How do I live with laryngeal dystonia?

Laryngeal 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 can make you feel self-conscious and embarrassed in company.

Giving a brief explanation to new folk 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 laryngeal 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 specific symptoms.

What the Society can offer

- **The Dystonia Society** is dedicated to 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.

The Society is also committed to ensuring that everyone with dystonia has access to the treatments they need.

- **Our Helpline** is open Mondays – Fridays between 10am – 4pm and offers an opportunity to discuss concerns in confidence, and to obtain information on dystonia and its various treatments, including ways of making living with dystonia easier.

  **Helpline: 0845 458 6322**

- **Local support** is provided via the Society’s regional support groups run by the Society’s team of volunteers.

- **The organisation** encourages and supports research into potential treatments and practical ways of coping with the condition.

- **Join us** – become a member and receive our quarterly newsletter. Call: 0845 458 6211.
In laryngeal dystonia 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, laryngeal 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 usually 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 laryngeal dystonia be treated?
To date, no cure exists for laryngeal dystonia, although a great deal of research is being undertaken around the world, with significant progress. Whilst treatment for this condition is not essential since it is neither life-threatening nor life-shortening, those who depend on their voices for their work will usually need to be treated if they are to continue in work.

Treatment of laryngeal dystonia can be difficult, and results of treatment vary greatly between different people. The principal treatment involves the injection of botulinum toxin to weaken the muscles affected by spasm. Injections have to be repeated every three months or so. Injections into the vocal cords are technically quite difficult, and a very precise dose needs to be given to avoid weakening the muscle too much.

Any excessive weakness of the injected muscles is usually temporary. Because of these difficulties, muscles are usually injected using electromyography (EMG) – a tool that helps identify which muscles are affected most by the dystonia, and is only usually performed by ear, nose and throat (ENT) doctors with special training.

Some people with laryngeal dystonia can gain benefit from speech therapy. In other people tablet treatment can be tried, although the results can be quite variable from person to person and side effects can occur.