



Speaking from Experience *Epilepsy Surgery*

Transcript for chapter 5 of 12: Discovering surgery

Denise and Frank's son, Luc, had surgery 1 year ago: Luc's neurologist had mentioned to us that surgery might be an option for Luc and it seemed obvious to us that the drugs weren't working and he did point out that the earlier you have surgery done, often the better, for a young child. Because they have a chance to catch up and so we really started to consider it very seriously because we were thinking that we've got to do the very best we can for him. If he can catch up, let's get it done as soon as we can.

Sarah, 3 months after surgery, and mother Frances: I discovered that surgery was available when Sarah, it would have been about 12 months ago. I found her in bed having a massive seizure, I had to call the ambulance and it was... Sarah is also part of the research of temporal lobe epilepsy. So we'd been told that there was an operation, but unless it affected her school life or her work, whatever, then they'd rather not. They were just going to keep trying medication. But, when she had that massive seizure then they started looking into it.

Maree, 11 months after grid monitoring and surgery, and husband Rob: I felt very uncomfortable about the fact that we had planned to have a family and what happens if I fall pregnant and have one of these Tonic Clonic seizures? So, I had real fear about that. So I actually decided to have a second opinion and I was referred by my local GP to a neurologist, who I saw and we went through everything. My whole history, I suppose. And explained where I was at now and what had gone on. And she said, "Look, I could try you out on different meds and things but she felt more comfortable by referring my to a guy who specialised in epilepsy. So, that's what happened. I was referred on and it all took place from there.

Mark, 7 years after surgery: Because I was still having seizures, doctors suggested that I may be a candidate for it but they'd need to pinpoint where the focal point was. I hadn't heard about surgery prior to that.

Barry, 2 years after surgery: The cold hard word was put on me by my doctor and he said it quietly and I took it with a little bit of surprise, because I didn't know about it. He said, "Barry, would you consider surgery for your epilepsy?"

Mark: I was kind of ready to grasp anything. You've got to say, yeah hey, I could regain what I consider to be a normal lifestyle.

Barry: I spoke about it with my parents and a friend. The friend especially said to try. I thought about it for the next several hours pretty hard and that I night I said, right, nothing ventured, nothing gained. So we went for it the next day. I couldn't get on the phone fast enough to tell my doctor, please book me in.

Louise, 9 months after surgery: Medications, they just weren't working. I was finding it really hard and I was on a high dose and I remember before I had the monitoring done for the operation, I walked in to see the neurologist and she said that really there was no other



option. We've got to give this one a try. So, I'd been thinking about it for a while. So, it wasn't something that came out of the blue.

Denise and Frank: I'm told that 5% of people are considered for surgery and we didn't think we'd get into that group actually. But it just worked out that that was the only option we had at the end.