



Speaking from Experience *Epilepsy Surgery*

Transcript for chapter 10 of 12: Recovery

Barry, 2 years after surgery: I can still recall the last clock face being at 10:30. I never felt another atom of pain or any visual realisation until about 4:30 that same afternoon. I saw my brother standing in the shadow of the window. And all I had was a bit of a sore head.

Louise, 9 months after surgery: When I woke up, I saw a happy face on everyone's face of my family. Just to see them all nudge each other, 'she's awake, she's awake'.

Denise and Frank's son, Luc, had surgery 1 year ago: It was pretty scary seeing what he looked like, because he'd lost a whole heap of hair, they'd shaved it all off. He had all this yellow stuff, which I think was to do with making sure there was no infection. It was like an antiseptic all over the scar. He had 40 staples in his head, underneath a piece of tape. So he looked pretty awful. It was a bit of a shock. Even though we'd been warned roughly about what he'd look like, it was still hard to see your child looking like that when they'd gone in looking pretty alright.

Barry: It was probably not until I had fully overcome the affects of the anaesthetic that I realised, my head's clear! It was such a fabulous feeling. I was just so sorry that it couldn't have been done so much earlier in life.

Denise and Frank: Actually Frank nearly fainted, didn't you? In the room.

Denise and Frank: [jokingly] Oh, no it was you, it was you.

Denise and Frank: No, no it was you [laughs]. They had to take him off and he had to lie down on a bed because just about keeled over. So, it's funny really...

Denise and Frank: It's the one thing I wasn't expecting to do. You know, I wasn't, but I did.

Denise and Frank: But they said in that recovery room that about one parent a day faints there. So, they're actually used to it. Because often parents there are so worried and they don't eat properly and it's a very heated sort of environment. So, they're used to it there.

Louise: Headaches were a lot worse after a seizure than the ones I was experiencing after the op.

Denise and Frank: Well, he was in hospital for six days after the surgery and the first few days he just about slept nonstop the whole time. After about, say, the fifth day he got out of bed and he had a little bit of physio. And he was a little bit weak on the left side, which they expected. That went away in about two days.

Louise: Walking was hard. I found it was like learning to walk again, being a baby [laughs]. I remember I celebrated when I could walk around the whole ward. It was pretty funny.

Mark, 7 years after surgery: I expected to sort of go through surgery and be up the next day and be alive and away with it. But unfortunately, it didn't quite work out that way.



Louise: It was sort of a month after the speech was better and the walking was a lot easier. It sort of took three months all up, until I was confident enough to get back to work.

Sarah, 3 months after surgery, and mother Frances: I didn't want to go back to school and have a big chunk of hair missing.

Denise and Frank: He had to stay home for up to four weeks and I was really dreading it, but he was fantastic. He was really cooperative, he was happy and he was just wonderful in every way. So I wasn't waiting, desperately, for him to go back to school.

Sarah and Frances: Hair's a big issue. A big issue. They really worry about it, don't you?

Sarah and Frances: Yep.

Denise and Frank: Although, he was really ready for it. He was wanting to be back at school and be amongst people and have more stimulation.

Sarah and Frances: This is how her hair has grown and that's less than three months. You can't even tell.

Mark: After surgery, unfortunately, I did get an infection, which did slow the healing up substantially. I had meningitis, so I was in hospital for quite some time after surgery.

Barry: In October, after the August, I suffered the depressive period.

Mark: I thought it was just me; just kind of feeling sorry for myself. It was later on that I realised that it is a very common kind of thing. I went through quite severe depression. I saw a psychiatrist and I was on medication for it. So I kind of came to terms with it after some time, but it was a bit of a scary period.

Barry: But as dad told me later on, "You were warned about this, but you never took any notice." I was too keen to do too much too soon.

Mark: I would think that 'back to a normal life' happened after I stopped taking the medication. Because the medication does slow you down a bit. And around about the same time, I was starting to drive again. So, the independence came back. I'd say two years it did take before I was able to feel normal again.

Sarah and Frances: I haven't seen Sarah depressed at all after surgery. It's like a big weight has been lifted off both our shoulders.

Mark: One of the things I've found since surgery that's been a real help to me, is talk to other people who have been through the procedure and to share some of those common experiences. They've had headaches, they've had the depression, the tiredness and those common experiences really have helped me overcome that side of it. Understanding what life was like before surgery and what it's been since.

Maree, 11 months after grid monitoring and surgery, and husband Rob: It wasn't an overnight recovery. My time for recovery happened over a long period of time. That was how it was supposed to be and that's ok and it wasn't going to go on forever.