



Ben's Story

Ben explains his epilepsy

Hi,

My name is Ben. I am 10 years old and I live with my mum and my kid sister Sarah. I have a condition called epilepsy and my mum thought it would be a good idea if I told you something about it.

When I was eight I was playing out with my friend Sayed in his garden. We were playing football and seeing who could score the most goals. I was winning when I started to feel a bit weird. I couldn't see properly and Sayed sounded as if he was miles away. Then, the next thing I knew, Sayed's mum – that's Yasmin - was leaning over me telling me I would be fine. I didn't know what was wrong, or how I was suddenly in the kitchen.

Yasmin phoned my mum and soon everything went crazy. I felt fine, just a bit tired, but Mum and Yasmin took me to the hospital. My mum said it was just in case I had concussion. My mum said that's when you bang your head hard, pass out and then the hospital just wants to check if you're OK. I didn't think I had concussion, but you know what mums are like! When I passed out Yasmin carried me into the house. She must be very strong!

The doctor at the hospital was great. She let me have a go with that thing doctors use – it's called a stethoscope. I could hear my own heart beating and everything. She asked me loads of questions, then went away and asked Sayed, his mum and my mum loads of questions too. After the doctor

looked into my eyes and did a blood test, she said I could go home.

Mum explained to me that the doctor said I had had a seizure when I passed out at Sayed's house. I didn't know what a seizure was and my mum didn't seem to know either. When I went to bed that night it took ages to get to sleep. I was worried that I might have another of these seizures.

I didn't tell my mum I was worried, but I talked to Sayed about it the next day. I asked him to tell me what happened after I started to feel weird. He said I just stopped running and then went kind of still and fell over. Then my arms and legs jerked a bit and then I was unconscious. He reckoned the doctor would just give me some pills or something and I would be OK. Sayed takes pills and he's OK.

Ages after having the seizure at Sayed's, it happened again. I was with my mum in the supermarket and I started feeling funny. I tried to tell my mum and then suddenly I was waking up with all these people standing over me. I was pretty scared at first, but then I heard my mum and I knew I was OK. My mum asked the people to leave me alone and a man that worked at the shop took my mum and me into an office.

As soon as I felt OK, we went home and mum phoned the doctor. She told me I would have to go back to the doctor, but I didn't mind that. Then Sayed came around and we played on my computer.

When I saw the doctor he told me that I had something called epilepsy. He said this is

something lots of people have and that there are probably other kids at school with it. It's to do with your brain - something goes wrong for just a few minutes and then it's OK again.

When I asked him what it is that goes wrong, the doctor told me that our brain sends messages to the rest of our body to tell it what to do. One bit of our brain works our eyes and another bit works our legs – something like that anyway – but if you've got epilepsy these messages get a bit mixed up sometimes, and that's when you have seizures.

I thought that it wouldn't be too good to keep having seizures all over the place, but the doctor reckons that if I take the tablets he's given me, I might not have too many. He said that a lot of kids stop having seizures if their tablets work really well. When I asked if mine would stop, he said we would have to wait and see.

I asked the doctor why I had epilepsy – did I catch it off someone? He told me that it is impossible to catch epilepsy because it is not that kind of illness, not like measles or chickenpox. He reckons that I might have fallen over and badly bumped my head or something like that and that had left a small scar on a bit of my brain. I tried to remember banging my head, but I couldn't.

My mum asked the doctor if I was having fits and he explained that they used to be called fits, but most people say seizures now. I think I prefer seizure, because at school we say people are having a fit when they are really angry, and that's not what happens to me.

The doctor told me there are loads of different types of seizures and what happened to me was a tonic-clonic. He also told me that there are lots of seizures where people don't fall to the ground or become unconscious.

The doctor at the hospital gave my mum a leaflet all about epilepsy because she was really worried about it. I told her what the doctor had told me but she wanted to find out more so she phoned the telephone number on the leaflet (Epilepsy Helpline freephone 0808 800 5050).

My mum had to go to the chemist to collect a big box of pills for me. The doctor told me that I will need to take one after breakfast and another one after tea. I didn't really see why I should bother taking these pills if I could still have another seizure. But the doctor said that sometimes it can be difficult to decide exactly which pills, and how many of them would be needed for each person. He called this 'trial and error' and said that if one type didn't work, then there were usually others that could be tried. He said that until I've tried them I wouldn't know if they would work for me. So, I agreed I would take them to see what would happen.

When I told Sayed that I had epilepsy, he said he has epilepsy too. That's why he takes tablets. He doesn't have seizures now though, because his tablets have stopped them. He said his seizures are not like mine. When he has one he just stares for a few seconds and looks like he's daydreaming. His type are called absence seizures.

For a few days I was kind of waiting to have another seizure and didn't really want to go to school, but when nothing happened I almost forgot I had epilepsy. Then it happened – I had a seizure at school. My teacher sent for an ambulance and I was taken to hospital. I was really annoyed because we were doing maths, which is my favourite lesson.

When word got round that I had epilepsy, some of the other kids started calling me names. I pretended this didn't bother me, but after a while I

got really fed up with it. One day this big kid called Brian ran in front of me in the corridor and pretended to have a seizure and the other kids laughed. Sayed shouted at them, but I just grabbed his arm and walked away.

After I had another seizure at school, some of the kids asked me what was happening and I told them all about epilepsy. This seemed to help and I noticed that the next time Brian tried his act, other kids told him not to be so stupid. I told my mum what had happened and she made me promise I would tell her if anything like that happened again. I haven't needed to, because things are fine now.

My tablets have been changed twice since I first started taking them. I still had seizures every two or three weeks and the tablets were making me sleepy, so I was fed up with them. We went to see the doctor again and he said he wanted me to try a different type of tablet. This one was a different shape and a different colour, and I reckoned it was worth a try. I do feel better now and I haven't had a seizure for three months, so I am pretty sure these tablets are working for me.

Mum has stopped watching over me all the time – she made me feel like a baby sometimes – but I know I have to be a bit more careful. We agreed that if I was careful she would stop checking on me all the time. She even let me go abseiling when our sports teacher organised it. That was great fun.

I hope you have found my story interesting. If you would like to read more about my life and my epilepsy, you can log on to Epilepsy Action's website: www.epilepsy.org.uk. You could also speak to one of the Advice and Information Officers on the Epilepsy Helpline freephone 0808 800 5050. The people there are really friendly and will try to answer any of your questions. They will

also send you leaflets about epilepsy if you would like some.

'Bye for now

Ben

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