

My story

Brave trail blazer

In October 2000, aged 7, Lucie Armstrong became the first child to undergo the operation for Deep Brain Stimulation (DBS) at a UK hospital. We talk to her mother, Samantha Armstrong, about how Lucie, now aged 17, has coped with dystonia, the operation and its aftermath.



● Lucie Armstrong

“Lucie developed idiopathic generalized dystonia in the early years of her life, but at the time we didn’t realise. She was our first child – and you don’t really know what to expect – but we began to notice a few problems during Lucie’s first year of life in 1993. She found eating difficult, her speech development didn’t go smoothly and toilet training seemed very difficult.

At the time, we didn’t link any of this together. We saw different consultants for each problem – but no-one realised that all these seemingly separate problems were linked to muscular control. We’d never heard of dystonia and certainly didn’t understand that Lucie’s tongue was going into spasm, which caused problems with eating and forming of words.

As Lucie turned three, we noticed she was becoming quite clumsy and frequently falling over. Her left foot was starting to turn in when she moved and gradually she started dragging it. By four years Lucie’s other foot had turned in. She became unable to walk – and it began to spread into her arms, affecting her hands. When she ate, for example, she couldn’t control her spoon and the food would go down her front. Although she’d started school, she was having lots of toilet accidents and after about a year, the muscle spasms spread into her neck so it was constantly in a very painful spasm and she had to lie down a lot of the time. Getting to sleep was a terrible struggle.

During this period, we’d been going from one paediatric consultant to the next. Nothing was diagnosed, although one consultant suggested she had cerebral palsy. As parents, we were constantly researching to find out who had the expertise and experience to help her. We moved hospitals from Derby, where we live, to Birmingham, Nottingham and then onto Oxford. Lucie tried many different drugs, had several scans and MRIs, was told she had epilepsy and was seen by psychologists – all to no avail.

We were eventually given a diagnosis of dopa-responsive dystonia when Lucie was nearly 7 years old. It wasn’t the type she ultimately had, but it put us on the right track. Lucie was given a drug to try to lessen the symptoms, and although it didn’t work, it did lead us to our neurologist Professor Tipu Aziz at the John Radcliffe Hospital, Oxford.

We’d heard about Deep Brain Stimulation (DBS) but didn’t know if Lucie was able to have the operation as she was young

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at 7 years old but by the time we came to meet Professor Aziz, Lucie was so severely disabled we couldn’t feed her and could hardly move her. She was in so much pain that the bed and sofa were too uncomfortable, so she slept on a bed on the floor. I would try to get spoonfuls of food into her whenever I could, but she could hardly swallow – her weight had plummeted to 15kg and she was dehydrated.

It was a miserable period. We had a week’s assessment for DBS at the Radcliffe and to be honest, Lucie was so ill by this time that I almost didn’t want her to have to go through with the operation. I was so incredibly tired that I almost lost sight of what was happening. It was a very bleak, miserable time.

The DBS surgery took place when she was seven. She was the first child the team had operated on, the only child in the UK and the youngest in the world, so she was very much a guinea pig. It was nerve-wracking but we’d been well-prepared by the team. The operation lasted about 5 hours and when they switched on the stimulator, we knew instantly that it had been a success. Her body was more relaxed, her fingers unclenched and within 6 weeks she was walking. It was fantastic.”

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My story (continued)

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“We’ve had a lot of down-times since then, as well as up-times. About eight months after the operation, one of the wires in her brain became dislodged which necessitated another operation. After that she got an infection, which made her so ill she almost died. She’s had the DBS taken out of her head a number of times, four battery failures and the skin at the wound site has failed to heal. And whenever one of these problems has occurred, all her dystonia symptoms have come back.

Lucie’s now been operation free for the past two years and has a state-of-the-art rechargeable battery which so far has been problem free. She’s in a wheelchair as she had to have surgery due to the spasms pulling out her hip joint (although we hope she will be walking again one day), but her eating is good - she’s slow, but she feeds herself and her bladder control has improved. Speech has always been a bit of a problem – the more stimulation of the implant, the more slurred her speech is but she can generally make herself understood.

It’s been hard work. The phrase, ‘He who shouts loudest has never been more true but it’s been worth it for Lucie. She now has a life she can live for herself. She’s in her last year of secondary school and we’re hoping she’ll go to college to learn independent living skills. Her wheelchair is powered so she has her own independence and we all go skiing together; we have an adaptive ski that she sits on and she loves it.

I do feel sad about the social impact. Lucie has friends, but probably not as many as other teenagers her age. It’s hard not to feel she’s been left out. But she never complains. She’s happy most of the time and last year she won the Princess Diana Memorial Award for her ability to improve the lives of others and overcome adversity. It’s not the first award that she has won and it won’t be the last – she’s here to stay and enjoy her life.”

To obtain the above leaflet about DBS, please visit our website: www.dystonia.org.uk or call our helpline: 0845 458 6322

