



## Speaking from Experience *The Many Faces of Epilepsy*

### Transcript for chapter 1 of 7: Diagnosis

**Melanie (24, diagnosed 16 years ago)** - I was diagnosed when I was about 7 years old. I started having facial twitching seizures, when I was younger. I was aware of what was happening, but I didn't know what it was and it didn't affect me in any way. It was only for very short periods of time. Things went on from there.

**Libby (68, diagnosed 23 years ago) and husband Jim** - I had two benign brain tumours. One in 1976 and one in 1989. My epilepsy started 9 weeks after the first tumour.

**Stephanie (23 years. Seizures from approx. 6 years, diagnosed at 16 years)** - From the ages of 5 I was having absent seizures. I wasn't diagnosed until the age of 16, when I had my first tonic clonic [seizure].

**Bev and Tim (11 years, diagnosed at 14 months)** - When he was about 14 months, I would notice that he would stumble when he was walking. He was only learning to walk, he was just a little baby. His eyes would roll back, and his head would nod. We decided to go and get it checked out. We went to a doctor, and found out that he had epilepsy.

**Melanie** - From there, things started to happen. My absent seizures were relatively controlled. Not too controlled, but relatively controlled. They did get a bit better, but my tonic clonic seizures were not reduced. I was having those, on average, every two weeks.

**Leonie (36, diagnosed 4 years ago)** - I was diagnosed with having epilepsy after I'd had a tonic clonic, but I was unaware that I was actually having seizures prior. They were partial seizures.

**Mark (46 years, diagnosed 6 years ago)** - My first diagnosed seizure was when I was 32. It was a real shock to me, because I didn't know what happened - just one day, I turned up in hospital. Following that, I had some more tests, went to a neurologist, and they then diagnosed epilepsy. I had no knowledge at all what epilepsy was. I guess I had some misconceived ideas about what it was, and so I didn't accept that [diagnosis] very well. Over time I went on a variety of medications. In the end, it seemed to be reasonably under control, for some time. But then I started having seizures again. These seizures were the tonic clonic, where you fall to the ground shaking. Quite a lot of seizures where I'd blank out for maybe a minute or so.

**Robert (32, diagnosed 10 years ago)** - My epilepsy started in June '89, approximately 10 years ago. Since then I've swapped and changed medications. My epilepsy was partially controlled. After changing medications, I went back to the neurologist and wanted to find out just what was wrong with me. I went for another CAT scan, and then an MRI, and it was found that I had a brain tumour. In 1995, I had the brain tumour taken out. Since then, my epilepsy has stopped.

**Mark** - My first diagnosis was that it looked like it was epilepsy. My neurologist wasn't sure, so just to be safe, he told me to take these drugs and not to drive. I felt my whole world had



dropped away. At that time, my job involved driving so I didn't know what I was going to do for the rest of my life.

**Melanie** - After the initial shock, and after getting a little bit more information. That information was received from a local support group in my area. After talking to a few people, I realised it wasn't such a bad thing. I wasn't alone.

**Bev and Tim** - I suppose, at that stage, because he was such a gorgeous little boy, I didn't anticipate any problems. I assumed that he'd be able to take some medication and that it would control the seizures. It didn't seem to affect him in all his milestones, when he was a little boy. He still walked and talked at the right age, and he still seemed to be functioning perfectly. I was more worried about his safety.

**Leonie** - Being told I have epilepsy, I went straight into denial. I was recovering from a stroke, which happened 9 months prior. Having a tonic clonic and being told that I had epilepsy was just unbelievable.