ABOUT THE DYSTONIA SOCIETY
The Dystonia Society is the only national organisation providing information and support to everyone affected by dystonia in the UK and to raising awareness of the condition and the needs of everyone affected.

Dystonia is a serious and widespread neurological disorder that causes physical disability and is thought to affect more than 70,000 people in the UK (including more than 8,000 children and young people). It is an incurable, long-term disorder which is treated as a disability under the Disability Discrimination Act.

We are working hard to:
- ensure that healthcare professionals understand dystonia better
- reduce diagnosis delay
- campaign to improve services where necessary
- fund research into the causes of dystonia and its treatments
- increase public awareness of the condition.

AREAS OF CONCERN

Ability to work

The majority of people with dystonia want to continue in work because it signals ‘normality’ and the fact that they desire to be productive members of society.

However, with dystonia there are certain factors which can make it extremely difficult for people to continue in work, especially full-time work. These are:

- The fluctuating nature of the condition in many cases where no two days are the same, i.e. one day a person may be able to carry out work duties but the next day the condition is chronic and means they cannot even get up let alone make it into work;

- The oral medication prescribed for people with dystonia has some very unpleasant side effects, among which is a feeling of exhaustion in the
morning. This obviously can have the effect of delaying their ability to undertake the journey to work and also duties which require physical dexterity or operating machinery, driving, etc.;

- Botulinum toxin treatments are given on a three monthly regime. The medication is at its peak of effectiveness in the middle of the three month period, but for the time before the medication kicks in and the time when it is wearing off in its effectiveness, the spasms and pain associated with dystonia can be extreme and mean a person cannot carry out their usual work. Also, there are once again some very unpleasant side effects of botulinum toxin injections including difficulty swallowing, extreme muscle weakness and pain at the site of injection;

- There is ignorance amongst employers as to the obligation placed upon them by disability legislation to make reasonable adaptations in order to enable a person with a chronic condition to continue in their work. These can include adapting work premises and environments, providing special aids and equipment in the workplace, allowing regular breaks for taking medication, or even providing designated support workers. However it is our experience that without advocacy a lot of employers have chosen to suggest an employee leaves their employment rather than undertake the expensive adaptations.

- Some forms of dystonia, i.e. laryngeal which affects the vocal chords and blepharospasm which affects the eyelids, can mean that a person either cannot speak or when the eyelids clamp shut, can render them effectively blind. This makes it very difficult to find employment which does not require someone to either speak or see.

- Because dystonia is a chronic, long-term condition, people in work require regular time-off in order to attend treatment and medical appointments, i.e. physiotherapy, speech therapy, pain clinic, etc. Employers are not always understanding or accommodating about this factor.

- Often spasms can be internal and therefore are not as obvious as those spasms which can be seen externally with extreme posturing. This then means that employers and fellow work colleagues do not always ‘believe’ that the condition is as bad as the person is telling them which can make for difficult and intimidating work environment.

- Dystonia is a very visual condition which can lead to people assuming someone has been taking drugs or drinking, due to the tremor and spasming. Whilst dystonia does not affect the cognitive skills or mental capacity of the sufferer, it can strip away a person’s confidence and they may choose to isolate themselves rather than feel they are constantly being judge.
Knowledge of conditions amongst doctors carrying out the assessments:

Dystonia is a long term chronic neurological condition for which there currently exists no cure, however, even though more than 70,000 people in the UK have the condition, it historically takes on average 2.3 years to get a diagnosis. This is the result of a chronic lack of awareness and understanding amongst medical professionals, especially General Practitioners who would be the first point of contact in an individual’s journey to getting diagnosis and treatment.

The condition regularly results in unemployment or long-term sickness, often leading to financial hardship, social isolation, anxiety and depression. Also, many individuals are forced to rely on those around them for everyday tasks, such as washing, dressing, preparing food, shopping and going out to medical appointments, etc.. The resultant loss of independence can put a strain on the entire family network leaving partners and close relatives no choice but to give up their own work to become full-time carers.

The current method of assessment for disability living allowance involves locum doctors provided by the private sector and our experience is that these doctors have, except in a minority of cases, never heard of Dystonia.

The test used by doctors would appear to be a generic one, despite the disability, and not tailor-made for each individual based on their own particular condition.

In our experience, in order to gain an informed assessment of the condition and whether or not a person with dystonia is entitled to disability living allowance and other benefits the person making that assessment should be a neurologist who specialises in movement disorders.

DWP does have information on their website regarding dystonia. It also states that all Atos HCP’s are ‘experts in the functional assessment of disability’ however the experiences quoted below would not appear to back this statement up.

Our members report the following negative experiences of medical assessments where the doctor clearly had no experience or knowledge of dystonia nor had made any attempt to educate themselves about the condition prior to the assessment visit.

