



## Speaking from Experience Young People & Epilepsy

### Transcript for chapter 4 of 8: Who do you tell?

**Patrick** - If somebody came to me on the side and asked me, 'what's the problem? I've seen you basically fall, in the last six months'. I'd tell them, but it's when people ask you up front, in a group and they're really naive about it, to everybody. It sort of annoys you a bit, because you don't want to tell them in front of everybody else, because it's a personal thing that you don't want to tell everyone about.

**Alison** – Basically everyone I know knows that I have Epilepsy. I don't hide it from anyone.

**Sian** – Some people try and, I suppose, put it into the background and try to ignore it. People asking about it and being open – when I was ready to talk about it – was nice.

**Cassandra and Daniel** - Most of my high school friends don't know about it. Most of my friends from primary school know about it, but I just haven't told most of my friends from high school at the moment. They don't know about it because I've kept it a secret for a little while.

**Cassandra and Daniel** – Two of my best friends know. One of my best friends, I have most of my classes with. The other one, the teachers didn't want us together, because we're too dangerous. She laughs at me when I miss out on stuff. I'll beg her to tell me but she'll laugh at me and try to make it into a big joke, so that I don't feel so bad.

**Alison** – my friends just know what to say. They're just great. They don't know what happens when I have a seizure, but they're just friends and they're great.

**Cassandra and Daniel** – Not many teachers actually understand it. One of my teachers, my home group teacher, and his son has epilepsy, so he understands it. But I don't actually have him for a teacher all day. He understands one part of it but he doesn't understand everything. I don't get into trouble from him. My other teachers don't understand and don't know what to do, so to them I'm just making up an excuse and I get into trouble.

**Sian** - Even though I did explain sometimes that I would just like to sleep it off in the sick bay, they insisted on calling my parents. I was determined, when I was at school, that I would like to remain at school, because it's hard to get there in the first place.

**Cassandra and Daniel** – I've grown up with epilepsy, so the community or school not realising it is normal to me. I don't really notice it. For people who are diagnosed later, it might be a little strange.

**Alix** – If I put my hand up to answer a question, I might stop. In the school yard it might affect how people see me. I might be called names for any kind of reason.

**Taylor** – I used to get teased a lot for having the seizures, but I sort of worked my way around that.



**Alison** – I've only ever really had one teacher that didn't understand. I told him that I have to read the pages in a book twice at a time, or re-read it. And he told me that I can't imagine then! I thought, 'Oh, okay...' I have an imagination; I just need to re-read the book.

**Sian** - The teachers crack down hard on anyone who is bullying, especially if they're bullying anyone who has a disadvantage or a sickness. You can't control when you have a seizure, and most of the time it might be out in public, because that's where you are when you spend most of your time at school. There's been nicknames like 'fit-girl', because I'd have a 'fit'. Me and my friend laugh it off, but it's there and it gets under the skin sometimes.

**Alix and Chris** – It bothered me because there were people that were at me all the time, having a go at me and saying I was weird. I just thought, well, they're not going to stop no matter what the teachers tell them because they're just that kind of person. They just need to pick on others. So, I just need to not listen to them so I can move past this.

**Alix and Chris** – I think we were lucky that Alix had that self-confidence and resilience to get through that because it could be very nasty. Detrimental to one's view of themselves, I would have thought.