

One woman's story of living with dystonia

I had the very first symptoms of dystonia in 1987. I woke up one morning with a very painful, stiff neck. I went to my GP who gave me a soft collar to wear. This seemed to do the trick and the pain went away a few days later as quickly as it had come. Over the next few years I noticed that whenever I went to bed, my neck muscles became very tight and kept pulling my head to the right. I also started having difficulty keeping my head forward facing in certain circumstances, e.g. having photographs taken, talking face to face with people and at the dentists. This pattern continued for the next seven years and I was eventually sent for an x-ray in 1994. The x-ray showed up wear and tear.

In 1998 my dentist spoke to me at the end of a treatment. She was concerned that she could feel a very definite head tremor and suggested I go back to my GP. This I did and was referred to my local hospital. In 1999 I had an appointment with a medical consultant who, on examination, diagnosed stress! He also came up with the suggestion that my head turning and pulling was a "learned trait". I questioned his diagnosis but got nowhere. When I told him that I taught Primary 1 children he wouldn't budge from his diagnosis and I was sent home with a piece of advice....."Go home and drink a glass of red wine every night"!

I made an appointment with my GP to discuss the outcome of my hospital visit and we came to the conclusion that perhaps the wear and tear damage to my neck was causing pressure somewhere and this was causing all my problems. By this time I had discovered that when I felt my head being pulled to the right, if I touched my chin with my finger, it relaxed. Unknown to me, this was a classic dystonia trick – a "geste antagonistique"

In October 2000 I thought my world had come to an end when I was diagnosed with breast cancer. I had surgery followed by six treatments with chemotherapy. After chemo sessions five and six my head felt really strange, as if it wasn't 'clearing properly'. This feeling continued over the next few months. Then in August 2001, the week before I was going back to school, my husband took me for a walk at Culzean Castle. I felt my head was strange right from the outset but tried to hide the fact. I had to hold it with both hands while walking. Eventually I had to stop. I was quite distressed and just didn't know what to do with my head, it felt really strange. My husband supported it for a time, holding it

straight with his hands. He managed to get me to a bench and brought the car as close as he could.

I returned to work the following week and had great difficulty keeping my head straight. Things got progressively worse over the next few weeks until October when the pain set in. My neck muscles seemed to be in constant painful spasm. I went back to my GP who prescribed pain killers. Over the next few weeks I was at my GP every week. He tried all sorts of painkillers but nothing worked. I was having great difficulty at school. By this time, I couldn't turn my head to the left. I also had to stand against the wall to support my head when addressing the class. I was finding it impossible to carry out every day tasks due to the painful neck spasms.

In November 2001 I was referred to the physiotherapist at my GP's practice. He observed me walking and asked all about my symptoms. He gave me some mid line neck exercises to do and an appointment for the following week. The exercises were very difficult and painful but I did my best to continue with them. On my next visit to the physiotherapist he informed me that he wanted to speak to my GP, who was on holiday at that time, before carrying out any further treatment.

I made an appointment with my GP the following week. He hadn't had any contact from the physiotherapist as yet. Three days later, when I got home from work, my husband informed me that my GP had been on the phone and I had an appointment to see him the next day. The physiotherapist had been in touch. GOOD NEWS.....at long last I was told that my "learned trait" was actually a neurological condition called Ideopathic Spasmodic Torticollis, also known as Cervical Dystonia.

Meanwhile, because of my symptoms and having just been treated for cancer, my oncologist sent me for a battery of scans to rule out anything sinister. The brain CT scan was clear so I could then be referred to a neurologist for confirmation of my diagnosis and then be referred for treatment. The waiting time in my area to see a neurologist was over eighteen months! I felt I had waited long enough so, much against the grain, I went private and was seen within two weeks.

The consultation lasted all of fifteen minutes, the diagnosis of Dystonia was confirmed and I was then referred to the Southern General Hospital in Glasgow. On my first visit I learned that there is NO CURE for my condition as yet. There are various treatments on offer, the best of which is Botulinum Toxin injections into the affected muscles. I had my first injections that day, after having the details of the injections explained to me and signing a disclaimer.

From first symptoms to diagnosis took fourteen years.

I now attend the hospital every twelve to sixteen weeks to have my injections and have to make the 80 mile round trip from my home to Glasgow. I will have these injections for life, unless my immune system starts to work against them and they stop "working".

I found it very difficult to come to terms with the lifetime implications of dystonia.

The biggest factor of my dystonia is pain. I have not had a pain free day since October 2001. The injections help to lessen the severity of the spasms but my neck muscles never relax totally. The pain ranges from mild to excruciating. A good day is when I can go about the house doing little things and only need to take paracetamol. A bad day is when I have to sit in my recliner chair, not able to do very much at all and need very strong painkillers and perhaps diazepam to try and relax the muscles.

Apart from the pain, the physical disability of my dystonia affects every aspect of my life.

I had to take early retirement from a job I loved. I can no longer drive as I can't turn my head to the left and can't guarantee that I can keep it forward facing. I also lose feeling in my arms and hands. I don't sleep well as my muscles go into spasm the minute my head touches the pillow and my head also shakes from side to side. I wake up several times during the night to find I have no feeling in my arms and hands. I constantly bump into things as I can't see where I'm going. I find it difficult to walk. My legs are fine but when I walk my neck muscles go into painful spasms and I can get very dizzy. The blood vessels to the brain get restricted when my head is pulled to the right and interferes with the blood flow. I also have difficulty seeing in front of me. Shopping is a pain. I can only see to the right so have to go up **and** down each aisle in the supermarket. I always need someone to go with me. I am no longer able to do my own housework. Appointments at the hairdresser, dentist and optician are problematic.

Hobbies are also affected. Some, I can no longer do.....swimming, gardening, DIY, jigsaws and walking.

Others, I can do to some extent. I can knit small items, but it takes me ages as I have to constantly stop and get the feeling back into my fingers. I can "bake" shortbread. I mix it up in the mixer and my husband puts it in and out of the oven for me. I had to re-think my holidays. Travelling is a pain so I no longer make long car journeys to the continent. After much trial and error, my best option is to fly/cruise.

On the positive side, lots of good things have come out of my chronic, painful condition. My husband and I joined The Dystonia Society, through which we have met lots of lovely people and made some very good friends. We attend regular meetings and related conferences. We have Christmas lunches,

summer outings and also take part in raising awareness. My husband can now cook, shop and do housework! I have more time to spend with my grandchild. I have just recently applied for my "bus pass" and on my "good days" can make the short trip to town on my own - my first bit of independence in 6 years. We go on holiday much more often and are able to holiday during school term and so can take up special offers. I have learned to take each day as it comes and make the most of 'my good days'.

My cancer was easier than my dystonia.