

My story

Jamie soldiers on...

For the past five years, Jamie Gordon and his young family have lived in Germany where he is currently the Head of News and Information for the British Forces Broadcasting Service. He talks candidly to Dystonia matters! about how dystonia has affected his life and the treatment provided by the German health service.

I don't remember when my condition became apparent. I had suffered a reasonable amount of anxiety in the past, mostly brought on by the sudden death of my mother. The panic attacks and general high levels of stress seemed to produce virtually every known symptom in the book. Why should an awkward head position not be included to the list?

Like most people with cervical dystonia it was those close to me that started commenting on the strange positions I would get into when driving or simply sitting down. The constant craning in my neck was uncomfortable more than painful and for a long time, probably almost two years, I accepted it as part of the larger complexities of anxiety.

Slowly I began to resent my neck even more. As I began to shed some of the other symptoms it was this that caused me the greatest distress. I could not understand why the most recent of these symptoms wasn't going away when I started to win the anxiety battle.

Driving became something I dreaded and at times I wondered if I was legal. My head would be cranked over to the right and invariably I used my right hand, elbow resting on the window ledge to support my head. There was a backward rotation as well which must have meant I was looking at the road almost askance at times. It was the only way I could feel any degree of comfort. Of course the additional stress I had about driving because of my posture only exacerbated the problem. My wife would mention it, almost critically, and that made me even more conscious of it. Of course at the time neither of us knew the true cause.



I am a radio presenter by profession. For the past 5 years my young family and I have lived in Germany working for the *British Forces Broadcasting Service* (BFBS). I am 38 years old and have been with BFBS for most of the last 21 years. I'm currently

the Head of News and Information and lead a small team of reporters whose job it is to go out and meet serving soldiers and their families. We are there to help promote all aspects of service life in Germany whether that means plugging the local garrison fair or interviewing the most senior officers about the implications of a deployment to Iraq.

It's a hugely satisfying job that gets to the heart of our audience. Prior to the news job I was, and still am, a DJ at heart. I sit in a small room, talk into a microphone and play music. It's an intimate position to be in but has the advantage of being mostly anonymous. Nobody can see you most of the time but of course guests do come into the studio and see what you're really like, apparently I sound taller on the radio.

When strangers enter your little world it can be an unnerving experience. Many presenters I know are essentially shy individuals, myself included, and although our job is very much being involved with our audience and meeting new people there's usually a sense of self-consciousness.

When you can't keep your head up or facing forward that feeling turns into inadequacy and embarrassment. It gets worse if you find yourself in amongst a group of people you don't know, the trouble is most of them know you because you're on the radio. You are thinking 'they must assume I am really strange because I am giving them the impression of trying to look around the back of them'. It's an odd feeling.

My story *continued*

I knew I wasn't as badly off as some. My condition paled into insignificance compared to people with facial disfigurement, chronic disease and any other condition that makes someone stand out. I just had a dodgy neck but it made me miserable.

Of course I developed the usual tricks associated with cervical dystonia to deflect people's attention and to relieve the discomfort. A good strong grip on the back of my neck with a bit of a rub would send out the signal that it'd been a hard day. Stroking the chin was a useful one, generally touching my face helped and propping my head up whilst at a table would also be a more bearable posture than trying to sit up straight and look ahead.

I still didn't know what was wrong although as I've mentioned I thought I did. Of course I talked about it with my doctor and there was consensus, it probably was anxiety related and when that was sorted the neck would improve. About two years ago I finally managed to resolve all the issues of anxiety but still the neck was a problem. I now slept on my back with my head turned to the right; it was the only position in which I could sleep.

My breakthrough came after my doctor at the military medical centre referred me to the physio. I had four sessions that included quite hefty manipulation and acupuncture, which was interesting! Eventually the physio, after yet another attempt at removing my head from my shoulders, calmly told me he was having no effect and he thought I might be suffering from spasmodic torticollis. He then started talking about botulinum toxin injections and I came away a little bemused. The physio then referred me back to the doctor for further non-physio based treatment.

Within the British Forces in Germany more intensive treatment is provided by the German health service. As a civilian within the military community the bureaucracy can be daunting.

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Article by Jamie Gordon

As luck would have it my GP was due to attend a conference at the Gilead hospital in Bielefeld where a consultant neurologist by the name of Dr Bonse was due to speak. He's the man with the botulinum toxin treatment in Bielefeld and is very good at using it.

I've now had 4 courses of treatment and I am lucky that the medical insurance BFBS provides here has covered the payment. Once a quarter I have to see a German GP who then provides a referral, which I then take to Dr Bonse. He then whips his thinnest needles out and carefully, occasionally painfully, treats my neck. A week to two weeks later the slow degradation of the treatment's effect is renewed. As I write I can feel that I need to go back in February or March but I am looking straight at this screen and tomorrow morning's drive to work will involve me looking straight ahead at the road.

I am always aware of it though. Don't get me wrong, the medication works beautifully but I know I have this condition and occasionally it still trips me up. A stressful meeting or a strange situation can trigger a faint but observable twist of the head. However the difference the treatment has made to my day to day standard of life is amazing. Unless I leave the injections too long I have a good four months of relative normality. I can go out and meet people with a degree of confidence that was impossible 18 months ago. I drive correctly, I sleep more comfortably and I don't worry about how I appear to people, although some would beg to differ.

At the moment I am fortunate to receive the treatment I need in Germany. The Dystonia Society work in the UK is vital in the face of some bizarre decisions by funders to restrict botulinum toxin treatment. Here's hoping those who hold the cash can hold their heads high because without these injections, some of us don't have that basic right.