



Speaking from Experience Young People & Epilepsy

Transcript for chapter 6 of 8: Getting support

Alix and Chris - I think it's important to involve a young person's friends in the Epilepsy and the treatment of it and how they can help. Kids at that age quite enjoy caring and, it seemed to me, helping out.

Sian – I met a group of friends who were very tolerant and understanding. Even though I was away, they always tried their best to include me.

Patrick – I've got probably three or four close friends, who I can really talk to. The rest, who are sort of half of my best mates, I don't really tell them about it. The priest is really helpful to talk to and the psychologist. I don't really talk to my neurologist a lot. My mum deals with him. I can also speak with my GP, if that's needed.

Taylor – When I'd change schools, I'd just explain to them what it was and how it affects me. If I'm grumpy on some days, just don't worry about it. If I do have one [seizure] this is what to do. They all understood and they were pretty good about it. They still do these days. They're still wary, in case I do have one. If I stay over at their place, they'll make sure I'm alright if I have one.

Cassandra and Daniel – It's good if we have people supporting us, such as our friends and family. If we have a seizure and we hurt ourselves, they can talk to people. If we're not able to talk, they can talk to teachers. Your friends can talk to teachers at school, paramedics, and our parents.

Patrick – If you have that warning sign, it's really important to notify your friends that something is going to happen. So that they can know that it's going to happen and can help you however possible. If they know what's going to happen and how to help you, if you're having a seizure. Protecting your head a bit, turning you on your side.

Alix - I just wish that teachers understood that, if this does happen, you just need to make sure it's safe for us and that it's safe for the other students and for them. Just leave us until we finish and see if we're okay after that. Someone who's having a seizure won't respond until the seizure has been completed.

Cassandra and Daniel – If it's at school [that Daniel has a seizure], the school will pull me out of class, notify me and tell me what has happened. If it's during class and he's in the gym doing sport, they'll send me down and I'll help him through it.

Sian – It's also just moral support too. Not all people fall unconscious, many people will stay conscious.

Alix – In that situation, what would help you, is just someone there to pat you on the back and tell you that you've had a seizure, but it's okay.

Patrick – My close friends reacted pretty well when I told them about it. They were positive about it and told me to keep a positive frame of mind about it. They've helped me in every



way possible. Whenever I go to school, they'll pick me up from the local bus stop. They drive me home whenever I want. Whenever I'm at their house, and I'm not feeling great, they'll take me home.

Cassandra and Daniel – Most of the parents have to know that we have our medication. They might get a little worried in case we're taking drugs or something while at their house – and you don't really want that. So, we tell them about our medication and if we have a seizure, they know what to do. We have to tell parents of where we're staying.

Alison - None of my friends push me into drinking or push me into having a late night. They know that I have Epilepsy. So, that's really great of them. I don't really see it as hard anymore. At the start I did get pushed into peer pressure a fair bit, but now I don't really care, to be honest. I'd rather care about my own than care about peer pressure.