



Speaking from Experience

Epilepsy in Childhood (family perspective)

Transcript for chapter 6 of 9: People's responses

Leigh and Ann's daughter is 10: Even though the figures state that there are a lot of people out there with epilepsy, I guess a lot of people aren't really meeting them and there's just that social stigma attached to it for some reason. And so there is maybe a little bit of fear there.

Anne and daughter Jessica, 15: We really didn't want Jessica to be seen as just having epilepsy; we wanted people to see Jessica for herself.

Bev and Tim (11 years, diagnosed at 14 months): All my friends are pretty calm about it. And if they need to know something, I'll tell them.

Anne and daughter Jessica, 15: When we told people that Jessica had epilepsy, generally we had a good response. Most people didn't know very much but we gave them either a leaflet from the epilepsy foundation or some information, and they were a lot more confident I think in having Jessica stay or go out with them on outings.

Sandra's son Elliot is 9: I think if people are forewarned, it's better for them, and I tell them what to do. I always give my phone number, I stay home if they need me, and I said that if the seizure does happen to go over 10 minutes ring an ambulance. And most people don't seem to have a problem with it.

Leigh and Ann's daughter is 10: My biggest fear is her being in a situation where she's away from people who know what to do. And if she has a seizure in a situation where she's not around people, and they don't know what to do, we could end up in a situation where we lose her.

Frank and Denise's son Luc is 6: I think it is important to let people know that Luc has epilepsy, mainly because they could see him having a seizure and unless they're prepared beforehand, they could panic. They wouldn't know what's going on.

Frank and Denise: I remember once we were in a shop and he had a seizure and people sort of look around thinking, what's he doing on the floor? I would say to them, "It's alright, he's having a seizure." Because otherwise, people might just not know what on earth is going on there. Maybe your child has fainted or, you know, really seriously ill or something and they get very concerned.

Sandra's son Elliot is 9: I would have found it very hard to sweep Elliot's condition under the carpet. The fact that he is having seizures quite frequently, in front of people. I mean, people criticize me, but how can you say your child's not having a seizure when he's having seizures in school and everywhere? And I think it's wonderful for my child that I'm not making a big thing about his seizures. It's not something to be ashamed of.

Frank and Denise: There's a range of responses. Some people may have a better idea of it than others. Some people accept it, some people look blank and say, "Well, so what?" And



other people, yeah, they do understand and they're prepared to help. They come closer to you, I find. I don't think it turns them away.

Frank and Denise: I suppose, it's not like you want to go out of your way to tell everybody he's got epilepsy, but when it's appropriate I have no problem telling people.