



## Speaking from Experience Young People & Epilepsy

### Transcript for chapter 3 of 8: Medication

**Alison** – I've been on heaps of different medications since I've been diagnosed. There hasn't been a medication that has been able to control it properly. At the moment, I'm going on different trials to see if one can actually control it properly.

**Alix and Chris** – She was put on one drug, with the idea that we would keep increasing the amount until they stopped. So, we kept increasing the amount, but they didn't stop.

**Sian** - He kept increasing the dosage on different medications, whenever I transferred to a new one. But it was clear that I already had bad side-effects.

**Cassandra and Daniel** - One of my side-effects is not being able to put on weight. I am eating and the medication that I'm on is meant to be a weight-gainer, but it has the opposite effect on me and I can't put on weight.

**Alix** – Gaining weight, nausea, I had to watch out for rashes because that was a symptom of Steven Johnson's Disease, which is deadly.

**Alison** – I've had a lot of side-effects, from dizziness and nausea to weight gain, weight loss. There's been everything.

**Taylor** – I was always angry and I'd just lash out over nothing. I'd sometimes fight my friends and fight people that I never really wanted to fight at all, over nothing.

**Patrick** – I do get a bit moody sometimes, with the medication and whatever has happened that day, if I've had a seizure. My mates know that to back off a bit on that. My girlfriend is very supportive of whatever I do. She helps quite a bit as well.

**Alix and Chris** - I remember thinking that Alix was just lazy and that she just didn't want to tackle these things, but she was just under the influence of the drug. I remember stopping her pocket money because she wouldn't get involved in things and I thought, 'Oh no, what have I done?' [laughs].

**Patrick** - I had a medication that made me have even more seizures, because I had an adverse side-effect. Getting your medication right is the most important thing because you want to have zero seizures.

**Alix** – A friend of my father's knew someone who worked for the Epilepsy Foundation and she referred us to a neurologist in Melbourne, who is my current doctor. She noticed straight away that I was having tiny seizures, which no one else noticed. After I awoke out of them, I didn't know what was happening, my parents couldn't see them. No one around me could even see what was happening. She put me on a much smaller dose of that medication plus a small dose of a different medication as well, at different times. Within no time at all, I was feeling better and I wasn't having seizures and I've been seizure-free for over two years.



**Sian** – We were eventually referred to a specialist, a neurologist who also specialises in Epilepsy. He's very good. When I was having side-effects, we might go up a few [dosage levels], but when they [seizures] increased, or they didn't work; they'd discard it. We have a great relationship with him. He gave us his mobile [number] so that in emergencies or if we were uncertain about a side-effect – because I'd get new side-effects that weren't listed. This medication is for the brain, and everyone is an individual, so it affects people differently. Some things happened [side-effects] that weren't on the tablet box, and it started to scare my parents. When I wasn't able to talk, that freaked everyone out. He was great and we still see him but now our appointments are quite spaced because I'm stable. I think he sees my stabilising as a personal triumph.