RealTimeHealth™
The Digital Health Network
GPO Box 70, Melbourne, VIC 3001 Australia
P 61 3 9654 9001 F 61 3 9654 9003
www.realtimehealth.com ABN 44 120 278 024
Melbourne Central Tower
Level 20, 360 Elizabeth St
Melbourne, VIC 3000, Australia

Speaking from Experience
Epilepsy in Childhood (family perspective)

Transcript for chapter 1 of 9: Diagnosis

Anne and daughter Jessica, 15: We had a bit of a frantic call from my son, who was four, saying that Jessie was acting a bit funny and when we went in there on the Sunday morning, she was not looking too good. So we took her off to the hospital, and she was nine then. So, it went from there. We had tests and followed up.

Sandra's son Elliot is 9: Yes, I first became aware that Elliot had epilepsy when he was five. I picked him up from school and had to urgently go into the house and when I came back he was in the car. He was still and just lifeless. I took him inside and lay him on the bed and called an ambulance – my eldest son. I was very scared, because I thought he actually died and then my son said, “Mum, he’s vibrating”. Actually, it was amazing because I knew that he was obviously alive then and that was a good sign. And then he had two more seizures and he was diagnosed with epilepsy.

Leigh and Ann’s daughter is 10: She was six years old, and I had a phone call from the school to say that she was using a computer and the teacher just thought she was having a panic attack. So I went down to the school and by the time I got there, she had probably lost consciousness, she was staring into space. She was very pale and limp the teachers looked pretty shocked. Leigh had just returned, he’d been down to a small town near home and we raced her down to the doctor and she was then taken by ambulance to the hospital.

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

Frank and Denise’s son Luc is 6: Well, he was four and a half and I remember in the evening, he hunched over from the waste and I thought it was a stomach cramp he was having. But it wasn’t. We were actually witnessing a seizure, and we just didn’t know it was a seizure at the time.

Leigh and Ann’s: And the very first EEG just proved normal, there was no problem. So we didn’t worry too much about that. But a neurologist suspected that it was a type of epilepsy, so she had a further test up in Melbourne. And it was confirmed.

Bev and Tim: He started off with very brief absences when he was little, very frequent. They would come about every five to ten minutes, so he could have 50 to 100 in a day. By the time he was about three, he was on medication, and the seizures themselves were controlled.

Leigh and Ann’s: Because we were also told that she might grow out of the epilepsy, we kind of assumed that it wasn’t going to happen again, because she didn’t have another one until she was nine years of age – when we purchased our own computer. She had been on computers before. If she felt funny, she’d get off them. But she’d successfully used computers, and felt a little bit strange on occasion.

Anne and daughter Jessica, 15: When she first started, she had various sorts of seizures. And this went on for about two years while we tried different medications and combinations.

Leigh and Ann's: That's not to say that all people with epilepsy have that response. It's usually people with this photosensitive response. Unfortunately, society just sort of thinks that anything that's flashing is going to make a person who has epilepsy have a fit, and that's not actually the case.

Sandra's son Elliot is 9: Elliot has seizures probably about four times a month. Tonic Clonc seizures, and now he's a bit less severe and he's having just 'stares' and he's not sort of vibrating and falling on the floor.

Frank and Denise's son Luc is 6: Luke's had complex partial seizures for at least two years now. He would have at least five or ten a day. They would involve some fidgeting, touching his lips or clothes. And sometimes they'd be more physically severe. He'd hunch over from the waste, stagger a little, fall down.

Sandra's son Elliot is 9: He doesn't remember anything about having the seizures, even when he has the Tonic Clonic ones, he's just very, very out of it for a long time. He doesn't have an aura or get any warning, he just goes down and then he's just very sleepy and he just wants to sleep.

Frank and Denise's son Luc is 6: He was having so many seizures and also just a lot of chaotic brain waves, like 'epileptic activity', it's called, going on almost constantly. So, I guess that was just interfering with how he could be involved with what was going on around him. He just wasn't able to concentrate because he there was so much going on in his head.