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My Dystonia Journey

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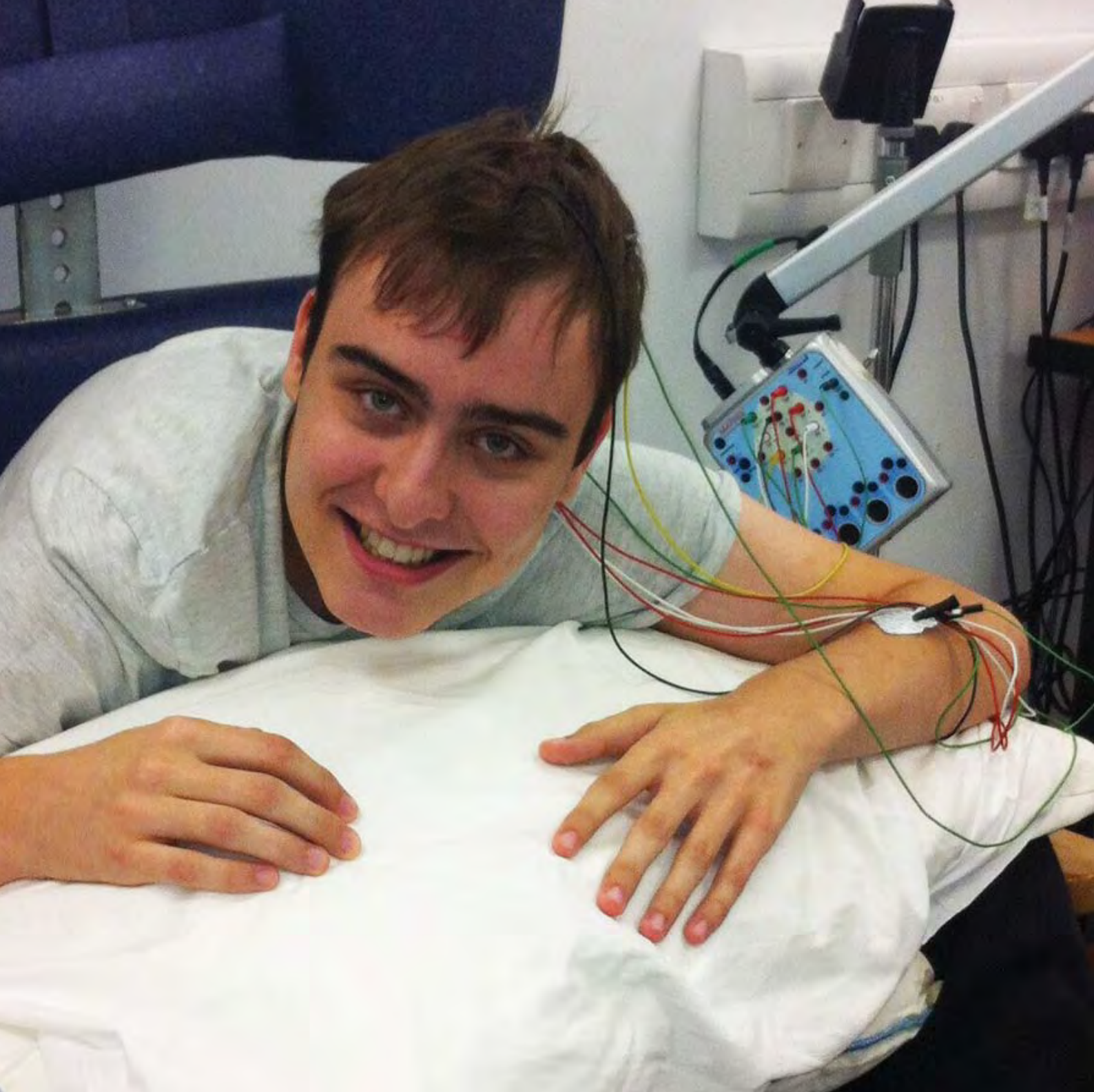

My Dystonia Journey

My name is Liam Carbery and I suffer from generalised dystonia affecting most of my body. I hope when you are reading this, it will give you an insight into the condition. This is my journey – yours may well be different. Some of you reading this may have only just been diagnosed whereas others have lived with the condition, like me, for many years.

What is dystonia?

Dystonia is a neurological movement disorder that causes muscle spasms, painful contractions and abnormal postures arising from problems within the basal ganglia. Dystonia cannot be cured.

Types of dystonia

- **Focal dystonia** – where a single region is affected
- **Segmental dystonia** – where two or more connected regions of the body are affected
- **Multifocal dystonia** – where two or more regions of the body that aren't connected to each other are affected
- **Generalised dystonia** – where the trunk and at least two other parts of the body are affected
- **Hemidystonia** – where one entire side of the body is affected

Getting my diagnosis

Dystonia in my case was very difficult to diagnose and started with bending of the trunk and bending of my legs. I have seen numerous professionals including neurologists, neurosurgeons, spinal surgeons and psychiatrists all of whom couldn't find any real explanation for my posture. Various tests including a muscle biopsy and electromyogram appeared normal. I am bent over on all fours and wheelchair bound.

Paediatricians were unable to diagnose my condition and felt the best course of treatment would be CBT (cognitive behavioural therapy) and intensive physiotherapy. I was transferred to QEHB in 2013 under the care of a neurologist. He diagnosed dystonia within the first visit. My illness is not psychological, although some psychiatric conditions may cause or exacerbate the dystonia. Because of the nature of my dystonia it has led me to see numerous specialists including those at the National Neurology Hospital in London who felt I did have dystonia and that it may be genetic due to my family history of Parkinson's and dystonia.

Treatments to expect

In the first instance, various drugs will be trialed. Specialists will look for the cause of your dystonia but sometimes that may never be found. I have tried various medications used for dystonia, to no avail. Botulinum Toxin injections are targeted into specific muscles that are overactive to reduce the spasms. Intrathecal Baclofen is where a special pump is fitted into the stomach connected to the lumbar spine so that a drug called Baclofen can go directly into the central nervous system to try to help decrease dystonia or spasticity. Deep Brain Stimulation Surgery is where fine electrodes are placed within the brain. Only a select group of patients are considered for this potentially life-changing surgery as there are a lot of associated risks with this.

Last, but not least… hope!

You will have down days and days where you don't feel like doing anything and you will find yourself wondering: 'Am I going to walk? Will I return to work? Will I ever live a normal life again?' However, with the right specialist you will get the help you need and you must have hope that one day you will return to the things you love doing.

Sites which may be of help:

- **Dystonia Society:**
  www.dystonia.org.uk
- **UHB:**
  www.uhb.nhs.uk/pi-neurosurgery-neurology.htm
- **Birmingham Community Health:**
  www.bhamcommunity.nhs.uk/patients-public/rehabilitation/intrathecal-baclofen-specialist-clinic/

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