



## Speaking from Experience Young People & Epilepsy

### Transcript for chapter 1 of 8: Diagnosis

**Taylor (19, diagnosed age 12)** – We didn't know what it was at first because it was such a weird thing for our family. No one had ever experienced it before.

**Alix (16, diagnosed age 11), and Chris (Alix's father)** - We thought Alix was a daydreamer that she was living in her own little world; which didn't seem like a bad thing at the time. But then the daydreaming started to happen when Aix was in dangerous situations, like crossing roads. She got to an age when she started to cross roads by herself. She'd get halfway over and stop and have a little moment to herself [laughs].

**Sian (18, diagnosed age 13)** - When I was in year 7, I started having Myoclonic jerks and I was dropping things. Sometimes I would fall over without knowing why. These were later identified as Myoclonic seizures.

**Cassandra (15, diagnosed as an infant) and Daniel (13, diagnosed age 9)** - Mum and dad took me to who I needed to see about it and they gave me some EEGs [electroencephalogram], and I find out that I had epilepsy.

**Patrick (17, diagnosed as an infant)** - I was diagnosed with epilepsy when I was an infant, basically. I stopped taking medication when I was about 8 years old, when we came back over to Australia from Bahrain. I was off medication for about 5 or 6 years and then I had a relapse just last year.

**Alison (19, diagnosed age 12)** - I was diagnosed when I was 12 years old, but I remember having my first seizure when I was 8.

**Taylor** – I was diagnosed at age 12, after multiple tests and a lot of visits to the doctor.

**Cassandra and Daniel** - I was 8 ½ months old when I was diagnosed with epilepsy.

**Alison** - I was at home when I had the Tonic Clonic seizure. Luckily my dad knew what to do. I was rushed to the hospital – this was the first time it'd happened – and the doctor at emergency said that I have epilepsy.

**Patrick** – The first time I had a seizure I didn't know what it was because I hadn't had one for such a long time. So, I didn't really tell anyone. But then it happened again and obviously I had to do something about it. So, I contacted a Neurologist and we started from there.

**Alix and Chris** - Help from a friend who was in the medical profession who alerted us to the fact that epilepsy wasn't just having large fits and that there were various version of it, that we knew nothing about.

**Taylor** – I knew absolutely nothing at all. I didn't even know what it was. I didn't even know it existed.



**Sian** – It's very terrifying to have your life change in an instant. One minute you're normal, and the next minute, you're different. It's very life-altering. I saw myself a bit differently too, and it took me a while to accept the change as well.

**Cassandra and Daniel** – I didn't feel that bad. I didn't take it that seriously. I just thought, 'okay, don't push yourself too hard'.

**Alison** – I think I was probably relieved, if anything. Because so many doctors had been saying that I was making it up, or they just couldn't find anything. In another way I felt that I was a weird, one-off sort of person. But it was better that I was diagnosed then and put straight onto a medication.