

Annette's Story

My first recollection of having what I now know to be a dissociative attack was when I was 20. I was on a weeks' dinghy sailing course. I was crewing on a 4 man dinghy and we had just tucked into some huge Mars Bars. I remember that a short while later I felt I just could not move. I just sat there, transfixed. I could not divert my eyes, blink or physically move. It was as though I was 'frozen'. The next thing I knew was that I was falling forward into the centre of the boat. I am not sure what happened after that but my next recollection was of being man-handled into the safety boat. By the time we got back to the sailing school I had recovered enough to walk back to my room and went to sleep. I went to see a doctor some point after that and I was told that I was probably unfit and I needed to do more exercise! I just couldn't bring myself to tell him that I went to the gym twice a week, sailed most weekends and went on skiing holidays.

At this point I was only having 'drop-attacks'. They were usually out of the blue and the only warning I got was when I realised I was on the way down. Sometimes I remembered the landings, other times I didn't and the length of time I was unresponsive varied greatly.

There was one time I was particularly bad. I kept falling over and slept a lot of the time. My Mum called out the GP and when he took my blood pressure, said I had to go to hospital as it was very high – something over 200. I had various tests done – all came back fine.....naturally! The Registrar at the time said it was probably a virus, maybe ME. I slowly recovered, regained my weight and gradually increased my hours at work having had at least a month off.

These attacks continued with no regular frequency or pattern. Sometimes I could go six months without an attack. Other times it could be 3 in a week. I did start getting sensations that I was going to 'go' and somehow I managed to sometimes prevent them but my legs would tend to go a bit wobbly afterwards. My GP was at a loss as to who to refer me to. I went to see a Neurologist who tested me for Epilepsy. The tests came back clear but no suggestion as to what else it could be.

I continued putting up with these drop attacks but they and the sensations that I might keel over started getting worse. My GP referred me to a Cardiologist where I had an Electro-physiology Study, Tilt-table test and ended up having a 'Reveal' fitted to monitor my heart beat and then catch a recording of my heart during an attack. Again, it all came back as 'normal'.

I went to see a Neurologist again who without even examining me said I needed to see a Psychiatrist. He was extremely dismissive and rude.

I decided to go to a Complementary Clinic where they performed some very strange tests and after being lots of different concoctions ended up wearing some sort of 'frequency transmitter'. Don't ask.....I know it sounds odd but you do anything when you are so totally desperate. I also went to see someone who tested me for any allergies as by this point I was convinced that my episodes were due to some chemical imbalance or some sort of allergic reaction. He told me that I was sensitive to milk, mono-sodium glutamate, sugar and.... cod. At this point the credibility of his findings went right out the window.

I became pregnant when I was 32. I couldn't understand at first why my drop-attacks had increased in frequency and when I found I was pregnant put it down to the hormones. After a few months, these attacks became so bad that I asked for a wheelchair as it was the only way I could see I could get about and continue to work. However, at 22 weeks, I was signed off sick as I was still keeling over even in the chair. I saw a Neurologist yet

again and that was a complete waste of time (and how he even became a physician I shall never know!) and as I was pregnant, he couldn't perform any tests anyway.

After I had my son I relented and went to see a Psychiatrist. After a few sessions, two of which I also had these attacks, he said that I was an 'enigma'. Not particularly helpful when it seemed he was my last resort. He also said that I was clutching at straws if I thought that food had any influence on the attacks.

Anyway, things just slowly improved again and I went back to work after a year off. The drop attacks continued as and when they felt like it. Four years later I became pregnant again. However, it was when we were on holiday and I was 21 weeks pregnant that my drop-attack followed through with a fit. This was the first of many after that and they have never gone away. During the pregnancy I wondered if these fits did actually have something to do with hormones and possibly sugar. I experimented and found that I felt much better once I left out sugar. The fits didn't go away but they certainly seemed to reduce in frequency.

After I had my daughter, the fits and drop attacks continued and my GP re-referred me to a Neurologist who felt that they were dissociative seizures and recommended Cognitive Behavioural Therapy. I went to see a Professor who after spending an hour with her lackey told me that my attacks were basically 'in my head'. I left at that point (rather prematurely!) absolutely crest fallen and I just couldn't cope with anymore disappointment. I vowed that I would never see anyone again and would just have to get on with it. I treated the attacks like sneezes in so much that they happen and then I forget about them. Life is too short to dwell on them and I have to make the most of life – such as it is. I know myself better than to believe that it is 'in my head' and doctors should appreciate that most of us actually are intelligent people and not village idiots.

In the end I gave up work as I was taken ill and it was obvious my employer thought I was making myself do them. That was over two years ago and I haven't been able to work since. They have been worse this last year and my own opinion that it is something to do with hormones but hey...what do I know!

These attacks have and do cause me a great deal of stress (something that I know is a trigger). It also has a huge impact on my husband and my children and despite my efforts to reassure them that I am OK, doesn't help when a few minutes later I could be on the floor doing my 'fish out of water' impression in front of them. I feel totally useless and extremely angry at the attitudes of professionals that I have seen in the past. It is only because an A&E Consultant believed that I was epileptic, having arrived at A&E in January this year that I did the Neurology rounds again. It is on this fifth lap of Neurologists that they have actually explained exactly what dissociative seizures are; that they are not 'in my head' and I am not making myself do them. To say that it's a revelation is an understatement. It is only now that this condition has a name that I have let my children talk about it at school (I had sworn them to secrecy before...with hindsight this was not a good thing). I was too embarrassed before to let people know about it as I really did think that perhaps I was going mad. Even my neighbours, teachers and some of my friends didn't know about it.

I am now on a voyage of discovery; finding out about the condition before I can even embark on my voyage of recovery which, after so many years of putting up with so much from so many people who are supposed to be there to help you, I think this is going to be a very bumpy ride. I am prepared to give it a go as the alternative is bleak to say the least. My family have also read this website and knowing that their wife/mother isn't a complete lunatic and that I am not dying has been incredibly helpful to them.