

Another member's experience

Keith Hall from Sheffield writes:

I started with dystonia in about 1984, when my head began to move very slightly. I was given different types of drugs, then taken into hospital for a week where I was tried on another drug, but all it did was make me sleep. Fortunately the symptoms just seemed to go away on their own. I was going through a bad time with my first marriage so just thought it was stress related.

After about six years my symptoms came back with a vengeance. My GP gave me painkillers and referred me to my local hospital. When I realised I would have to wait six months for an appointment, I decided to pay to see a specialist, who told me I had spondylitis and that nothing could be done. I also went to see a chiropractor, who cracked my neck, which I wouldn't recommend to anyone. My head was now moving from side to side quite badly. I kept my appointment at the hospital, where Professor Saga diagnosed torticollis and I started on botulinum toxin from that date.

I was having injections every three months. They stopped the pain, but not the movement in my neck, and sometimes affected my swallowing. While having botulinum toxin I was also trying different kinds of drugs, none of which worked in my case. All this time I was having problems sleeping, as I couldn't get into a comfortable position because of the movement in my neck.

In 2000 I started to lean over to my right hand side. It was only slight at first, but over the next 12 months it gradually got worse. I was now leaning to about a 45-degree angle. Walking became a real problem and, as you can imagine,

work was getting very hard. Then, while on holiday, I heard by chance of Deep Brain Stimulation. On my return I went to my Dystonia Clinic and asked if there was any chance of having DBS. The doctor didn't even look up from his notes and just said that there was no funding for this type of surgery in Sheffield. This hit me hard and I became very depressed, so I decided to pay for the surgery myself. I went back to the hospital and asked to be referred to someone who could carry out the surgery. I was referred to Professor Aziz in Oxford, who said that I would be an ideal candidate for DBS if I could raise around £20,000.

I was back at work on light duties; I had a computer and a phone in the office and was more or less left to my own devices. I wrote to every football club in the Premiership, most supermarkets in my local area and any other contact I could think of. I then organised a disco and auction at the company's sports club, where we raised over £5,000. It was a very emotional night for me and I can't thank my family and work colleagues enough.

The company I work for had agreed to fund two thirds of the cost of the operation, so I was even more determined to raise the rest. My next fundraiser was a race night, which raised nearly £3,000. With the funds in place it was just a case of arranging for the follow up surgery to be funded by the NHS. By mid May everything was in place and in June 2002 my wife and I went to Oxford, where I was to undergo DBS. I had my first operation on Wednesday 5th June, when the Professor inserted two electrodes in to my brain. I was pain free as soon as I woke up from the operation. A week later I had another operation to implant the stimulator (battery) into my chest and was back at work within five months.

After a few adjustments I was starting to see some improvement, but I bumped my head at work and broke a wire in my head. I was due at a dystonia conference in Hull and Professor Aziz was also there. He told me that he had pencilled me in for a revision, so it was off down to London for more surgery. Everything in my head was replaced and a metal plate inserted to keep the wires in place.

In March of 2004 my wife and I went on a Caribbean cruise and, on the first day aboard, I walked through a security scanner which I hadn't realised was there. This (unbeknown to me) switched off my stimulator. I was fine while on holiday but my symptoms started to return when I got back. I went along to see my surgeon and he switched my stimulator back on. About a month later my system stopped altogether. The surgeon decided that the system



Keith Hall, centre, at the House of Commons with his MP, Meg Munn, and Dr Stephen Ladyman, then at the Ministry of Health

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needed to be replaced so, after some arguments over funding, I was back in hospital, where the battery was replaced. I know that I will probably need more surgery but, hopefully, it will be just to replace my battery again. I am now relatively pain free, but still lean over quite a lot and find walking long distances hard. However, I have been honoured to meet a lot of people who I consider would benefit from this operation and I would like to think

that I could help them if I can. I have been to places I could never have dreamt of going to and would like to thank the Dystonia Society for inviting me to their 20th anniversary celebrations at St. James's Palace last year. Also thanks to my MP for arranging our meeting with the Health Minister and our visit to the House of Commons earlier this year.