Case study

Jenny Lake

A member of the Society, Jenny Lake, told us how speaking to one of the Society’s keen activists has led to a better life...

“I went into shock when I was first diagnosed. I could not see a way forward but over time I found there was one. At last, I have a normal life again and am happy. I had the usual problem encountered by dystonia patients of not getting diagnosed correctly. I finally saw the neurologist at Derriford Hospital, Exeter, and he confirmed I had dystonia.

I finally joined the Dystonia Society and the helpline proved to be a lifeline. They put me in touch with Nicky Parkin, one of the Society’s keen activists who had to abandon her career because of dystonia. Like me, Nicky has cervical dystonia and she became very much a lifeline for me when I occasionally felt a bit down.

My injections helped immediately. I had lost my co-ordination and I couldn’t cut my food. But, within a week, my dexterity had returned and I could cut up my food again and drink without a straw.

However, I still spent many hours lying on the sofa to stop my neck aching. My eyes also ached as well because my head was so twisted. I walked my lovely labrador Poppy every day to keep the rest of my body fit. I was completely focussed on wanting to get better, pushing myself.

In 2008 I got the all clear after a year to get back to driving. My husband found me a small automatic car, although it took some time before I got my confidence. The first time I went shopping it was quite nerve-wracking, I thought I’d never get back home, but I kept on going a little further each time.

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Howard Jenson is a member of the West Yorkshire Support Group. Dystonia matters! met up with him in March to learn more about his dystonia.

““I have benign essential blepharospasm with apraxia of eyelid opening. I’d been noticing for some time my eyes had become sensitive to light and also the tendency for them to blink a lot. This gradually became worse towards the end and before I finally got the correct diagnosis, I was effectively blind. My eyes would close for indeterminate periods, perhaps only seconds, but nevertheless both scary and potentially dangerous. I simply could not control the blinking to the extent that my wife had to become my guide and protector when outside.

I insisted I was referred to the local eye hospital. On both of my visits I saw a ‘member of the team’ ie. not the Consultant, and was told I had blepharitus, which is basically an infection, for which I was prescribed a course of antibiotics. Needless to say there was no improvement. I was then told my eyelids were drooping and offered surgery to adjust them. The surgery took place and, of course, I was no better.

I then swallowed my principles and paid to see the consultant who insisted I had ‘Dry Eye Syndrome’ and would have to live with it. He ignored my repeated question regarding the excessive blinking other than to declare it was as a result of the dry eyes. I knew I did not have dry eyes and started to try and work out logically what could be the cause of the condition. By this time my quality of life was pretty awful. I then told him that my GP had sent me for the X-ray and CT scan and that I had also seen the neurologist. At that point he changed his mind about my diagnosis, declared it to be blepharospasm and refered me to another ophthamologist who did botulinum toxin injections. I now receive four botulinum toxin injections around each eye. The botulinum toxin is meant to numb the muscles that are causing the spasms to take place. So far I have had four sets of injections and each has had a different response. I don’t feel the correct regime has been found yet. Currently my left eyelid is drooping which means vision in that eye can be problematic. My eyes themselves are fine, it’s the eyelids that are the problem.”