



## Speaking from Experience Young People & Epilepsy

### Transcript for chapter 2 of 8: Symptoms & seizures

**Alison** – It causes me to forget my words, and just say ‘um, um, um...’ That’s because it’s in my memory of language area in my brain.

**Alix** – I have absent seizures. So, basically I just stare off into the distance and I keep doing what I’m doing. If I’m walking I’ll just keep walking, but I just sort of zone out and can’t hear anything for about 20 to 30 seconds.

**Cassandra and Daniel** - I have Tonic Clonic seizures and what I call ‘wobbly legs’ and ‘black outs’. I don’t actually know the real names of the other ones, so I just call them ‘wobbly legs’ and ‘black outs’.

**Taylor** - It’s just sort of a 30 second to one minute burst of shaking and tightening of my muscles, that I can feel.

**Cassandra and Daniel** - ‘Wobbly legs’ basically it’s like I’m drunk. I lose all balance in my legs. It moves up my body and my speech slurs. I have to sit down and it happens for about one or two minutes.

**Patrick** - I have Tonic Clonic seizures, usually nocturnal. This means that you basically shake for 2 to 3 minutes. I don’t know how long they last, really, because I’m in bed. But I have had them during the day as well, and they last for about 2 to 3 minutes – full shaking and jerking. Sometimes you injure yourself. Sometimes you bite your tongue or the side of your mouth. You become conscious and you just feel really groggy and on a different wavelength. You don’t feel too great.

**Alix and Chris** – I would wake up out of them and realise that something had happened. People would be looking at me and I would just feel like I’d woken up from a sleep.

**Sian** - I go unconscious when I have a Tonic Clonic. I wake up, not knowing what happened. I blank out for the five minutes... usually they last for a minute or a minute and a half, but I’ll blank out for the five minutes because I’ll fall asleep afterwards. It’s very scary when you can’t remember something.

**Patrick** – I’ve had a seizure when I was on a bus this year. It’s a pretty scary thing, waking up and having strangers in your face saying, ‘what’s the problem?’

**Cassandra and Daniel** - Sometimes we do get a bit of a warning, but most of the time we didn’t even know it was going to happen.

**Taylor** – I used to, when I would have them during the day, have a five second aura – I think it was called. I’d get a weird rush all through my body, with a bit of a tingle. It was a different feeling, and all of a sudden I’d just go into one and I couldn’t stop.

**Patrick** – For everyone, it’s a different feeling. For me, it’s racing thoughts and you’ve really got to be careful and know when to take that feeling into hand and do something about it.



So, if you're going to fall to the ground, you've got to get on the ground before you fall to it. Take some precautions.

**Alix** – I was really surprised by how many kinds of Epilepsy there are and what kinds of things turn them on, like light and sounds and all those kinds of things.

**Cassandra and Daniel** – Flashing lights seem to cause problems. They seem to cause headaches and we start to feel sick. So, discos have never really been a big thing for us.

**Alix** - I knew Epilepsy as falling on the ground and having a full-on seizure. So, I didn't really know how me staring off into the distance related to that. But, they explained it all, and my parents did some research on the internet and so did I. I realised that it wasn't that big of a deal and it wouldn't affect my life that much.