

My story

Stepping forward



In January 2009, Lucy Russell successfully underwent deep brain stimulation (DBS) and now has a rechargeable battery that can be charged from outside the body. Her mother, Nicola, tells us what happened.

“Until she was 6, Lucy was a perfectly healthy active little girl who loved dancing and playing with her friends. But in February 2008, we noticed that as she walked, she was kicking her right

- Lucy Russell leads the cheers

foot out. We thought she may have twisted it, but when we took her to the doctor, he just said it was in her head and we should ignore it.

However, Lucy seemed to be getting clumsier. Sometimes she'd be walking or running, and she'd just fall down. It wasn't like her at all. When she began dragging her right foot, I started to get really worried. The hospital did X-rays and we were referred to a neurologist for MRI scans. But by this time it had spread to her left leg which, when she was sitting or lying down, began to kick up into the air. Her left hand also began to be affected and walking and movement started to be such a problem that we began using a wheelchair.

Lucy had some blood tests and when the results came back, the doctor told us it might be dystonia. He said there were lots of different types but he thought it was dopa-responsive dystonia. Lucy was prescribed Sinemet Plus, but by the time we were realising it wasn't working, a different blood test had shown that Lucy had early-onset torsion dystonia. Lucy had been a very lively little girl – and suddenly it all had to stop.

It was very hard. I used to think she was taking it in her stride, but although she dealt with it very well, I realised later it had been getting to her. She'd sometimes get very upset because she couldn't join in with her friends. But her school was fantastic – when Lucy started using a wheelchair, they moved the classroom onto the ground floor so there was minimum disruption for Lucy and everything was accessible.

After her diagnosis, Lucy was given Trihexyphenidyl to try to control the spasms. We'd already found out about DBS and when we were told it could help her, we were referred to the Evelina Children's Hospital. Four months after the diagnosis, Lucy had the operation. I know now that we were lucky and Lucy had a very fast turn-around from the time of her first symptom to when her operation took place – but at the time, we were so worried, it felt like it was really dragging on.

I was a wreck during the six hour operation. I didn't know if it was going to work or whether there would be complications, but as soon as Lucy came round, it was like a huge weight off my shoulders. When her battery was switched on, although her symptoms were still there, it was obvious that they weren't as severe. Before the operation, her left leg kicked up into the air so much that she had to hold it down – sometimes she tucked it under her other leg. After the operation, her leg still kicked up, but day by day, you could see it getting lower and lower.

Just a few days after the surgery, Lucy took a few steps up and down the ward. It was amazing as before, she'd been so bent over she couldn't stand straight. She still doesn't walk perfectly – she sometimes drags her left foot, but she's out of the wheelchair and she's so much better than she was.”

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