

My story

The 'neck'

Judy Reeves is a 51 year old woman who has lived in London since 1966 when joining her family from the Caribbean. Here is her remarkable story of knowing something was seriously wrong and how, through painstaking research and self-diagnosis, she came to terms with what is likely to be spasmodic torticollis.



In 1981 when I was about 26 years old, I was in a bad relationship and had become homeless and unemployed. My world collapsed when the boyfriend I was living with decided he had found someone else and I was to move out. It was at this time that I first noticed my neck was involuntarily twitching and pulling to one side. It started with just a few twists and twitches. I wasn't sure what was happening.

Eventually my neck was becoming increasingly painful and I tried to compensate by stiffening up the muscles. I eventually went to my GP who was an elderly white haired gentleman with a dickie bow tie and very much of the old school. He didn't know what was wrong with me and said it was probably psychological. I was prescribed some valium and anti-inflammatory medication.

By then I was in a terrible state, emotionally as well as physically. I had just started a new job and wasn't entitled to sick pay or even time off. I remember the strain of travelling on a busy underground to get from Willesden to Euston and back, so I started taking a taxi to and from work. This was distressing since the money I earned each week was more or less spent on taxis. I would roll out of the taxi and tumble into the office each morning and collapse in floods of tears in front of bewildered colleagues.

Each trip to the GP resulted in different anti-depressants which did nothing for me at all. At night my head could not be stabilised on the pillow, it was twitching out of control and, consequently, so were my emotions.

I cannot recall every event in sequence but my GP sent me for physiotherapy at the local hospital; they didn't quite know how to help. They did things like throwing a ball at me and I had to catch it. Then I was given a soft collar which I felt only drew attention to my condition. I was given a hard collar which irritated my neck and people were noticing and enquiring what was wrong. If they asked me if I had a stiff neck that was fine. That was 'normal', everyone can relate to having a stiff neck. In a way the collars gave me a good explanation. Every time I went outside I felt that everyone was staring at me. Indeed some were, out of curiosity perhaps but it made me feel terrible.

One day I saw an advert at the back of the local newspaper for a woman who could heal all types of ailments, so I made an appointment and went to see her. Well, she asked me not to tell her what was wrong because she could 'see' – of course she could – it was a very physical thing! She told me that a member of my family had put a curse on me but she could help me. I needed to come back with £500 for the special candles and she would dispel the curse. I wasn't desperate enough not to be able to recognise a charlatan, preying on my vulnerabilities, when I saw one.

I continued with the GP sending me here, there, everywhere and giving me different medication on each visit. He kept telling me my problem was psychological and I kept saying that I would be happy to have psychological treatment. Eventually he referred me to

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a psychiatric doctor who asked me if I was taking drugs (recreational ones). The answer to this was an emphatic no! She too was baffled by my condition but offered to find me a counsellor who could see me in about 6 weeks time.

At that point I thought I couldn't wait that long. Who knew anyway if it was going to help? I had accumulated most of the tablets the GP had prescribed so I took them with large swigs of whisky from my

My story *continued*

sister-in-laws drinks cabinet. I fell into a deep sleep on the sofa and suddenly woke up being violently sick. Next morning the GP was called. In his patronising manner he wanted to know what I had 'done last night.' He wrote the name of the psychiatric hospital and told my brother to take me there.

I stayed there for three years as a voluntary patient on the psychotherapy unit. Somewhere along the line I saw a neurologist who backed up what everyone else had said that it was not a physical problem but a psychological one. I was told that the talking therapy would, apparently, be the best thing for me.

I found asylum in the hospital and felt safe among people who shared something in common with me. My stay also gave me the time to do my own research. No one had ever mentioned to me what the name of my condition was but I had found the exact symptoms which I was experiencing in a medical book so I knew what it was called – spasmodic torticollis.

Eventually the psychotherapy unit closed down and I left and started my own rehabilitation back into the community. I was managing fairly well with 'the neck' as I call it.

I have had some really low bad points with 'the neck'. I have little confidence in myself, low self image/esteem which perhaps were there anyway but worsened by the constant struggle to hide my dystonia. I constantly feel that people are staring at me because I look odd. There was a long period of time when I became

almost house bound had it not been for work. I have been to healing sessions at a church with a friend who thought it would help. I also tried to turn to God and started going to the church every Sunday.

My dystonia is a lot more stable at present, but tiredness, stress, and anxiety effects how well I'm doing on any given day. In my current job, I have recently been referred to see the occupational doctor because there are tasks I am required to do and I am not able to do them.



I had not realised until recently that help, support and treatment were available. One day on the internet, I happened to type the words 'spasmodic torticollis' into a search engine just to see what my manager would find if she looked it up. There were hundreds of entries. It has felt like a very lonely road until now. I had no one to talk to who had the same or similar experience. I have felt like a freak of nature.

My emotions are mixed at the moment. I am glad to have found a possible way of getting some treatment and being relieved of 'the neck' but at the same time I feel angry about being left to get on with it because it was 'psychological.'

FOOTNOTE: Since writing this article, Judy has had her first set of botulinum toxin injections.

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For more information about spasmodic torticollis, or if you have any other questions about dystonia, call our

HELPLINE

0845 458 6322

or visit our website:
www.dystonia.org.uk

