



Speaking from Experience *The Many Faces of Epilepsy*

Transcript for chapter 3 of 7: Other people's reactions

Bev and Tim (11 years, diagnosed at 14 months): When I first mention to people that Tim has epilepsy they will naturally think of that stereotype of epilepsy of Tim falling down and frothing at the mouth and perhaps hurting himself. Once I explain to them that he only has Absent seizures and that he just might have a brief period of time where he's not aware of what's going on around him, I think they're greatly reassured.

Mark (46 years, diagnosed 6 years ago): Sometimes when I've said I have epilepsy and people have said "Oh yeah" and they've kind of looked away and haven't quite known how to take me. I guess it's because they didn't quite know what epilepsy was. Maybe they put it in the category of some kind of mental illness, mental disabilities, I'm not sure.

Robert (32, diagnosed 10 years ago): When I tell people that I have epilepsy, most people reacted, in a way that I was deformed. In a way that epilepsy was something that had never been, or that was from the dark ages. A lot of people thought that I was going to fall over all the time or start, as they said, shaking or rattling and rolling and whatever.

Bev and Tim: Every year we need to go and sit down with the teachers and explain to them about Tim's condition, because he doesn't look any different to anybody else. It's very hard to remember that Tim sometimes forgets things and he lacks concentration and sometimes he doesn't have the stamina to keep going, like the other boys at school. So, we try and explain that to the teachers. Some teachers are wonderful and they give him lots of extra attention, and they make sure that he doesn't miss any information. They repeat things to him. Other teachers find it difficult to remember.

Melanie (24, diagnosed 16 years ago): I think that people will get the kind of reaction that you want them to get. Certainly there are those people who are very surprised by it. Generally, people are surprised when I say "Oh yes, well I have epilepsy" "Oh *really?*" [laughs] That sort of thing. But it's not something that, I mean if you're happy enough to tell somebody about it and you show confidence about your own epilepsy, I take control of it, it's mine and any opinion you have about it isn't any consequence to me. Then people will pick up on that.

Stephanie (23 years. Seizures from approx. 6 years, diagnosed at 16 years): Because I'm from an Italian background, there are many superstitions and beliefs as to what epilepsy is all about. My father's family actually thought I had the devil in me. They believed that there was something terribly wrong with me, when they heard that I had epilepsy.

Bev and Tim: The boys in the class call me 'teacher's pet' because I just needed a bit of extra help; I needed things to be repeated for me.

Libby (68, diagnosed 23 years ago) and husband Jim: When I have seizures, if there are other people around some of them are inquisitive. Some of them turn their backs. Some of them come over and help and ask what they can do. One particular fit in the supermarket, I



got my feet stuck under the apple barrel when someone put me on the floor, and that actually broke my leg because the spasms are very strong.

Melanie (24, diagnosed 16 years ago): Comments like, 'is it catching', is not uncommon, even as a 24 year old. It's something that you will experience time and time again. And each time you experience it, it gets easier.

Bev and Tim: Mum ended up calling The Epilepsy Foundation because I wanted to give a talk to the boys to say that I did have epilepsy and just talk about that and I got up and I gave a speech about epilepsy to all year five and year six.

Melanie: There is a certain amount of responsibility to explain to people if they feel that there is an issue. For you to reassure them that, look, 'I'm happy to do this, it's my responsibility to take on what I feel that I am comfortable with'. Not up to letting other people impose what they think is appropriate for you to do.

Libby and husband Jim: I remember one fit that we had at a pet shop in Brunswick Street and she just sank onto the floor and we went into coping mode. Me holding her hand from cracking. You hold it like this to stop it cracking. It helps with the pain. And people just walked over us [motions people walking over them], "Thank you. Excuse me."

Leonie (36, diagnosed 4 years ago): Some people can over react, seeing a person having a seizure. And I know that there has been a time when a friend of mine used CPR when I was having a Tonic Clonic. She thought that, because I'd stopped breathing, which is not all that unusual during a Tonic Clonic phase, she thought that perhaps I was having a heart attack, because she couldn't find a pulse as well. So, when I woke up later and had a very sore chest, that's what had happened. She did CPR.

Bev and Tim: After that had finished, a lot of the boys came up to me and said, "I don't think I could have done that. Well done. That was a good speech", and stuff.