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Speaking from Experience
The Many Faces of Epilepsy

Transcript for chapter 2 of 7: Seizures

Libby (68, diagnosed 23 years ago) and husband Jim: My epilepsy has changed over the last 23 years, since the first tumour. At the beginning, it was only very gentle on one side. As the years progressed, particularly after the second tumour, they became much worse. They're very uncomfortable because my left side squeezes right up and you can hear my wrist bones scratching together. I've had three major seizures. The new word for them is Tonic Clonic, but a lot of people will understand them as Grand Mal and it means the same thing; when you lose consciousness. My particular one is I come and go a bit. I'll hear something and I can answer a bit and then I'm unconscious completely.

Leonie (36, diagnosed 4 years ago): The partial seizures that I was having were what can really only be described as a type of déjà vu affect.

Bev and Tim (11 years, diagnosed at 14 months): He started off with just very brief absences when he was little, very frequent. They would come about every five to ten minutes, where he would have 50 to 100 a day. By the time he was about three he was on medication and the seizures themselves were controlled. And then by the time he was about seven we noticed, we thought we'd take him off the medication and just try him without any medication, and he seemed to be seizure free. So, the doctor thought that it was quite possible that he had grown out of epilepsy, which was a great relief to us. And he was medication free then until he was 10, and with a very large growth rate – and he grew a lot in this last year – the seizures have come back again.

Leonie: The déjà vu effect was more like having a spiritual entity arriving and giving me a message; someone standing behind me and telling me something. Telling me the same thing again and again. I didn't realise, until later, that that was a partial seizure.

Bev and Tim: I can tell that I've had a seizure by I could be playing a game of some sort and somebody scored a point or something and I won't have noticed it and I could look up and I can sometimes sort of figure out that I have had it.

Melanie (24, diagnosed 16 years ago): As I've matured, the seizures matured with me. They would become more pronounced, more involved. To the point where, if I do have a seizure, I know it's going to be a Tonic Clonic seizure. I know that it will involve all of my body. It's like a falling down, jerking and twisting movements and a really laboured breathing, that sort of thing. But it's certainly a scary experience, but I know what it is and I know what's going to happen. So, it doesn't scare me as much, I think, as the people around me.

Mark (46 years, diagnosed 6 years ago): The seizures that I've had did vary, I didn't have them with any sort of regularity. I would have these vacancies where I would just daydream. People would be talking to me and I would be away with it. In fact, sometimes people would say that I would have a contorted look on my face. One of the girls at work said I had an 'evil' look. There must have been a kind of a grimace on my face. I didn't know it was happening to me until later on she said "Are you okay?" So, I wasn't aware that that had occurred. The other ones that I had were the Tonic Clonic, the full blown ones. In one night I had three of those. So that was quite a traumatic night.

Libby and husband Jim: It frightens other people and I feel I have to cope with their response, rather than my own feelings and the only way to deal with this is to have a sense of humour.

Robert (32, diagnosed 10 years ago): The seizures that I mainly had were during the night time, being nocturnal. I really didn't know what type of seizures I was having. People did tell me thought that I was having a Complex Partial seizure. Which I know as being dazey and then from that daziness I was going into the stiffening and the Tonic Clonic seizure.

Libby and husband Jim: When I'm having a fit, I always tell everyone around what is happening and what to do to help me, and that makes it much easier for them, I think. And it makes it easier for me.

Leonie: I'm very well controlled now and I don't have, I have very few seizures, but in the early days when my seizures were not so well controlled, having partial seizures could increase to a very strong level of fear. And sometimes I would lose my speech and my brain would just scramble so I couldn't think of anything. I couldn't get it out, I couldn't understand. So, my speech was gone, my brain was scrambled, and as far as I was concerned that was it, Tonic Clonic is pending.

Melanie: I certainly have lived with an element of fear about having seizures in public. Both at work and especially when I was in high school.

Libby and husband Jim: When I have an episode, Jim copes with it extremely well and makes me calm and he keeps saying to me "You're still with us". Those sorts of comments, and his holding of me, are great. I don't think I could do without him [laughs].

Melanie: The kind of seizures I have are very physically involved and they're certainly hard for people to deal with. So, I made a conscious effort then with my medical regime to control my epilepsy because it was really well controlled with my medication and I didn't want to have seizures to put other people in a position where they had to deal with my epilepsy, because it made it easier for me.

Libby and husband Jim: I have to switch off and stop worrying, otherwise I'd panic, I think. Why don't I somehow have a switch off mechanism that I can just stand back?

Mark: Because I haven't seen any of my seizures, I don't really know what happens other than what's described by my friends, relatives, my wife, not when I've had the seizure. She's said that Tonic Clonic, full blown ones were quite scary and they can be dangerous because once I did fall and quite a lot of my face. So, I was found out the back bleeding from my face.

Leonie: On days when I'm having very strong partial seizures and I have that feeling that it's getting too strong, I will lie down and lie on my side and just try and relax physically but thinking of something in my mind that would take me away to a different world. Just a relaxation routine. Which is the best way for me to cope through a seizure.

Libby and husband Jim: I'm very lucky with my seizures because I would get up to three and four minutes warning, which means if I'm home by myself I've usually got a mobile phone in my pocket and a list of neighbour's numbers, and I can set myself up. It's very boring because afterwards, I'm half paralysed down the left side and I need to be able to use the wireless or the television to amuse myself. So I grab the television control and make myself comfortable in a chair in front of the television. And that passes the time, which is usually about half an hour afterwards when I can walk again.

Leonie: The main fear, apart from the fear that comes naturally with a seizure, probably the worst thing that I worry about is wetting my pants. Unfortunately, the two Tonic Clonics that I've had, I've wet my pants.

Libby and husband Jim: Wherever I am, I've always told the people I work with, the people in the shops about this condition. And I feel quite safe going out; they'll look after me.