

**Only a doctor can diagnose and treat Epilepsy!**

# Epilepsy Support



## **Solo's Story.**

My story begins in the mid 80s when I started having “funny turns.” I had three young children and these episodes became more and more frequent. It was a while before I could face going to my GP about them. I felt he maybe a little sceptical as I couldn't describe clearly what was happening to me other than the episodes were strange and disorientating and just a bit frightening. When I finally decided to pay him a visit, I knew I had been right to be worried when he peered over his glasses at me and raised his eyebrows. It wasn't until my first “collapse” whilst cutting a child's birthday cake, with a knife in my hand, that he referred me to both a neurologist and a cardiologist at the Manchester Royal Infirmary. At the time we lived in North Wales. After extensive investigations and several stays there as an inpatient, a diagnosis of Temporal Lobe Epilepsy was made and I was started on phenytoin...and I had to stop driving. Living in a country area, this was devastating as the bus service was almost non-existent. The phenytoin didn't control my seizures and so two other AEDs were added but they still continued and gradually became worse. It was then that I was referred to Dr Steven Brown of the David Lewis Centre. I was under his care for the next 10 years and lucky enough to have the continuity of always being seen by him.

My life and that of my family, took a dramatic turn when I repeatedly went into status epilepsy and was admitted to the Assessment Unit of the David Lewis Centre for a period of 6 months. It was a terrible time as the children were so young. It was there that they discovered I was also having non epileptic seizures (formerly known as pseudo seizures) running along side my temporal lobe seizures. It was a long, painful struggle getting better but with a lot of support I made it out of the door and started to function again even though my seizures continued to be very frequent. Dr Brown felt that the majority of them were now temporal lobe but warned me that non epileptic seizures are common and it's often very difficult to differentiate between the two. I felt at that stage that I was wearing two labels and as hard as I tried to explain, many people misunderstood the meaning of non epileptic seizures. The word “pseudo” conjures up all sorts of ideas such as “fake” and “simulated.” I became very unhappy and depressed thinking that the whole world thought I wasn't genuine. I've met many people since who've been told that either some or all of their seizures are non epileptic and they have been through exactly the same emotions as me. And yet these seizures are completely out of one's control, just like any seizure and need treatment.

I lost continuity of care when Dr Brown left and I was never seen twice by the same neurologist in Manchester. I have now developed other health problems which have been linked closely to phenytoin and I've been in hospital several times. I regret not having found out more about the side effects of AEDs and always urge people to do so. Because of the lack of continuity of care I have now been referred to hospitals nearer my home and things are a lot better for me now.

I have never quite got back on my feet since those early days but I am very sure that if there had been Janey's Epilepsy Support then, I would have made better progress. Since I joined a year ago my life has turned round completely and I'm beginning to regain some of the confidence that I thought was long gone.

This is an Epilepsy Support article that is written, not by trained medical experts such as a Doctor but from the experience and view point of a person with Epilepsy or who cares for a person with Epilepsy.

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