



Speaking from Experience *Epilepsy Surgery*

Transcript for chapter 6 of 12: Considering the risks

Maree, 11 months after grid monitoring and surgery, and husband Rob: When I heard about the surgery, the possibility of surgery, I had a lot of fears and needed a lot more information to reduce those fears.

Barry, 2 years after surgery: Surgery had to be better than the worst of the worst seizures that I used to suffer. You never know unless you try, and I was prepared to try.

Mark, 7 years after surgery: I was told there were risks but in a lot of cases I just thought that this was going to work and I didn't think too much about the down side.

Sarah, 3 months after surgery, and mother Frances: The things that worried me were the things that went wrong.

Maree and Rob: Whether, you know, she would survive the operation. What sort of damage could be done during the operation? And a whole lot of different issues. Just fear of the unknown, basically. Because I thought, "Oh, brain surgery, that means you're going to die." You know? That'll be the end of you.

Denise and Frank's son, Luc, had surgery 1 year ago: We thought that even if it wasn't a complete success, it was going to be better and it was definitely worth the risk because we knew we just couldn't go on the way it was. Any improvement was going to be worth doing it for.

Sarah and Frances: My feelings about surgery was, it's very scary. I mean, this is your baby. You know, it doesn't matter how old they are, having major surgery.

Mark: The risks were stroke and infection. Like with any major operation, there are risks involved. Paralysis was one possibility. I guess it all depends on how the surgery procedure went itself.

Maree and Rob: In the beginning, I didn't consider the risks. But when I found out that it was a definite, that surgery was possible and then we went through the different procedures and that sort of thing, and that yes, there are risks involved, I did have to consider things. Yes, I did have to think about them, but it sat ok with me. I felt willing to take that risk.

Denise and Frank: The neurologist made us feel really good because he'd had so many kids that he'd done surgery on and had fantastic outcomes. So, we really felt that we trusted him and that it was going to work or that it was definitely going to be worth it. We didn't really worry about, ok, there's a very small chance that it won't work at all or that, you know, something will go wrong or whatever. We didn't really think about that because there was this great confidence from the neurologist.

Sarah and Frances: I was told about the risks that might go wrong with the operation. I didn't tell Sarah, the specialist was fantastic, he actually asked Sarah to leave the room and he discussed it with me and I felt that Sarah didn't need to know.



Maree and Rob: Her vision might be damaged. Her speech might be damaged or perhaps even movement of facial movement or arms, I think, was also an issue.

Sarah and Frances: I'm glad mum didn't tell me.

Denise and Frank: We were told as with most surgery, there's a small risk of clot or stroke. But they were very minimal, as in a fraction of a percent. So, in the whole big picture, we thought that's a risk worth taking.

Sarah and Frances: What can happen, and what might happen and what did happen. No, I think one person is enough to worry, you don't need two people to worry.

Denise and Frank: It's not like mending a broken arm or something; it was quite complex. The neurosurgeon had to be very careful that he didn't cut too close to the motor area because there would have been some paralysis if he'd touched a certain area.

Denise and Frank: Or weakness, at least, on the other side of the body.

Sarah and Frances: At the end of it, we actually looked at it in a positive way. That she was actually very fortunate to be given this second chance in having the surgery and perhaps never having epilepsy again.