

My story

What a difference!

Following the intervention of the Dystonia Society, Alan Jones from Rugeley, Staffordshire finally won funding from his local Primary Care Trust. This funding was for his DBS operation, which has enabled him to start to cope with decades of distress and suffering which was brought about by generalised dystonia.



● Alan Jones

At the age of four I had a slight limp in my right foot which was very painful. At the time it was said I was too idle to exercise, which was a familiar story. My doctor sent me for physiotherapy, which did more harm than good. I couldn't explain the amount of pain I had in all my joints, particularly in my back. This continued for about 17 years until my condition got worse. I suffered memory loss and had problems with remembering where I had left things. Also, at the time, my mum and dad divorced – looking back, I put this down to thinking it was my fault for having this condition.

My school years were the worst. The kids at school took every opportunity to call me names and push me around, just because they felt I was different. After leaving school, I started as a welder in a local firm but this had to finish when I was told that my disability may cause harm to myself or others. My hands had started to shake slightly when the job required me to keep still all the time.

As time went by I began to get used to being a recluse. I did venture out after a day of feeling really sorry for myself and that's when my world took a turn for the better because I met my wife. A year or so after that first meeting I explained what I felt was wrong with me but she said she didn't care as it was me she wanted. So we got married in 1979. Two years later, my wife gave birth to our daughter, who is now 28 years old.

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In 1984 I was sent to London to see Professor Marsden who diagnosed generalised dystonia. To have answers about the cause of my pain and movements was in some ways a relief for my wife and me. But we had a daughter now and suddenly we were being told that she might have the gene that caused my condition. At that time there was a 50% chance of having the gene and, thankfully, tests showed my daughter didn't have it, but we didn't want to take any further risks so I decided to have a vasectomy.

Following this, my wife and I went through a rocky patch in our marriage. Looking back, I realised it was my fault. However, rather than her having had enough of me, it had the opposite effect and she helped lift the dark cloud that hung over me.

We decided to move home to sort our lives out. Now we have an extended family with my son-in-law and grandchildren, aged eight and three and they keep us all busy.

Three years ago, we heard about deep brain stimulation and went to see Professor Aziz at Oxford, who thought I could benefit from this type of surgery. An application was made to the PCT for funding but they turned me down. This was despite the fact I was often taking higher than the recommended dose of drugs to control my spasm and pain. My generalised dystonia affected my speech, neck, back and legs, causing involuntary movement and painful spasms.

The Dystonia Society got involved after my wife contacted them and, after two years, the PCT finally agreed to fund the operation. Thanks to the Dystonia Society and my wife (yes, we still are married!) I was admitted to the John Radcliffe Hospital on the 7 April and had the operation the day after.

Wow, what a difference! No more pain. I am able to stand upright for the first time in over 20 years. The movement is just magical. You cannot imagine how my life has changed. To cap it all, I have enrolled for an IT course at my local college, which starts in September.