

# Case Study

## Dystonia, what's that?

### **Andrew Russell writes:**

I recently had a diagnosis from a Dr. Warner, a neurologist and adviser to the Dystonia Society, at the Royal Free Hospital in leafy Hampstead, in north London. He told me clearly that I had a condition called dystonia (specifically myoclonic dystonia in my case) and that I had suffered from it for quite a period of time. Subsequently each person I told, from the family to people at work, reacted in the same way. As I mentioned the word 'dystonia' they looked puzzled and after a short while said, 'What's that?' It was my reaction too when I was first told.

This mystery disease had really started to make itself clearly known to me over the last three years. For me it was muscle spasms in my left side and the affected area centred in my head, neck and shoulder muscles. Very often having to hold my neck with my hand when talking to people I got tired of saying 'I have a bad neck and shoulder and am having a course of physiotherapy' or 'I've been to the osteopath and he is trying to get to the bottom of it'. My condition had effectively baffled all the people I had seen who had tried to deal with it. My GP had told me to take anti-inflammatories and suspected a trapped nerve in the neck; an orthopaedic consultant had decided the root cause was 'wear and tear' at the base of the neck; physiotherapists had worked on my posture and emphasised the importance of sitting up properly. At a recent visit one such therapist had said 'you will always have trouble with your neck and will just have to make the best of it'.

In the end, splitting up with my partner, who must have been somewhat exasperated at my struggle with my condition, proved the unexpected step I needed. Moving to a new area of London to share a house with my brother, I had to register at a new medical centre. During one of a number of visits there when I was off sick due to the headaches, grey hair, dizziness and problems with typing and writing I saw an Osteopathic centre opposite the surgery. Popping in I noticed that there was a visiting doctor specialising in musculo-skeletal medicine working with the osteopath who came in once a month to deal with 'acute and difficult cases'. On a hunch I booked an appointment with him. He examined me and ended with the words 'Eureka, I think we have a diagnosis'. He wouldn't say what it was but said I had a neurological problem. He sent a short letter to my new doctor who called me in for an examination. Shortly after this I was put forward as an emergency referral to the Neurology Department of the Royal Free Hospital. I was seen by a Senior Registrar who put forward a tentative diagnosis of

dystonia which two months later was fully confirmed by Dr. Warner. Creative thinking had saved the day!

During this process large pieces of my life's jigsaw fell into place after many years of not quite fitting together. I explained to Dr. Warner that I remembered my father always having a movement disorder. He had a continual body tremor and problems with his co-ordination and balance and often complained of a considerable amount of pain in his muscles. Yet whilst he was working the focus was fixed on his anxieties and bouts of severe depression which really developed during his middle life. These probably came out of his struggle with his condition. However I never heard anyone, his parents or my family, talk about his physical symptoms. Everyone was embarrassed by them. I do know now that he had tried to get life insurance when I was very young and this had always been refused and later doctors had suspected he may have been in the early stages of Parkinson's disease. My father was a very private man and deeply embarrassed by his physical condition and in those days the condition of dystonia was much less well known. I do not think his GP knew of such a condition.

During my visits to the Royal Free Hospital I started to think back and wonder when I got my first symptoms. Was it really just a few years ago? I had to admit to myself that even as a teenager I had a stiffness in the left side of my neck and shoulder but put it down to carrying a bag of newspapers over this shoulder. When I was stressed or excited or very tired I noticed a tremor in my body and aged sixteen and seventeen had noticed some difficulty in eating at the table as my arms muscles shook a little on my left side. I sometimes felt dizzy and tired and would have to lie down till it went off. All this was put down to 'nerves' by my GP and as I prepared to go to university in



1977 I was prescribed tranquillisers for this condition. This hid the symptoms and I continued to take this medication for over a decade – ironically it was the right medication for dystonia. Yet even on them by the mid 1980s I could still feel a restriction in my left side and a faint sensation of pins and needles in my left hand.

In 1989 I decided to come off the tranquillisers and immediately suffered muscle spasms, an increased tightness in my left side and difficulty in turning my head to the left. At the time I believed it to be the price of taking medication for a long period of time. I was so glad to be off the pills I was willing to put up with considerable discomfort and worked hard at easing it with walking, swimming, yoga and tai chi. I also had regular massage and periods of counselling for what I perceived as 'psychological stress'. My aromatherapist would tell me that at times I was 'banana shaped' with my left shoulder higher than the other and my head pulled to the left side. My counsellor noticed a tilt of my head to the left side, a slight limp and a white left hand. For over ten years I coped with this and then the strain on my body began to affect other things; my writing and balance and I found my head pulled and shook when I spoke to people making it difficult to concentrate on people's conversations.

Now I know it is a disability; one that I must accept, allow for and perhaps even embrace. One that needs treatment with drugs and botox injections to still spasming muscles and much more research to find an effective cure. Unanswered questions for myself and for my father have now been resolved. The only way is to move on, secure in the knowledge that scattered through the British Isles are officially over 40,000 other sufferers. That is a much better

figure than that of less than a hundred officially diagnosed in the early 1970s. My father suffered from this general ignorance and a great embarrassment of his condition. It would only be in 1985, the year of my father's early retirement, for the formation of the Dystonia Society to create an organisation that publicly recognised this condition and that people could turn to.

I have been luckier than my father, my condition is at least now diagnosed, but still only after perhaps twenty or more years of suffering with it. Given this I agree with the opinion that dystonia in its many forms probably still affects considerably more people even today's official statistics show. This must be partly because it can come on so slowly and is rarely recognised in its early stages. It is also an embarrassing condition which even when disabling may stop people from bringing it to the GP's notice. For myself and many others there will have been many attempts to flag up the symptoms with the doctor only to be told it was 'something else' - a neck or back problem or worse it is partly put down to nerves. To any 'problem patient' out there I say please persevere! Once a diagnosis is gained I now know that the Dystonia Society can quickly fill in any personal lack of information with their excellent helpline, well produced leaflets and informative videos. That and attending a local dystonia group quickly makes you feel connected with others who have the same condition and no longer alone with your diagnosis. Finally with local fundraising events and with each yearly dystonia awareness week more and more doctors and the public generally will become informed of this condition and subsequently more will not be saying 'Dystonia . . . what's that?' but 'Ah yes, I know what this condition is!'