

Inside Ouch, Seizures and Shopping, October 2016  
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Presented by Emma Tracey and Beth Rose

EMMA            This is Inside Ouch. I'm Emma Tracey, this is Beth Rose.

BETH            Hello.

EMMA            And we've got Helen Purves with us, a fellow BBC-er in Manchester. Hello Helen.

HELEN           Hello.

EMMA            And you have a very interesting disability. What is it?

HELEN            I do, I have simple and complex partial temporal lobe epilepsy. So when most people think of epilepsy they will think of convulsive epilepsy where somebody will have a sort of convulsive seizure, perhaps fall to the floor and become unconscious, I don't have that kind of epilepsy, I have non-convulsive epilepsy which means that, well I suffer from what are called simple partial seizures and also complex partial seizures.

During a simple partial seizure I will almost blank out for up to a couple of minutes, although usually much shorter than that, and I will stay conscious but to outside appearances I will just go very pale and not be responsive at all. I think of those as like a little seizure and I always carry a pen and

paper with me, always.

The piece of paper and pen comes in handy when I'm having a complex partial seizure where I act very confused and it's almost like somebody with severe Alzheimer's where I'm just unable to focus and I'll just wander around. I find it difficult to keep a grip on where I am and what's going on. So my colleagues have found it really useful to give me a piece of paper and a pen and the act of following the ink coming out of the pen and going onto the paper seems to focus me and keep me occupied until my seizure's over, so it works really, really well.

BETH                      So do you just scribble? Is that what you do?

HELEN                     Yeah, I don't know what I'm doing when I'm writing, I don't write words or draw pictures, I just, yeah randomly scribble almost like a child but it just keeps me occupied, so instead of wandering around kind of talking nonsense and seeming confused I just sit very studiously at a table and draw and it just works really well to keep my brain occupied. It's a very odd epilepsy, it's a very odd condition.

EMMA                      Yes. No, a friend of mine, when he feels a seizure coming on he starts tapping out words on the counter top and counting out the syllables, so I guess it's the same thing, it's just a really sort of focused, like tap your head and rub your belly or something to try and focus your mind on something.

HELEN                     Yeah, although my neurologist has told me it doesn't work. ((laughs)) I mean it keeps you occupied but it doesn't stop the seizure. But you do, because it's something that you feel that you can control it, you feel that if only you kept yourself together it would all stop.

And I get a slight warning, so if you've ever had déjà vu, I don't know if you've ever experienced déjà vu, most people have, that's actually the kind of brain activity that for me starts a seizure. Now, I'm not a neurologist but my understanding is that that kind of activity of a déjà vu is where what you're seeing gets to your brain before your consciousness of what's going on does. So you feel like you've seen something twice and for me that's how a complex partial seizure starts, so if I have a feeling of déjà vu than that means to me that I need to get out of harm's way, but often I don't have the opportunity to do that so I'll be, especially if I'm zoning out, you know, sort of sitting on the bus and not really thinking about what I'm doing then often, especially if I'm stressed or I'm hungry then those are all triggers for me and I can just drift off into a complex partial seizure and then I'll come to, and for some reason for me - everyone experiences it very, very differently with non convulsive epilepsy - but for me I will go and shop. I think it's just something about me that loves to buy stuff.

EMMA

Well I mean, it could be worse, right? You're quite happy and smiley talking about, but there's quite a serious side, you have a little child a similar age to my own child?

HELEN

Yes, and I have to admit it does pray on me quite a bit that I could have a seizure whilst out and about with her, so I have to try and avoid situations where I'm on my own with her, I wouldn't hurt her obviously but I have to be aware that yes, it could come on at any time and as yet I've not really come up with the solution for that, like I just try and make sure that my friends and family are about me but I don't quite like the feeling that I can't be left alone with my daughter, that's not a very pleasant feeling.

EMMA

And do you spend time on your own with her or do you just

make sure there's someone around all the time?

