



Speaking from Experience

Epilepsy in Childhood (family perspective)

Transcript for chapter 3 of 9: Medication – finding the balance

Leigh and Ann's daughter is 10: The fact that Natalie went on medication was entirely up to us as parents. And I really felt I needed, well, Leigh and I needed some guidance in whether or not she was really a candidate to be on medication.

Anne and daughter Jessica, 15: It was hard to put her on the medication because I knew there could be side effects and I was worried about what impact it would have on her general health. So it was something we had to think about very carefully.

Leigh and Ann's daughter is 10: Putting your child on medication isn't a thing you would do lightly. You sort of think, let's hope she won't have another. The fact that it was a static seizure, I suppose I was terrified that she would have another, finally made us decide to do it because it seemed fairly minimal.

Bev and Tim (11 years, diagnosed at 14 months): The seizures are manageable with medication, but of course the medication itself has side effects, which we wonder, we're kind of caught between the devil and the deep blue sea in some respects.

Anne and daughter Jessica, 15: Jessie didn't have control of her seizures for a long time, it probably was nearly two years and we had a whole range of medications and a combination that we went through and that was really difficult because we'd have a good period of a week or even a month and then the seizures would start again. So you would get your hopes up and think, yes this is going to work and then the seizures would come back. It was a very hard time, because you couldn't see anything at the end of the whole process, I guess.

Bev and Tim: Tim came off medication for a couple of years because he seemed to be seizure free. And we had hoped that he had grown out of his epilepsy, which evidently occurs often once they have finished their growth period. But he's had a very big growth spurt and his epilepsy has resumed. So he's back onto medication again.

Frank and Denise's son Luc is 6: You might find medication that will control it and your child might not even have any side effects and they'll go on to live a completely normal life. Or even if you might be one of the ones who has to consider surgery, that it could be like a miracle, like it has been for us.

Bev and Tim: It's taken us all year to find a balance of Tim's medication. He initially was on one particular type of medication which caused an anaphylactic reaction. So he had to be taken off that fairly promptly. We then went on to another type of medication and that's taken some time to balance as well. Because if you have too much of the medication he becomes too tired and irritable, if he has too little, he's still having seizures. So you have to find a balance. And of course, as he grows, the dosage will change.

Frank and Denise's: Luc's still on medication since the surgery and he may have to be on it for up to two years. Because they don't want to suddenly withdraw it and find that the seizures come back again.



Sandra's son Elliot is 9: Getting Elliot to take his medication isn't difficult at all. He takes tablets. I did have problems when he was taking liquid; he didn't like it at all.

Leigh and Ann's daughter is 10: We remind her, day and night, morning and night, whether she has taken her medication. And normally you get a snarly answer saying, "yes" [laughs].

Anne and daughter Jessica, 15: Jessie, in later stages of taking medication was responsible for making sure she took it morning and night time. Initially, I was the person who was always reminding her, "Have you taken your medication?" And we found that started a bit of confrontation, because it seemed like I was nagging her. So, we got a dosette box and that was really helpful. And we would make it up on a week basis.

Frank and Denise's: He's very good about taking it. He's wonderful. We've got to the stage now where he gets the tablets out of the bottle and counts them out. And that's really good because he has to take three. And so he'll put them in a little bowl and then we put them into some water to dissolve because they taste quite nice.

Anne and daughter Jessica: Yeah, it was good using the box because I didn't have to keep on trying to remember whether I've taken it or not and mum wasn't nagging me a lot.