



Luke – Dystonia (and mum Julie)

Like most 18 year olds, Luke likes nothing better than kicking a footy around with his mates, or riding his bike.

What makes this remarkable is that all these sorts of activities were simply impossible for Luke until just recently, when Luke underwent deep brain stimulation. This therapy has freed him from the symptoms of dystonia that wracked his body and left him wheelchair bound from the age of six.

“Two days after they turned the stimulator on, I could really feel the difference. I walked over into the park,” Luke recalls.

“The day after that, I was able to kick a footy.

“About two and a half months later my mate brought his bike over and I decided to give it a go. I rode it right up the road. Mum was looking out the window and she saw me go past. She was so shocked!”

Luke was a healthy, happy little boy until the age of six. Then he began to complain of aching in his legs and started falling over. He had a cold that didn't respond to three courses of antibiotics and his voice became croaky. His parents Julie and Ian took him to visit various specialists – ear, nose and throat, speech pathology, orthopaedic – but no-one could give a diagnosis and Luke's symptoms continued to worsen. Finally an orthopaedic specialist suggested that Luke may have a brain tumour and he was immediately referred to a neurologist.

While a brain tumour was quickly discounted, the true cause of Luke's problems took longer to pinpoint.

Julie, herself a nurse, remembers: “It took around three months until we got a real diagnosis. I kept getting mixed up because the doctor would say ‘he's got dystonia’. I knew he had dystonia because I knew of it as a symptom of something else. We'd never heard of dystonia as a disorder in itself.”

Meanwhile, diagnosis or not, Luke's condition wasn't improving.

“He kept getting worse. I was pregnant with my fourth child and carrying Luke every day back and forth. He was falling over and his legs were twisting – he was in a lot of pain. At night, he would lie in bed and cry.

“We got a wheelchair for him the day before my daughter was born.”

About 18 months after the symptoms first began, Luke's dystonia became even more severe and he was admitted to hospital to trial some medication.

“He was in for eight weeks and he just went downhill. He went from being unable to feed himself to not eating at all so he had to have a naso-gastric tube. He couldn't do anything for himself at all.

“It was awful, I thought he was going to die. He was just fading away really.

“In the end he seemed to get a little bit better and we just said ‘we want to take him home’. Over the next year he really improved. We bought a van with a wheelchair lift and knuckled down to getting used to it.”

As time went on Julie and Ian continued to research possible treatment options for Luke.

“We looked at different things. We went to a symposium in Canada about six years ago and they were just starting to talk about deep brain stimulation. It was being done in France and a few places in America, but it was early days.

"Then, three years ago, the son of a friend who lives in Chicago had the surgery. It took 20 hours – I still don't know why. He had a stroke between the two surgeries. He was okay afterwards, but his parents didn't feel the benefit had been worth everything that they'd gone through. This was only three or four months afterwards so he was probably still at the stage where they were getting used to it. Anyway, we put the idea on the backburner."

It wasn't until Christmas 2004, when Julie and Ian heard of a Sydney family who were raising money so that their daughter could travel to France for DBS, that they revisited the idea.

"It got us thinking about it again. So we got on the internet and started emailing and ringing doctors around the world. We thought we'd go to London, France, Chicago or San Francisco.

"I looked up the dystonia research website and there was a Perth neurologist listed as a contact in Australia. We thought we should go and see him, in order to get Luke referred somewhere overseas.

"He said 'why are you going overseas? We can do it here.'

"The whole idea of being able to have it here and have the support of friends and family was such a relief. It would have been such a huge thing to go overseas because we had thought we would probably need to take the whole family, get jobs and housing and stay six to twelve months while Luke was stabilised, maybe in a country where we couldn't speak the language."

Luke underwent the first stage of the procedure in May 2005, which consisted of surgery to insert the leads into a specific target in his brain. The surgery took six hours and he had no major problems. He was drowsy for two days and spent those first two days in high dependency care. All he had was a slight headache.

Luke completed the second stage of the surgery one week later on his 18th birthday. His stimulator was switched on three weeks later. Julie recalls that they were advised to be patient about seeing any change.

"Our doctor said 'go home and I'll see you in eight weeks. You might see a slight improvement in that time'. We got out to the car and Luke said 'I feel like a lead weight – I feel like I've got a tonne of bricks on me.' It was because all his muscles had relaxed – and that was within 20 minutes of it being switched on.

"The next morning he completely stopped dribbling for the first time since he was eight or so. That's when I knew something was happening.

"The following day he was walking around the house more easily – he wasn't falling or holding the walls like he would have before.

"A day later, the kids came running in and said 'come and look at this, mum'. I thought 'what's happened?' I looked out the front window and Luke was walking over to the park – about 50 metres. He said 'I just want to keep going'. And he did. It was our daughter's birthday. Eleven years before, he'd gone into a wheelchair on the day before she was born. Now he actually walked properly on her eleventh birthday.

"The third day, he was in the park kicking a football. He's never done that. Picking it up, standing on one leg and kicking. This was within three days of being switched on.

"Our doctors didn't believe it. I thought 'you're missing out on this' so I videoed it all and took the tape

in to them. Their jaws just dropped.

“It wasn’t long before he was walking from the bus to TAFE, about 800 metres.”

A couple of months later, Luke mentioned to Julie that he was keen to ride a bike. Julie was cautious and suggested Luke might only be able to do so with training wheels.

“A couple of days later Luke’s mate was over. I was looking out the kitchen window – and the next thing I saw Luke go past on his friend’s bike – like it was normal! He said ‘it’s easy’. He hadn’t ridden a bike since he was six.

“Two weeks later he bought a bike. He rode it 10 kilometres that day.”

For Luke, life couldn’t be more different than how it used to be.

“I’ve been able to go out with my mates a lot more. They don’t need to drive our car for my wheelchair – I can hop into any car. I can do so much more. I can ride a bike, kick a footy, play cricket, everything!”

Luke has finished his TAFE course and has recently secured a part-time job at a hardware store.

Like most teenage boys, a driver’s licence was a priority, and Luke has recently passed his test.

“I never thought I’d drive.”

Luke’s advice to other young people with dystonia is to consider all the treatment options.

“I’d tell them go for it. Don’t be too scared.”