



Speaking from Experience *Epilepsy in Childhood (family perspective)*

Transcript for chapter 4 of 9: A special doctor

Anne and daughter Jessica, 15: Going through the whole medical process and dealing with doctors can be quite stressful, especially when your child's not well. So I learnt some really good strategies on insisting on information and asking questions. And if I wasn't happy, then I'd ask again or I'd ask for a second opinion. So, I think parents need to be a little bit assertive, and I know it's difficult when your child's not well, but if we don't sort of ask then we don't find out.

Leigh and Ann's daughter is 10: I think it's important to find a doctor or specialist that you feel comfortable with; that you're able to communicate with and build a rapport with. Because often in the medical profession, they'll use medical terminology and it's just way above your head. So you need to ask questions and find out as much as you can and it's your child so you need to find out all the things that are relevant.

Sandra's son Elliot is 9: Elliot's neurologist is just wonderful. He rings me up at Christmas and says have a happy Christmas. He's like a friend, and he's like a friend to Elliot. He's excellent with children and he wants Elliot to have the same sort of things that I want for Elliot. He wants him to lead a normal life, not to be so drugged up that he's seizure free and can't even live a life. And we both enjoy going to see him, he's very caring. And I think how lucky I am to have found such a great specialist.

Anne and daughter Jessica: We had a really good working relationship with our specialist and that was something that helped us in a lot of really difficult situations. He was very accessible, in that if we had problems or seizures, we could give him a call. And that's really important, because you don't want to keep battling to get an appointment. He was always approachable when we visited him in his surgery or at the hospital and the thing I really liked was that he always spoke to Jessica first. So it was always, "Hi Jessica, how are you going?" and then he would ask me how things were. And I think that's really important with children, because they need to be consulted and felt that they're part of the whole situation. He was also interested in Jessica's general wellbeing, so not just to do with epilepsy, but how she was getting on at school.

Frank and Denise's son Luc is 6: I think it's so important to be happy with your neurologist, particularly, because you need to feel like they'll listen to you and they care about your feelings and what you want to do. Not that you're just there to be told what to do.

Anne and daughter Jessica: I felt it easy to talk to him because he was like another friend, not just like another person doing his job to get the money. I felt that he really cared about me.

Frank and Denise's: The decision about surgery was probably the biggest decision we've ever made. We were frightened at first, most people would be. And it's not as if it's another part of the body that you could mend afterwards. When you start touching the brain, it has to be done exactly right. There's no room for error. And so it was a very big decision for us. We



probably thought about it for many, many weeks before it was suggested to us. But eventually we realised that there was no other choice for us, none of the other standard medications were working. And I felt we owed it to Luc to give him a chance. We'd been told about the risks and they certainly weren't as high as you might initially expect.