



Speaking from Experience

Epilepsy in Childhood (family perspective)

Transcript for chapter 2 of 9: Initial reactions

Sandra's son Elliot is 9 - When Elliot was first diagnosed, I knew quite a bit about epilepsy. My father was a headmaster at a special school in Perth. I was never shielded from children having seizures. My father showed me what to do.

Leigh and Ann's daughter Natalie is 10 - I didn't know anything about epilepsy. At the time, we found a lot of information and did a lot of research through the epilepsy foundation. Books, videos, those sorts of things.

Sandra - Elliot was in hospital when he was born, for five months and was never expected to live. He had a major, long operation. Had three convulsions, and then went on to epilepsy. So, to me, the path we've been on has been like a rollercoaster. I probably didn't freak out like most people, because we hadn't had a very easy ride.

Bev and Tim (11 years, diagnosed at 14 months) - I didn't anticipate any problems. I assumed he'd be able to take some medication and that would control the seizures.

Frank and Denise's son Luc is 6 - We didn't want to be told anything else. I knew that if it was epilepsy, we would be in it for the long haul and it wouldn't be an easy path. So, denial was the first thing. As the medical tests came through and we couldn't avoid the truth, then I got angry and felt like kicking something. I couldn't really do that because there was nowhere to lay the blame. It was just one of those things that happened. It wasn't doing Luke any good. It wasn't doing the family any good either. So, eventually it merged into acceptance and we got on with our lives from then on.

Leigh and Ann - I was relieved that it had a name, because when I first collected Natalie from school after she'd had a seizure, I was shocked because I thought she may have had a brain tumour, or something. She was all pale and floppy. The fact that they did diagnose her with something, made me relieved. There was something we could do about it.