HELEN I try to make sure there's someone about all the time, but it's impossible, I mean there's always going to be times when I'm alone with her. I have had a seizure when she's been there but there is some kind of instinct about me where, so if I have a seizure in the street, for some reason always make my way home. So even though I'm not conscious of what I'm doing I'm able to walk about, I'm able, not really to hold conversations with people, but I always make my way home. And with my daughter, so far, I'm really crossing my fingers, I've been able to kind of keep her safe, put her somewhere safe when I experience that aura. But to be honest with you now in talking to you it is making me quite aware that I probably should have some contingency plan.

BETH How often do these seizures occur?

HELEN Well, when I'm well medicated, not that often, and it is quite rare, but I would say I would have maybe one or two a year.

BETH And how did you come to be diagnosed with it?

HELEN Oh my goodness. My diagnosis story, ((laughs)) this is quite a story. When I was 16 I first told my mother that I was experiencing these seizures and she'd been a mental health nurse in the 1970s, and in the 1970s people with this kind of epilepsy were often considered kind of mentally ill and they would be institutionalised and my mother had seen people that had been institutionalised from mental illness. So she told me never to tell anyone what I was experiencing.

BETH

Oh no.

HELEN

And I went through all my exams, my GCSEs, my A levels and the stress every single time would bring on a seizure, so pretty much every exam I had I had a seizure in the middle of it and lost loads of time and I was predicted really great grades and did really badly but I got into university. Luckily I did a vocational degree, journalism, so I kind of did okay because course work obviously was fine, and I got through my degree and I got through my masters and then the day I handed in my dissertation I had five seizures that morning and I decided that I would hand myself in to my doctor and admit and I would be locked away.

So I tidied up my flat, I packed a little suitcase, I put everything in my handbag that I would need, should I be immediately shuttled in to a padded van and then I went to my doctor and I said to him, you know, "I've been experiencing these seizures," I was trembling I was so afraid, but I thought I've got my education, if I'm institutionalised I shall have my brains to keep me through the boredom and tedium, because I don't know what it's like.

And my doctor, instead of immediately locking me up he just looked vaguely disturbed and said, "Right, I'm going to get you a consultant appointment for the hospital," and he said, "Off you trot, go home." And I was like, oh my goodness, I can go home. But I didn't get a letter, so two weeks later I went back and I kind of said to him, "Okay, what are you referring me for? What's going on?" And he said, "Well, I'm going to make you go and see a neurologist," and he shuttled me over there straight away and I was promptly diagnosed with epilepsy. ((laughs))

BETH

Wow.

HELEN                   And it all fell into place.

BETH                    So before you had the diagnosis and you were telling your mum that you were having these seizures how did you describe them before you knew what they were?

HELEN                   Well that's it, that's the difficulty. How do you describe kind of this weird déjà vu and then I get this aura and this feeling that I'm floating outside my body and then it's almost like a roller-coaster ride, you get this gastric uprising that you get, you know, the butterflies in your stomach and then it feels like you're just out of control and whizzing about and it's crazy and sometimes you can see kind of, well I do anyway, every seizure's different, but I see sort of pictures and lights and things.

And for a while I thought, almost arrogantly, that maybe God was speaking to me and I had a little kind of religious phase and when I described it to my mum I was like, "Well I think I'm seeing spirits." If you're not religious it does sound a little bit crazy, but as an atheist I kind of thought well it can't be God because I don't believe in God. But then every epileptic person will have a completely different experience so the range of experiences from non-convulsive epilepsy can be massive and it's something... I mean when they told me that I had epilepsy I was absolutely baffled and I spent a long time, as you do, Googling and the range of experiences that people have are absolutely immense, the only constant really is that it kind of affects your memory over time and stuff.

EMMA                    You've been listening to Inside Ouch. I'm Emma Tracey, thank you to Helen Purves.

HELEN Thank you.

EMMA And Beth Rose.

BETH Thanks a lot.

EMMA We do lots of other stuff here on Ouch, we do Facebook Live, so you can like us on Facebook to watch some of those. There's one on the page at the moment with Daniel Biddle, a 7/7 bombings survivor. We also do articles, they're on [bbc.co.uk/news/disability](http://bbc.co.uk/news/disability). You can follow us on Twitter @bbcouch and you can email us on [ouch@bbc.co.uk](mailto:ouch@bbc.co.uk).