



Speaking from Experience

Epilepsy in Childhood (family perspective)

Transcript for chapter 8 of 9: Impact on lifestyle

Anne and daughter Jessica, 15: When Jessica was diagnosed with epilepsy, we had to really think about our whole lifestyle and what she was doing. There were a lot of things we had to look at and say, well maybe we should not do those, or modify them? One thing she couldn't do was walk to school by herself, but we still encouraged her to do swimming and bike riding and other activities, but with supervision. We tried not to limit her to doing things that other kids wouldn't normally do.

Bev and Tim (11 years, diagnosed at 14 months): Tim has a fairly normal life. Some things, however, we need to take a bit of extra care with. If he's swimming, I like him to swim with someone else or at least to have an adult watching him, because I wouldn't like him to have a seizure in the water. I don't let him swing on the flying fox because I think that he could easily have a seizure and fall off a flying fox. And I guess he will not have a career as an acrobat, a tightrope walker or a fighter pilot, will you Tim? [laughs]

Sandra's son Elliot is 9: There are things I wouldn't let Elliot do because of his epilepsy. I don't like him climbing trees, in case he has a seizure. Swimming alone is a no-no and having a bath by himself.

Bev and Tim: He has poor concentration, and I'm sure that's related to the medication that he's on. It does affect him in that way.

Anne and daughter Jessica, 15: It was a bit hard because I got annoyed at not being allowed to do things by myself as much as I would have been allowed to. Apart from that, it was ok.

Sandra's son Elliot is 9: He had a seizure on his bike. He came off the bike, chipped a tooth, knocked a tooth out, very huge lip that came out.

Bev and Tim: I need to be careful when I play some sports with hard balls, like with cricket or T-ball or baseball or just anything with a hard ball or it's up high.

Sandra's son Elliot is 9: He ran for his school and he came 13th out of about 60 children and increased his position from 10th in the school up to 3rd. And I was just crying my eyes out. I went and hugged him.

Anne and daughter Jessica, 15: I wasn't really afraid to try new things and that. I was probably afraid that something would happen and I'd have a seizure. But I knew that because I had supervision, and that, nothing could go seriously wrong, really.

Sandra's son Elliot is 9: Elliot wanted to do it, and I think it was important for him to do it. And he said, "Mum, I actually had people calling out my name and cheering for me."

Bev and Tim: I am the same as anybody else. I'm not different in practically any way. I've just got epilepsy.

Frank and Denise's son Luc is 6: We've generally just tried to be relaxed and as normal as possible. So, I don't think we over protect him. It's only when he is in a particularly dangerous sort of place, like our backyard with concrete, because he did actually fall over really badly one day and grazed the side of his face and he got a massive big bump on his head. And so I think it's been more that we've been aware of potentially dangerous situations, but not to the point that we're always hovering around. We've been trying to be a bit balanced about things so that he doesn't feel like we're always worrying about him.

Sandra's son Elliot is 9: My belief in how Elliot should be brought up is as normal as possible. He should be able to swim, skateboard, ride a bike, because I think that even if he does lose a few teeth, that is minor, he's lived life.

Leigh and Ann's daughter is 10: I didn't really want her to be on the computer, and I just kept thinking how was I going to look, like, she's just been in hospital overnight in intensive care, oh she's just let her back on the computer again. To go ahead and possibly have another seizure. But I did let her go on, with reservation. I mean, she went on and I just sat there and watched her like a hawk. Her hands began to tingle, her pupils were shifting in size and she became quite flushed, herself. And felt a bit crook and decided to get off the computer. So, it sort of dawned on her then that, yes, this thing had caused the thing that had put her in hospital overnight.

Sandra's son Elliot is 9: Elliot has not known life without epilepsy, and he's never said "I hate having it", but he would like it to go because he knows that driving a car is a big must in Elliot's life. He loves cars and would like to drive a car.

Frank and Denise: We can't separate Luc's epilepsy from his other problems, his intellectual disability. So, really it's had a huge impact on our life and it affects everything about what we do, where we go. It sometimes makes us not go to places that we would have gone to.

Sandra's son Elliot is 9: My life is different with Elliot with epilepsy, because if I didn't have a child that was disabled, I would be working full-time. I used to work when I had two children, and I love people and I love working, but I can't see many employers allowing me to skip and say, well, "My son's had a seizure, I've got to go."

Frank and Denise: I left work because we knew Luc had problems with his speech and I wanted to give a lot of attention to helping him to do speech therapy before he started school. And then, as it happened, he started having seizures around about the time I left work, and so it worked out really well.

Anne and daughter Jessica, 15: I told my employers what was happening and they were really supportive. So, I think it's really important that we tell people what's going on, so that we can work together.