations that can exacerbate the condition.
- Extra time to complete duties.
- Extra support from managers and colleagues.
- Additional breaks to ensure members can take their medicine or to take a rest as tiredness can make the symptoms worse.

To find out more about the work of the Regional Equalities Forums and Usdaw's equality work contact your local office on **0800 030 80 30** or visit: www.usdaw.org.uk/equalities

Join Usdaw

You can join online at:
www.usdaw.org.uk/join



Scan the QR code to join today.

What Happens Next

Once we process your application, you will receive a membership card with our Helpline telephone number and a New Member's Pack giving details of all the benefits and professional services available to you.

