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Speaking from Experience
The Many Faces of Epilepsy

Transcript for chapter 4 of 7: Employment & relationships

Mark (46 years, diagnosed 6 years ago): One of the things that obviously affected me was that I couldn't drive. So it meant going from a field job where I had to be based in the office. I found most people seemed to accept it reasonably well. The difficulty was that when I had a seizure in the office no one knew what to do. So, whilst there was support, they didn't have the knowledge to know what to do when I started thrashing around on the ground. In fact, in one case they thought they were doing the right thing for me by laying me on my back. I ended up turning blue because I was choking. It wasn't until a medical staff came and turned me over on my side that I was ok. So, I guess the employers, sorry the *employees* were really good. The company kind of kept by me, and I was able to transfer to another part of the company and keep on working. Which I guess was a saviour for me, because it really kind of kept me going to keep on working.

Melanie (24, diagnosed 16 years ago): As I've gone along and my seizures have become more controlled and that I have a lot less of them and the I'm more confident in my own ability to do jobs well. I will disclose to somebody a lot earlier.

Stephanie (23 years, Seizures from approx. 6 years, diagnosed at 16 years): I was concerned about telling my prospective employer, but at the same time I always kept in mind that if they had something or had a problem with that, then maybe they weren't worth working for.

Leonie (36, diagnosed 4 years ago): I wanted to get back to work, as most people would, but the possibility that I could have seizures in front of a colleague, a seizure in front of a patient was something that was very hard to cope with.

Robert (32, diagnosed 10 years ago): My employer was very good about it. They gave me a week or so off work, initially. And then they probably supported me the most when it came time for my surgery.

Melanie: You don't tell every person that you meet on the street, 'yes, I'm Melanie, and I have epilepsy'. But, I mean, you tell people when it's necessary, when you spend a lot of time with them. When it's a possibility that you may have a seizure with them.

Robert: I did tell my fellow work mates I have epilepsy. One of them actually helped to drive me to work, because I wasn't driving at the time. They were aware that I could have a seizure at any time and the main thing was that they knew what to do.

<u>Libby</u> (68, diagnosed 23 years ago) and husband Jim: Our grandchildren are absolutely fascinated by seizures. They will never go away. They consider themselves very lucky if they're in the house when one happens. They almost breathe all over me. One of them said, "Libby, you seem to be out of control." So, I think that's good because they realise that people who are damaged physically are still capable of thinking. They behave quite normally towards me and they watch out for me.

Bev and Tim (11 years, diagnosed at 14 months): We don't allow Tim to get away with anything [laughs] but we do often allow him to have a rest in the afternoons. So that as a family, probably all that we do is make sure Tim has a rest, because we can't stand him being so grumpy.

Leonie: My husband, George, he coped very well, knowing that I was diagnosed with epilepsy. He coped much better than what I did, I thought.

Libby and husband Jim: Libby is a very independent person and she didn't want to admit that she needed me to help her, and she didn't. She coped very well on her own, including going overseas and getting a job.

Stephanie (23 years, Seizures from approx. 6 years, diagnosed at 16 years): I used to be concerned about having a seizure in front of my boyfriend when we were in the early days of our relationship. But I guess when you get more comfortable with that person, you really don't care what happens in front of them anymore. Even though I've never had one in front of him, in four years, which I've been lucky, he's just always seemed to have missed out.

Libby and husband Jim: I feel that Libby, because she's a very independent person, resents the idea that she needs to have a person with her all the time.

Libby and husband Jim: Yep. I don't need someone there all the time [laughs].

Mark: It is a lot of pressure on the partner. Thankfully in my case, my wife was extremely supportive during a lot of difficult times.

Robert: Having a seizure in front of my girlfriend was probably one of the worst things that ever happened to me. The reason why is that I think she realised what was happening and what was going to happen, or what could happen in the future. As in, would she be with me, for example in a marriage situation, for the next 20 years, next 30 years. Was this going to keep on happening every second night or every third night or so?

Libby and husband Jim: I believe that *we have* the epilepsy, this is the way that I look at it. And this enables me to continue doing what I'm doing, as Libby's minder.