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Speaking from Experience
Epilepsy in Childhood (family perspective)

Transcript for chapter 7 of 9: Schooling

Anne and daughter Jessica, 15: One of the things we found very upsetting in the state school was that the principal felt that Jessie should go to a special needs school. And I was really distressed about that because I didn't think that Jessie had any deficits in her learning abilities, it was that she needed some extra help through the school work. We actually used a psychologist who did an assessment and gave us a very positive report, and we were able to go back to the school and say I'm sorry but a specialist school isn't appropriate. We just need some different strategies for assisting Jessica to do her work.

Leigh and Ann's daughter is 10: It's just that in their whole teaching career they may not have struck someone with epilepsy, and again have this feeling that they're going to be out of control with the situation. They're learned, they're teachers, they should be able to be in control, but here we are with a child that it just could be a little bit tricky should they have a seizure for the teacher. It's not their fault, it just exists.

Frank and Denise's son Luc is 6: He goes to a normal primary school and he has a full-time integration aide, which they would have had to have because of the safety issue. Because at that stage, at the beginning of the year, he was falling over so they didn't want the risk of injuring himself at school. So, they're very good. They have another child there who has an integration aide their full-time and they've been very, very good with him. But his behaviour has been quite challenging for them, but they handle it with a sense of humour, which is very fortunate. So, we're really lucky. We did shop around a lot and that school was recommended to us.

Sandra's son Elliot is 9: Elliot's school work, well, he's not academically inclined and he is behind the rest of the class. The epilepsy and the medication, I don't know how much affected he is really.

Leigh and Ann: I think with the school's point of view, with Natalie's very first seizure, a lot of the children were unaware that she actually had epilepsy, and it wasn't diagnosed anyway. They thought that she was going blind because of the visual disturbance. From the second seizure, it was much more dramatic and then the teacher sort of took it on board to explain to the children all about epilepsy – for which, I was grateful. I think it's great that people are aware of epilepsy. But unfortunately it was also explained that she could lose control of her bladder and that's what one child in particular latched onto and sort of made a comment that, "Don't sleep with Natalie, she may wet the bed." Which of course all epilepsies are different and we shouldn't really just encompass the whole lot by saying that just because you have epilepsy, or you have had a seizure, that you will lose control of your bladder, because that's a fallacy. Some people do, some people don't. So, that was a bit unfortunate.

Anne and daughter Jessica, 15: When we had concerns about them wanting to send Jessie to a special school, we used The Epilepsy Foundation, one of the workers came along to the meeting and acted as our advocate, which was really great because we were feeling very stressed by the situation. It was good to have someone there standing up for you. So, we were really pleased we used that service.

Frank and <u>Denise</u>: What Luc does at school is quite different to what the other kids do. I think they actually give him 10 minute bursts of work to do and then he has a break or he does something different; because, obviously he can't cope with anything more than that. But I think they try to have him involved with what's going on in the classroom but just not for the same length of time as the other children.

<u>Anne</u> and daughter Jessica, 15: When Jessica was going to secondary school, I actually visited the school and spoke to the principal and said that I was looking for an environment where Jessie would not only get help with her education but be supported just in general. The school that she went to was really good. They had a support teacher and we provided information and it's been a really positive experience.

<u>Bev</u> and Tim (11 years, diagnosed at 14 months): Every year we need to go and sit down with the teachers and explain to them about Tim's condition, because he doesn't look any different to anybody else. It's very hard to remember that Tim sometimes forgets things and that he lacks concentration and sometimes he doesn't have the stamina to keep on going, like the other boys at school. So, we try and explain that to the teachers. Some teachers are wonderful and they give him lots of extra attention, and they make sure he doesn't miss any information. They repeat things to him. Other teachers find it difficult to remember.

Leigh and <u>Ann</u>: I thought it was very important to inform the teachers of Natalie's situation, and to give them an action plan; which is what we did shortly after she had the second seizure. It has been written up and is in a very prominent place.

<u>Bev</u> and Tim: With some of the teachers that he might encounter at sport or at swimming lessons or at tennis lessons, I need to explain to those adults who are working with Tim some of the dangers that Tim might face. He's found important, of course, that he explains his epilepsy to the children at his school as well. And perhaps at his age now at 11, it's the first time that he's found it necessary to tell other people about him having epilepsy.

<u>Anne</u> and daughter Jessica, 15: They had a really good response to if Jessie was being teased. So it was stopped straight away. And I think that parents need to recognise that if there's teasing, they need to say, "Hey, look this needs to stop."

Anne and daughter <u>Jessica</u>, 15: I hardly got teased at all; only once or twice.

Bev and <u>Tim</u>: I wanted to give a talk to the boys to say that I did have epilepsy and just talk about that. And I got up and gave a speech about epilepsy to all year five and year six.

Anne and daughter <u>Jessica</u>, 15: In secondary school it was a lot better because the teachers and students understood more and I got the extra help I needed. So I was improving on work, not falling behind as much and also I think that because the environment was better and I felt welcome and not like I was the odd one out and I didn't belong.

Frank and <u>Denise</u>: Since Luc's surgery, the teachers have been saying to me, "Wow, he's like a completely different person now." They just can't believe the difference. He's really alert and he's involved in what's going on in the classroom.

Sandra's son Elliot is 9: Every time we had a school outing from the school, or a camp this year which I'm going to shortly, they've always asked for me. And it does annoy Elliot, because none of the other kid's parents are asked for, just me. And he doesn't want me there all the time. He doesn't want to be different. So, I'm going to send Elliot off to 'Noah's Camp' and he won't have me, but there will be people who are caring and who'll cater to his needs.

Anne and daughter Jessica, 15: Jessie hasn't had medication for the last five months and we've had no seizures for some time and the difference has been just amazing. She's a lot quicker at doing her school work and a lot more energetic and I just think that it's a combination of not taking medication and not having seizures. It's been great.