



Speaking from Experience *The Many Faces of Epilepsy*

Transcript for chapter 5 of 7: Medication & side effects

Mark (46 years, diagnosed 6 years ago): My seizures were reduced in severity with medication. But I had some difficulty because there doesn't seem to be any *one* medication which is ideal. In fact, the difficulty I had was the one that I found was most appropriate, I found I was allergic to.

Melanie (24, diagnosed 16 years ago): Since I was about 18, excluding other factors like lack of sleep, the medication alone has controlled my seizures very well.

Leonie (36, diagnosed 4 years ago): My seizures are controlled by medication. I'm on two different tablets which they mix together really to control the partial seizures and the possibility that I may have Tonic Clonics as well.

Melanie: During my sort of pre-teen years, when I was really growing fast, I found that the amount of drugs that I was taking would have to be really well monitored. As I got bigger, I would have to take more of the drug to compensate for the fact that obviously I had grown. There was always sort of maybe a couple of week period after I'd had a growth spurt and maybe then I'd have a couple of seizures in succession or maybe two or three in a week or maybe one or two in a day – which was unusual for me, in any case.

Robert (32, diagnosed 10 years ago): My seizures weren't controlled by medication in the beginning. My seizures were probably partially controlled by medication.

Stephanie (23 years, Seizures from approx. 6 years, diagnosed at 16 years): I'm able to control my seizures with medication. At the moment, I'm very well controlled. That's why I'm allowed to get my licence. I guess it's a result of a well-balanced diet, or well-balanced life style. If I don't get much sleep, if I don't look after myself, of course I may have a few seizures.

Bev and Tim (11 years, diagnosed at 14 months): The seizures are manageable with medication, but of course the medication itself has side effects and that's not a very good thing for Tim because he is often tired and irritable and lacks concentration and forgets a lot of things.

Leonie: I had double vision. For the first week or so I could hardly get out of bed and get up and walk. As time wore on, I got used to the drugs but I still had tiredness, sleepiness. It would be quite easy, if I was going to the movies, to fall asleep right in the middle of it. Occasionally I'd have nausea for no real reason, but they're the main three things. I still occasionally suffer all those things. But minimal, it's minimal.

Libby (68, diagnosed 23 years ago) and husband Jim: My epilepsy will never be stopped completely, because I have far too much brain scarring. But the drugs are beginning to help now. They've cut it down to either when I wake up in the morning or at night. There are a great percentage of people whose epilepsy is completely controlled by drugs. Some have

surgery and that cuts out their epilepsy altogether. That's something very new, that's not appropriate for me.

Mark: The reason I went with surgery is the doctor offered it as an option where there was a reasonably good chance of it stopping my seizures. And in doing that, I felt that I could return to what I considered to be a normal life.

Melanie: I've been taking that medication now since I was about eight. So I don't feel that I get any side effects from them. Then again, I may have side effects from them that I've been having for so long that I don't consider side effects any longer.

Stephanie: There's side effects that I've had over the years. There's been extreme weight gain, fluid, hairiness. Which I guess for women, they're not the ones that you want. Memory difficulties, cognitive difficulties. The way I think, the way I read, the way I... you know, just the way I think. It's like you're in a drug haze. You walk around and everything's sort of foggy.

Libby and husband Jim: At the very beginning, the psychologist that I went to then decided to ask me how much side effects from the drugs I was prepared to put up with. We discussed it together and I said, I will have *this much* side effect, despite the fact that I will have more episodes. The side effects can be very annoying. I think that I have some memory loss. Also, there's one thing that I would really like to say and it's embarrassing for some people to talk about: the drugs have affected my libido. Now, the first neurologist I talked to about that said to me, "You're 50, what are you worrying about?" I actually left him, I felt quite damaged by that comment. I was able to talk to a senior neurosurgeon about it. He said, "We're very hesitant about bringing this up with a patient. It's better if they bring it up with us." So, it's been a bit annoying, Jim, hasn't it?

Libby and husband Jim: [laughs] Yes.

Mark: After surgery, I was actually never told that I would be seizure free. The neurologist was able to tell me that from the history so far, it looks like it was a success. But they can never 100% guarantee that, but I feel that in myself, it has worked.

Melanie: My doctor suggested I had the opportunity to go off my medication, if I so chose. After I had been seizure free for three years.

Robert: I'm still on medication after surgery, because I've been told by the doctor that my brain has been affected in some way. Therefore, the medication will need to continue for, it could be for the rest of my life, but initially for the first two or three years.

Melanie: My medication controls my epilepsy brilliantly, I would suggest. I know that my epilepsy has been mild in comparison perhaps to other people's. And the fact that my medication controls it so well is something I wouldn't risk. I have a driver's licence, and if I have problems controlling my seizures, I would lose my driver's licence. And, for that reason, I continue to take my medication. It doesn't interfere with my life in any huge way. Once in the morning, once at night. That's something I'm willing to take on for the rest of my life, if I have to. It's worth a driver's license to me and it's worth the lifestyle I'm able to maintain.



Libby and husband Jim: One of the great things that has helped me with my epilepsy has been some of the doctors that I've had. First neurosurgeon was magnificent, he was like a father figure. I have changed neurologists once, because I felt like I couldn't get what I wanted from the first one. The second one I have a terrific relationship with. We're on first name terms, not that that gives you a good relationship, but it helps. It's being equal. He's very interested in what I have to say, because he can make a diagnosis on that. I know what's wrong, but he's the expert. We're both human beings, but he's the one with the expertise that I need, and he's quite willing to share that with me. And if I went to a neurologist who didn't do that, I wouldn't stay.