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.

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.

‘I can’t deny this treatment may have saved my acting career’
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, 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.

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.

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 Society Helpline: 0845 458 6322 www.dystonia.org.uk