Case 1
“I claimed Incapacity Allowance which I got, no problem, but then a few months later applied for DLA. I had to attend a ‘medical test’ which was done by a so-called doctor who did the most basic of physical tests. I asked this doctor (whose command of English was not that good) if he had heard of Dystonia. He hadn’t. I then asked him if he did this test on everyone he saw to which he replied ‘yes’.”
He asked me if I had used the stairs to get to his office, which I had. This was marked against me as I was clearly able-bodied enough to walk. I tried to explain to him that Dystonia causes so much “unseen” pain that walking can be very painful and near-on impossible at times. He didn’t understand what I was saying.

The whole test took only a few minutes and needless to say the outcome was that I was not entitled to DLA.

I found this very stressful and it had a huge impact on my health. Even writing about it now nearly 5 years later still makes me angry!

**Case 2**

“It’s disgusting the way they make you feel when you go for the so called examination. The tasks are so simple my 2 year old granddaughter could perform them, but that doesn’t mean she’s capable of going out to work”

**Case 3**

“I underwent a medical by a Healthcare Practitioner (HCP) provided through Atos Healthcare. The HCP had never heard of blepharospasm and appeared unfamiliar with dystonia – he couldn’t find it on his computer ‘pick list’ and I had to explain to him that it was a neurological disorder. I was unable to keep my eyes open during most of the medical, which lasted 23 minutes.

He conducted a simple eye test with me facing a brightly lit window (I’m photophobic) and again instructed me to keep my eyes open. My visual ability to read was tested by being asked to read a very short line from a form – which I was able to do – but I am unable to read more than a couple of lines of writing without my eyes closing and losing my place.

I was asked closed questions and not allowed to explain how my condition affects my functional ability in activities of daily living.

I had presented a letter from my consultant stating that my condition was unlikely to improve significantly in the future, and in fact was more than likely to deteriorate. The HCP read this, but did not comment.

I also asked him to read the Dystonia Society leaflets and a list I had compiled of my symptom’s and triggers – he briefly scanned over these and declined to include them in my file.”

**Case 4**

“Surely it should be a pre-requisite of Atos doctors to familiarise themselves with the DWP info on the claimant’s specific medical condition before examination?”

**Reporting changes in circumstance:**

For people with fluctuating conditions, such as some forms of dystonia, we are concerned about the increased obligation on the individual to report changes in circumstances in the proposed PIP reform. We are especially worried by the proposal to introduce penalties for those who do not report
changes in circumstances of their condition. With conditions such as dystonia the symptoms and the effect on their life can change from day to day, and in some cases from hour to hour. There are triggers which can exacerbate dystonia and other movement disorders, amongst which stress features quite significantly for example.

This would put a great deal of pressure on both applicants and DWP personnel who would be dealing with the direct reporting of changes.

Also, for most forms of dystonia there is a treatment regime of botulinum toxin injections which last classically over a three month period. However, sometimes these injections are effective, and sometimes they are not. Even when they are effective there is a build up period to the medication kicking in and then once it is half way through the treatment, the effect begins to wear off.

The oral medication can mean that there is a ‘hangover’ period during the morning which means people can struggle to function until the last effects of the strong muscle relaxants has worn off.

We are concerned that with regard to DLA claimants who have dystonia the issue of variability of symptoms and the lack of account taken of this in assessing functional ability is significant. Also, no account seems to be taken of the expert opinion of those medical practitioners who know the claimant best, i.e. the general practitioner and the Consultant, who can speak on a personal basis about the way the dystonia affects an individual known to them.

**Case 1**

“the only thing I can say is that with my kind of dystonia it varies from day to day, if I’m ill or I’m feeling low or I’m tired. One day I can do something no messing and other days I can’t do anything at all. There is a day to day challenge to do what people take for granted. Also the drugs you take to try to control the symptoms affect the way you function”.

**Case 2**

“My form of dystonia is the eyelid problem (Blepharospasm), as other’s know, the lids can sometimes stay open, but, with no warning, they can clamp shut, making me functionally blind. You just can never tell from one day to the next. Mind of late has been worse rather than better”.

**Case 3**

“some questions would be easy to answer if one’s symptoms were constant and regular but as many of us know, dystonia isn’t like that for everyone. My symptoms are intermittent and therefore difficult to judge. I haven’t been called for an assessment yet but think it is sad that we have to hope for a ‘bad day’ just so that we can be believed and correctly assessed”.

**Emotional trauma of applying for benefits and going through the process of assessment**:

Dystonia is a very visual neurological movement disorder and people are often stigmatised and judged and bullied due to this factor. Added to this, the
symptoms are extremely distressing with people talking about feeling as though their body is 'out of control' and experiencing chronic pain.

The resultant emotional upset can be considerable and can lead to people feeling very isolated or choosing to isolate themselves. The dystonia society helpline responds to significant numbers of calls each year where suicidal thoughts or intent are mentioned because of the anxiety and distress that dystonia causes. Some of these calls are as a result of DLA having been either refused or removed after periods of being granted it, for no apparent reason.

We cannot underestimate the traumatic effect on people of feeling that the medical professional carrying out their assessment does not understand or appear to want to understand what it is like to live with their chronic on-going medical condition.

Angie Brown
Helpline and Support Manager
The Dystonia Society
www.dystonia.org.uk
Helpline 0845 458 6322