



Speaking from Experience *Epilepsy Surgery*

Transcript for chapter 8 of 12: Tests... and more tests

Maree, 11 months after grid monitoring and surgery, and husband Rob: There's a lot of detailed stuff to go through. It wasn't simply, 'ok you're going to have surgery, come back on this date', you know?

Mark, 7 years after surgery: I had a couple of MRIs which creates an image of the brain to see if there was any scarring or any kind of physical cause, which it didn't. So, I think there was MRIs and PETs and SPCs; a whole range of diagnostic testing, as well as psychological testing.

Barry, 2 years after surgery: There were oral tests, memory tests.

Sarah, 3 months after surgery, and mother Frances: The journey to the operation was a lot of tests. MRIs, PET scans, SPECT scans, a lot of travelling. She was monitored for five days.

Maree and Rob: The first thing I had to go for was the video monitoring.

Mark: Going to hospital, I'd be hooked up to an EEG machine and a video camera which would record me having a seizure. So they could pinpoint more accurately the source of the seizure.

Barry: You're to stay on top of the bed, let our bodies be seen by the cameras so that the cameras have a chance to detect where our troubles were, what they did to us. Because by then I guess, they could determine which part of the brain is affected.

Mark: They would go through a period of withdrawing medication, trying to keep me awake, trying to build up stress to cause a seizure.

Louise, 9 months after surgery: The only thing that was difficult was when you had to try and stay up at night for a long period of time for a few days. So, that was hard.

Mark: It was leading up to Christmas; it was my daughter's birthday. We had her birthday party in the room. So, yeah there was a lot of stress on me and the whole family during that time.

Maree and Rob: It was really stressing for me to see Maree all wired up and yeah, in hospital.

Sarah and Frances: She had these things on her head...

Maree and Rob: She had a whole mass of wires attached to her head.

Mark: It took two weeks, stuck in a chair in a room which I couldn't move out of before I had a seizure that was in the time within the nuclear medicine area was open to record the image that they needed to.



Maree and Rob: I think having the grid implant, having the grid put in was one of the hardest, probably the hardest time out of all the tests and everything I had to go through. It was, when I came out of surgery I remember just having no energy and actually in pain because it was quite a large piece put in and it's, I had a lot of headaches...

Maree and Rob: and nausea...

Maree and Rob: nausea, no energy, no strength, no appetite. And each day it improved but it was quite a painful time, especially the first couple of days. A lot of bad headaches and yeah. But as each day went on, I got stronger and stronger. They were trying to build up my appetite again before the next step which was only a week after the grid implant.

Louise: I was always lucky because my family has been a great support. My mum would come in every day.

Maree and Rob: The grid implant was to map the brain and that was to be done in the same stint in hospital as the surgery. So, over a two week period, the first week was to cut Maree's skull open and put a grid a bit bigger than a credit card, plastic film with little electrodes on it. Over the area of the tumour and the site where the epilepsy was centred and monitor that and stimulate that and do all sorts of tests.

Sarah and Frances: I felt very confident. I never thought for a minute it was a waste of time, having all the tests.

Mark: I guess as time went on I thought, gee I've got to go through with it because I'd just invested all this time and stress. I felt like I couldn't quit out of it, it was a journey that I had to complete. I couldn't just stop it halfway.