

# My story

## *I've been given back my life...*

*Jo Noble, 39, a marketing manager from London, outlines her encouraging story after undergoing DBS in October last year.*

My first memories of dystonia are from when I was 10.

Suddenly I developed writer's cramp. I am by birth a left hander but writing became incredibly painful and uncomfortable – my writing was jerky and tense and just keeping the pen on the paper was a problem. By the age of 12, I thought 'I've had enough of this' and started writing in my right hand. It was surprisingly easy to switch and at first my writing flowed. However after a year I developed writer's cramp in my right hand, plus my left hand had deteriorated too. Now, everyday skills like putting on make-up or drinking soup were becoming increasingly difficult, so I transferred these skills and others to my right hand too.

At this time we went to my GP but unfortunately he didn't realise I had a neurological condition and simply gave me sleeping pills and told me to 'work hard, play hard and it will all go away'. Well it didn't, and I spent the rest of my teens wondering what on earth was going on with my body. I thought I was a freak because it wasn't a medical condition – my GP had said so. So when at 17 my dystonia started affecting my legs and suddenly I couldn't walk normally anymore, I was devastated, scared and confused. I turned to alternative therapy and tried loads of treatments – hypnotherapy, bio-feedback, reiki, homeopathy, acupuncture etc but nothing helped.



● *Holidaying in Peru at Machu Picchu*

Then when I was 21 my GP retired and I visited my new GP. Thankfully he realised that I had a neurological condition and referred me to *The National Hospital* in Queens Square. Finally dystonia was diagnosed – only 11 years after my first symptoms.

I was put on various pills but nothing helped, however I carried on living a 'normal' life. Of course I cried many tears and I did have my down days but I got myself a career job in central London and went backpacking around the world for 2 years when I was 23. Don't get me wrong, life wasn't easy, in fact a simple thing like walking from the station to the office was a real trauma, not just because of the pain and discomfort but also because I was so self-conscious of my bizarre gait. I'll never forget the curious and rude stares of passers by.

Because none of the pills were working I decided to go off radar from the hospital and carry on life as best I could. However at 29 my dystonia had moved into my neck and I knew it was time to revisit *The National*. At first I just had trouble nodding but slowly the dystonia took hold – I developed an intense pull to the left and it became really painful trying to keep it fixed in one position. It made socialising and working very stressful and embarrassing. Meanwhile I had also developed a tremor so basically I couldn't sit or stand still. My body was constantly on the move. One kind soul once asked me rudely to 'stop shaking in my seat because it was driving HER mad!'

The hospital gave me regular botulinum toxin injections in my neck but they never worked adequately – they helped with the pain but never the pull, or I had severe head drop. There was no middle ground. At this time the hospital had suggested DBS but I was convinced there were other, less-drastic options open to me. It took me another 3 – 4 years to decide to go for it. I was mentally and physically tired of the constant struggle to just do normal things. Life was a trudge and I'd had enough. Plus I wondered just how much worse I'd get if I didn't have the op, as it was my walking had become more laboured, and my neck and tremors were getting worse. I knew the time had come to do something about it. I used to say that I'd made a decision but I didn't have a choice and in October 2006, I had my DBS op. I couldn't have gone through the stress and trauma of brain surgery without the love and support of my family and friends for which I'll be forever grateful.

*"Now the only tears I cry are for joy, relief and intense gratitude for the skill of my surgeon and his team".*

## My story *continued*



- *A photo taken before my operation at The National Hospital for Neurology and Neurosurgery in London.*

left hand but that's not important to me. Basically my body is now relaxed and calm and I'm so much happier in myself.

My friends call me the bionic woman and are delighted that I can now carry drinks in both hands from the bar without spilling anything! I really do have to remind myself just how difficult everyday life was before the op and even now I'm still overwhelmed when I think how much I've improved. I feel like one of those Duracell bunnies, only this girl is powered by Medtronic!

Now the only tears I cry are for joy, relief and intense gratitude for the skill and expertise of my surgeon Prof Marwan Hariz and his team, and my neurologist Dr Steve Tisch at *The National* who have given me back my life and allowed me to function normally again.

*...all I can say is 'watch out world'!*

I was so scared about the op, my strategy was to keep myself insanely busy for months beforehand. Thankfully it worked.

It's now nearly a year since my op and life is so much easier and more relaxed than before. My neck is now 100% perfect, the tremor has eased and walking, at a moderate pace, is normal too – no more wheelchairs at airports. I have much more control and function in my left hand and my writing has improved too. I still can't write with my