



Speaking from Experience Young People & Epilepsy

Transcript for chapter 5 of 8: Challenges

Alison – I reckon the most challenging part was about 15 or 16 because that's when you're trying to find your real close friends and trying to look cool. You're just a little kid, really.

Cassandra and Daniel – I was worried to go out, to go to the movies, in case I had one there and no one could help me.

Alix – When I have a seizure, I don't realise I'm having it until I wake up and I see people staring at me. It really doesn't help if, once I realise that I've done it again by accident, if someone is pointing and laughing at you and teasing you and calling you names. It just makes you feel bad and it doesn't help at all.

Patrick – When you're almost an adult, it gets a bit harder to deal with because you've got other pressures on your mind and school is on your mind as well. It's harder to deal with because you've got a lot more on your plate. It's you that you're worrying about. Your parents are also worrying, but it's you who's got the problem in the end and it's you that has to deal with it.

Sian – You become more aware of hazards that other people take for granted because it wouldn't happen to them. They wouldn't fall to the ground because they'd be able to brace themselves if they tripped, but I can't if I had a seizure. If I tripped down the stairs, I wouldn't be able to catch myself. You just become aware of stuff like that.

Taylor – People just go and get their licences and drive around and do stupid things. I can't even get my licence.

Sian – Driving, I've just got my Ls. I was actually permitted to get them earlier this year, because I had to be six months without a seizure happening.

Taylor - It affects relationships with my mum and dad too, because I can get tired and we argue. Because I don't have the independence, through having a licence, I need them to drive me everywhere. They don't want to do that sometimes.

Alison – I think I put my parents through a lot of stress – a few fights. I could've been a bit better along the ride, but oh well. They were there for me.

Taylor – From where we lived at one stage, it was probably an hour of travel to see the paediatrician and probably three hours to Melbourne to see a specialist. So, always backwards and forwards. When we moved to the next town, it was still roughly three hours travel to see the specialist. Probably once every two or three months it was backwards and forwards. There would be hospital stays and all these tests – MRIs and blood tests. It did get tough with travelling but mum and dad always put up with it.

Alix and Chris - Things start to become more important, when you start to miss stuff in secondary school. I think it's more retarding to your education than it is in primary school.

Cassandra and Daniel - If you have a seizure in class and it's during a test, you might black out, miss a bit, and get the wrong answer or something. It does go towards our reports and it does mess up our reports. It can be horrible to get a low mark...

Cassandra and Daniel – He has trouble concentrating as well. He'll just phase out or black out on what he's meant to be doing and start on something else. So, he'll miss out on half the lesson and might fail the test. But it's because he phased out and didn't know what he was doing.

Alix – It's hard doing speeches in class, because sometimes I would zone out and not everyone knew that I had Epilepsy. So, there would be some embarrassing moments and times when I would just not want to be there and do anything, because of that.

Patrick – School attendance is probably the main thing this year, as well as my cognitive affects – thinking at school and learning basically. Social events at school also comes into it. It's hard to concentrate. I suppose that schooling life is just a bit harder when you're not there. Because you miss out on things and other people are talking about things and you just don't have a clue what's going on.

Alison - Epilepsy has made me miss out on school for weeks at a time. Rather than just a day here and a day there. It made me miss out on learning large bits of school, and missing out on life with my friends.

Taylor – I have missed out on doing a lot of things with my friends. Like school sports, because I'd always get suspended as a result of getting in trouble at school, because of the side effects of the medication. That was not too good.

Alison – P.E. [Physical Education] was something that I found really difficult. Because when my heart rate went really high, I'd get a seizure. Sometimes, they didn't realise that, they just thought that I was trying to get out of it, like some of the other girls. But the case was that I would have a complex seizure when my heart was going too fast and I was overheating. Sometimes teachers just need to be informed. When I informed them, they understood.

Taylor – I wasn't really someone who needed a teacher's aide or anything like that. But I probably could've had a bit more help. A bit more one on one help with my school stuff. I started to fall behind because of my tiredness.

Cassandra and Daniel – Staying up late when you're staying over at a friend's place, although it's sometimes not a good idea to stay up very late, if you want to have fun. But if you get too tired, it's better to just drop down into bed and go to sleep

Alison – To minimise the effects of Epilepsy, the best thing you can do is to not stress out. I know that when I stress out, I can have about 30 seizures per day – up to that, anyway. Late nights are really bad. I don't really drink that much alcohol anyway. I know that does affect Epilepsy, and the medication, but I don't really drink.

Alix – I'm just taking the right balance of the right medications, at the right times, and the right dosage. I'm watching how late I stay up, and not doing anything that I shouldn't be.



Sian – Yes, I can stay up late, but maybe not too late. I don't stay out all night. I'll be home by 12am, or maybe 1am. Not too late.

Taylor – The only thing I really can't do is stay up all night. That ruins my sleeping patterns for the next few nights and it could cause seizures. That's the number one thing that I can't do.