How do I live with voice dystonia?

Voice dystonia can be a challenging condition to live with. The poor quality of your voice can make it difficult for you to make yourself understood and may make some people feel self-conscious and embarrassed in company.

Giving a brief explanation to new people you meet can ease their concerns that you might strain your voice by speaking, for example: ‘I have a neurological condition which affects my speech but it’s not painful and I won’t do any damage by talking to you.’ As with all forms of dystonia, a positive attitude is important. Learning about voice dystonia and communicating with others with the condition may help you come to terms with it and to find the best ways of coping with your symptoms.

Dystonia and mental health

Mental (emotional) 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 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.

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, regional support groups and events about dystonia across the UK.

You can find out more and sign up for our free e-newsletter on our website. Alternatively you can email or call the Society.

Helpline
0845 458 6322*

Website
www.dystonia.org.uk

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

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Voice dystonia is also known as laryngeal dystonia and spasmodic dysphonia. In this condition the vocal cords are affected by involuntary spasms. These involuntary spasms of the vocal cords cause the voice to change in quality.

When the vocal cords are pulled together (adductor laryngeal dystonia), the voice tends to have a ‘strangled’ quality. If the vocal cords are pulled apart (abductor laryngeal dystonia) the voice can be ‘breathy’ and very quiet. Like most types of dystonia, voice dystonia can be made worse when people are anxious or tired.

In most people the condition has no known cause and usually starts in mid-life, but does not affect the mind or the senses. Sometimes the vocal cords are the only part of the body affected, but in some cases other muscles nearby can be affected such as the neck, mouth and the muscles around the eyes.

What is dystonia?

Dystonia is a neurological movement disorder. It causes involuntary muscle contractions which lead the affected parts of the body to develop abnormal movements or postures, with or without tremor. Dystonia can affect just one part of the body or several different areas. However, when it develops in adults it most commonly confines itself to one part of the body.

What causes dystonia?

Dystonia is thought to be due to a problem in a part of the brain called the basal ganglia – structures deep in the brain that control movement. Although the precise way in which these structures malfunction is not fully understood, much research is ongoing which is giving us a greater understanding of the condition.

How can voice dystonia be treated?

To date, no cure exists for laryngeal dystonia, but there are a number of treatments available to manage the condition.

Botulinum toxin injections, which weaken the muscles affected by spasm, are the most commonly used treatment. Injections need to be repeated regularly and the right gap varies widely between patients - some need injections every couple of months while others report benefit from the injections for longer.

Treatment of voice dystonia can be difficult, and injections are usually only performed by doctor with special training. Botulinum toxin provides significant relief for the majority of people but it is not perfect - usually easing symptoms rather than completely eliminating them and the outcome of injections varies between patients.

A number of surgical procedures have been tried for voice dystonia. Some people get very good results – but overall the results are mixed and the dystonia may return after a period of time so most ENT doctors recommend sticking with the botulinum toxin injections.

Some people with voice dystonia can gain benefit from speech therapy. In addition, a speech and language therapist can give guidance on keeping the throat healthy and managing stress both of which can improve the performance of the voice.

In other people tablet treatment (medication) can be tried, although the results can be quite variable from person to person and side effects can occur.