also help, in particular when many sites are affected and not always accessible to the botulinum toxin injections, such as deep neck or respiratory muscles. Side effects are frequent at the beginning of the treatment, such as dry mouth, blurred vision or constipation but usually reduce over a few weeks. The doses are increased very slowly. These drugs are usually not prescribed to patients after the age of 70, because of risk of memory loss.

Also, Clonazepam (Rivotril) and Diazepam (Valium) have muscle relaxant properties, as well as decreasing the level of anxiety and can be helpful to control severe dystonic spasms. They have addictive properties, and the neurologist in charge of your dystonia should monitor them.

Physiotherapy can be beneficial to patients with neck or hand or generalised dystonia. Because of the specialised nature of the movements in dystonia, this treatment needs to be provided by a specialist neuro-physiotherapist who has knowledge of the condition.

Pain management programmes can often be helpful. These programmes give guidance on mental and physical techniques that can help manage pain.

Psychological support such as counselling and cognitive behavioural therapy (CBT) can help as dystonia is also associated with higher levels of stress, anxiety and depression.

Deep brain stimulation (DBS) is provided in severe cases where other treatment options have failed. DBS is currently funded by the NHS for generalised dystonia, neck (cervical) dystonia and dystonic tremor. DBS is a surgical procedure in which two fine electrodes are inserted into the brain and connected to a battery under the skin. This sends a pulse to the brain that blocks the signals causing the dystonia. For the majority DBS can substantially reduce symptoms but rarely eliminates them entirely.

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, local support groups and events across the UK.

Helpline
0845 458 6322

Website
www.dystonia.org.uk

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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
Segmental & multifocal dystonias

Dystonia is a neurological condition where uncontrollable and sometimes painful muscle spasms are caused by incorrect signals from the brain. Generally, when dystonia starts in adulthood, it affects only one part of the body and is called focal dystonia. However, in a minority of cases, it can spread to a second part of the body and occasionally can affect three or more parts of the body.

When adult-onset dystonia affects 2 contiguous (neighbouring) parts of the body (such as the eyes and mouth), this is called segmental dystonia. When adult-onset dystonia affects 2 non-contiguous parts of the body or more than 2 parts of the body, contiguous or not, the condition is called multifocal dystonia.

Most adult-onset dystonias have no cause yet identified (this is called idiopathic). It is not known either why such dystonias appear or why they sometimes spread in this manner. Multifocal dystonias usually appear in the age range 30 to 70 years old. Idiopathic dystonia does not usually shorten a person’s life span or affect the cognitive skills needed for daily living.

Description

There are a number of other terms that doctors also sometimes use to describe different types of segmental and multifocal dystonias. (The most frequent is cranio-cervical dystonia).

// Cranial dystonia (or Meige syndrome) is a dystonia affecting two or more areas above the neck including eyes, mouth, jaw and tongue. Most commonly, this type of dystonia starts around the eyes as blepharospasm and then spreads downwards, progressing over time from the eyes to the jaw and mouth. If this cranial dystonia then spreads to the larynx and to the neck, it becomes a cranio-cervical dystonia. The percentage of patients with blepharospasm who progress to Meige syndrome has been estimated between 23% and 36% in different research studies.

// Other areas affected by segmental and multifocal dystonias can include two or more of the following: neck, eyes, hand, voice, mouth, tongue and/or jaw, foot and occasionally the limbs. Neck (cervical) dystonia often spreads to the hand and the voice dystonia can be associated with cranio-cervical dystonia. However, it is possible that dystonia in any of the areas mentioned can spread to any other.

The age of onset can influence the pattern of spread. The characteristics of dystonia in the different areas that can be affected are the same as for focal dystonia.

Treatment and support

Treatments are available and most people do manage to develop successful strategies for living with dystonia, combining treatment with other types of support.

The treatment of segmental and multifocal dystonia is similar to focal dystonia, but some points are worth mentioning:

Botulinum toxin injections, which are the most efficient treatment of focal dystonia, need to be performed in cases of segmental or multifocal dystonia at the same time in the different dystonic sites.

For instance, if the eyes and the mouth are involved, it would be best to find an injector who could inject both the eyes and the mouth muscles during the same session. Non-synchronised injections may increase the risk of developing immunity - for instance if a patient is injected for the eyes in ophthalmology and 2 weeks later for the mouth and throat in the neurology (or ENT) department. In addition, control of the dystonic spasms is greater when the different areas affected all calm down at the same time.

Oral medications such as anticholinergic drugs (Procyclidine, Trihexyphenidyl) can