

Derek Thompson

Speaks about his dystonia...

For years Derek Thompson, the Casualty star, tried to hide the fact he suffered from dystonia, a neurological disorder which caused his neck and head to spasm. Here, Derek, 58, who lives with his partner, Sue, and their son, Charlie, 17, in Bristol, talks for the first time about the disease and how treatment saved his career.



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For 20 years I have played Charlie Fairhead, the much loved charge nurse in BBC1's Casualty, who is so good at getting his patients to open up to him. Yet when I found myself suffering baffling and painful symptoms, it was more than two years before I sought medical help. In the meantime I tormented myself with fears that, like my mother, I was suffering from Parkinson's disease.

I was a sickly child, always ill with pneumonia and asthma, and grew into an adult obsessed with fitness. That stood me in good stead in my career, especially with the hectic filming schedule on Casualty. But about five years ago, I was on a short break in Spain when I woke up one morning

feeling strange – my neck was twitching, which was causing my whole head to nod.

What I didn't know then was that though the movement felt almost violent, it didn't appear like that to anyone else. I look back now and think how curious that I didn't find it scary. Eventually, it eased off and I went down to breakfast. Then, towards the end of the day, when I was tired, it started up again and carried on until I went to bed. I was ready for the twitching to present itself again the next morning, but it had gone.

Back on the set a couple of weeks later, I noticed that whenever I was tired, I would get really vicious cramps in my neck, as if I'd wrenched a muscle. I'd suffered whiplash in a car accident 16 years ago and assumed the neck problem was linked to this, as well as to age and physical deterioration.

Over the next year, I suffered the odd bout of head tremors, which were more annoying than painful. But what was much more tedious was the dull pain of frequent neck cramps – at the most inconvenient times and nearly always when I was working and under pressure. Though the tremors were hardly visible to the observer, things became much worse shortly after my mother died three years ago, at the age of 81, from pneumonia.

It was a stressful time for me and I developed major tremors and sudden, uncontrollable movements of my head, as if I was nodding from side to side. They could last for several hours, but at other times they would be more transient. The spasms felt really dreadful because of my inability to do anything other than simply wait for the episode to pass.

I thought I had Parkinson's, but rather than doing anything about it, I was in denial. I wouldn't face up to what was happening or let anyone know about it. I was good at disguising the movement and would pass it off, yet again, as the old whiplash injury. I thought I would tough it out until the day I found myself knocking on the Parkinson's specialist's door.



The silly thing was that I was surrounded by the medical advisers to the show – I now know it wouldn't have taken them long to rule out Parkinson's. Then, and I don't know why, I suddenly told my father I was having severe tremors in my neck and head and it must be Parkinson's. He told me

to seek a proper diagnosis, and so in 2003,

I was referred to a neurologist. He put me through 15 minutes of tests, such as standing on one leg and waving my arms about, and hand and eye co-ordination tests. He announced I had dystonia, explaining that it is caused by a malfunction of messages from the basal ganglia, the area of the brain that controls movement.



Derek Thompson *continued*

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While it's not clear why it happens, it normally strikes in the 30's or 40's when it is localised. There are various forms, including laryngeal dystonia, which affects the vocal cords and makes the voice 'strangled', and blepharospasm, which causes the eyelids to shut tight, effectively blinding sufferers.

Focal dystonia of the neck is most common in the over 40's; while the muscle spasms aren't permanent, they can sometimes last for hours at a time. In 30 per cent of sufferers, the spasms can spread into adjoining muscles, but I would have to wait and see. The good news was that it was benign – I wouldn't die of it. I was told the only viable treatment is injections of botulinum toxin to 'paralyse' the muscle so it doesn't spasm, but my condition wasn't acute enough to need it. I went away happy. For the next couple of years, I adapted to the condition, though things gradually got worse. Everyday life was fine, but work was a different story.

Close ups were difficult; I could hold a particular position for the camera, but if, say, lighting dictated I had to turn in the opposite direction, the movement could be awkward and I would end up with my chin jutting up at a strange angle.

Of course, my family knew about the condition, but I simply told colleagues I had a neck injury and couldn't do certain movements. I had good days, when the symptoms were muted, and then there were the bad days, when I was stressed and fatigued – towards the end of shooting, my neck would completely lock up.

The most stomach churning moments were when I watched the programme and could see how my performance had been affected by the dystonia. Once, I had a long speech to deliver, but towards the end my voice lost its way because I had been concentrating on trying to control my neck. I'd been taught coping mechanisms. Placing a finger on the chin or the cheeks plays a sensory trick on the brain. Such gestures interrupt the inappropriate messages being sent to the muscles from the basal ganglia and momentarily stop the spasms and tremors.

At first, it was a novelty. It annoyed me, but I channelled that annoyance into the performance. But it moved from being a challenge to a struggle. I'm an optimistic person and never envisaged the moment when I might have to give up acting, but my patience was wearing thin. I'd never admitted what a burden it was keeping this secret from so many people, but when I spoke to someone on the Dystonia Society helpline I felt the weight being lifted off my shoulders.

I went to see Professor Kailash Bhatia at the Institute of Neurology, who thought I would be a good candidate for botulinum toxin. I had my first course a year ago,

'It was more than two years before I sought medical help'

five tiny jabs in the neck muscles using a long, thin needle. 'Is that it?' I thought. But over the next week the effects were profound. Every day was a good day. I could move my neck freely and only when I was very tired was there a twinge of cramping.

Towards the end of each three month cycle, the cramps increase, but even then I am 70 per cent better than before the injections. I'd forgotten what it felt like to have easy movement and to be free of the nagging pain.

Thanks to the Dystonia Society, I've learned a lot more about the illness and last weekend at their AGM they made me patron. I am speaking out about it for the first time because I want to increase awareness of this debilitating condition. I am lucky BTX is particularly beneficial to my kind of dystonia – it is very difficult to inject the vocal cords in those suffering from laryngeal dystonia, for instance. For the worst affected, deep brain stimulation may be the answer. An implanted pulse generator, similar to a heart pacemaker, sends electrical currents through electrodes in the brain. These block the signals causing the disabling symptoms.

Dystonia is often misdiagnosed: some GPs refer patients to physiotherapists or osteopaths – which can be harmful. Others have even been sent to psychiatrists. This condition may not be fatal, but those severely affected often have to give up work and their quality of life is impaired. I was worried that BTX may become ineffective over time, but Prof. Bhatia has a patient who has been successfully treated with it for 15 years. Botulinum has been fantastic for me – I can only compare it to getting movement back in a paralysed limb. I can't deny this treatment may have saved my acting career.