

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



### **My Child has Epilepsy**

***Gigi Interviewed a parent of 4 children, 2 of whom have Epilepsy***

H is in her late 60s. She has four children, who are now in their late 30s/early 40s. Two of them suffer from epilepsy. This is her story.

#### **When and how did you discover that your children had epilepsy?**

A was only about 14 months old when she had the first seizure I was aware of. In the middle of the night she suddenly started crying and convulsing. I was terrified, and had no idea what was going on. When we called out the doctor, he suggested it might be a febrile convulsion brought on by a fever (A was having a difficult time teething and had also recently had her whooping cough inoculation, and apparently young children may suffer seizures under either of these circumstances). The following day we took her to the hospital for tests, but, in spite of the fact that they kept her in overnight – I was reluctant and extremely distressed about that – nothing abnormal showed up.

I vaguely recall a second seizure while she was still very young, during which we put her into a tepid bath, as advised, to lower temperature, but subsequent to that there was nothing out of the ordinary for several years. It was only when she was maybe four or five that I started having an uneasy sense that something was 'wrong'. She was a very bright child and spent a lot of time thinking, so we didn't register her petit mal (absence) seizures for some time. You would be talking to her and she seemed suddenly to drift away into unawareness for a few seconds, then 'come to' and continue the conversation. It was very strange. At the time I knew little about epilepsy and certainly didn't associate it with A's spells of not being 'with it'. At school I had known a girl who had convulsions three or four times a day, and that was how I pictured epilepsy. However, when, aged about 7, A started having full-blown tonic clonic seizures at school, more exhaustive tests were carried out – she had to remain in hospital for a week at one stage – and an EEG finally defined her as suffering from 'petit mal with a tendency to grand mal'.

Then came the difficult period of balancing and adjusting medication. Initially they overprescribed Phenobarbitone, with the result that one morning I had to call out the GP because I could not wake her up. Later on, the medication made her driven and hyperactive – definitely not a case of simple childhood liveliness! Things did improve, however, when she came under a specialist at the London Hospital in Whitechapel. She was prescribed a mixture of Phenobarb and Zarontin, which seemed to stabilise and control the problem for a long time.

My son, J, was a different kettle of fish altogether. He started presenting signs of epilepsy as a 14-year-old. At the time he had a very long journey every day to a school he vehemently disliked. When he began to have seizures in the early morning before school, we really thought he was faking them, a combination of attention seeking and manipulating us into changing his school. Eventually it became clear, from the tongue-biting and other hard-to-simulate manifestations, that it was genuine, and, again, he was diagnosed epileptic following an EEG. His reaction to the diagnosis was a long way from A's acceptance, he was a real worry because he rebelled against it. His actual seizures were a lot more violent than A's, though less frequent, every six months or so.

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. 1

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The situation worsened as he grew into young adulthood. He either refused to take his meds or altered the dosage to what he felt was appropriate. At 17 or 18 his lifestyle was out of control; he was taking other drugs, and living intermittently in squats with friends; obviously this was very difficult for us at the time, though as he matured he became more responsible.

### **How did you feel personally about your children's condition?**

I have always been desperately upset about it. Even now, I am devastated when one of them has a seizure. It seems so unfair on them, and we are so powerless. Normally, if there is something wrong in your child's life, as a parent you can actively help or get assistance. In this position, it is very hard – you can do very little and you have to watch them suffer.

### **Given that two of your children are affected, is there anything you feel may have contributed to their epilepsy?**

There is no history of epilepsy in the family, as far as I know, but on my husband's side there are allergies, eczema and asthma. J and A are the two of my children who have inherited these conditions, which I think is significant. In my opinion – and this is only my opinion – they may have had an allergic reaction to their whooping cough vaccinations. I am suspicious, because a warning was put out some time later that asthmatics should not have that particular form of jab.

### **How, as parents, have you handled the situation over the years?**

We felt very strongly that our children should live 'normal' lives and have treated them accordingly, encouraging them as much as we can. Early on, A's primary school contacted us to suggest that she should refrain from taking part in gym, sport, drama or swimming, in case injury resulted. I was furious when I confronted the head teacher about this. Eventually they gave in, but we did have to state in writing that we would take full responsibility if she had an accident.

I believe children need to have access to the full range of experiences on offer. Not to be treated like freaks. After all, accidents can happen even to those without this type of condition.

### **What level of help and information was available?**

It wasn't like these days, obviously, when you can obtain information on the Net, and so on, but, to be honest, as I began my research (my instinct is to find out as much as possible about the unknown so that you cease to fear it), I discovered that lots of information was to hand, especially in books and, to a lesser extent, from our helpful and interested GP. I think that at the time there was an initiative to modernise thinking and treatments. After all, it was not long since epilepsy sufferers had been regarded with superstition, institutionalised in asylums and given ECT. As a carer for the elderly, I know many people who have suffered in this way. Sadly, there is still a great deal of fear and ignorance. Watching somebody losing control is still terrifying and mistaken ideas about how to deal with it are still rife. Even the other carers in my work place are frightened when they handle a seizure.

Once I became more knowledgeable, I gained in confidence and was better able to cope. Suddenly I noticed it around me more too! I always seemed to be helping out grateful epilepsy sufferers in shops or in the street!

### **How have others reacted when you have told them about it?**

People have always reacted well and with understanding, but then I have always been very positive and upfront about it. I tell others if the subject crops up naturally, and explain anything they need to know. It is really important to be direct, not to hide things and not to worry endlessly about what people will think – they may surprise you. We must talk openly and calmly about it in a non-committal, impartial, conversational way. It is just a part of life.

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### **Has the experience of parenting epilepsy sufferers changed you at all as a person?**

The experience of parenting has changed me as a person! Living changes you as a person! Every experience has an impact. Some may say that a mother or father in this position would become more tolerant, determined and understanding, but let me tell you something; life in a large family makes you more tolerant and understanding, of necessity. You just all learn that every member of the family is different and special and needs to be accepted as an individual personality. Epilepsy is just one small piece of the personality jigsaw, no more important than the others, and should not be focused on more than necessary.

### **In what ways have your children's lives been affected?**

Obviously there have been limitations in what they have been able to do – A still can't drive – but very, very few. Epilepsy has helped them grow in strength and determination and I feel so good about the qualifications they have achieved and what they have done with their lives and their talents. They are both settled and confident, both obtained good jobs with ease and both are married with stable relationships and lovely children of their own, none of whom suffer from epilepsy. It is a fantastic achievement. I am enormously proud of them, and always will be.

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