

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

# Epilepsy Support



## **Our Daughter and her Epilepsy - The Early Years by Bagpuss**

I can still see it in my mind's eye. I was curled up on an armchair, book in hand. My youngest daughter was asleep in bed. My husband was out lecturing at Evening Classes. My eldest daughter was crouched on the floor drawing. The television was switched on in the background. Suddenly my daughter fell backwards. The upper part of her body was hidden from sight under a table. She was shaking, at first I thought she was shaking with either laughter or silent sobs. I asked her what was the matter and got no reply so I got her legs and pulled her towards me and when I saw her face I was absolutely terrified. She was totally white her lips were completely bloodless. Her eyes were open wide and her pupils totally dilated. She was no longer shaking. I thought she was dead because she didn't seem to be breathing. I just held her and rocked her I really didn't know what to do because I was so very afraid. I couldn't leave her to phone for help. I was absolutely panic stricken. Then she gave a great sigh and started to breathe again her colour gradually improved to normal but very pale flesh tones.

I laid her down gently on the floor and ran to the telephone and called my next door neighbour. I said I think my daughter had concussion from falling backwards and asked if she would mind taking me to the hospital. I knew it would be a couple of hours or so before my husband came home and couldn't wait for him. A friend who lived with my neighbour came in to babysit my youngest while we went off to hospital. I had heard that if someone has concussion you mustn't let them go to sleep. I didn't know if it was true or not but wasn't taking any chances. I kept on talking to her making her respond, she kept muttering she wanted to go to sleep when she made any sense at all. The hospital is only about 4 miles from home but it felt like 40. Eventually we arrived there and booked in. We were seen quite quickly. Dr. listened to what I had to say about concussion and she was sent for an x-ray.

We were then placed in this little side room and left. I was told I could let her sleep so she went to sleep and I started to calm down and run over in my mind what had happened. Although I knew next to nothing about Epilepsy the more I thought about the events the more I became convinced in my own mind that it wasn't concussion and felt it more likely to have been an Epileptic seizure. Eventually my husband arrived and joined us. He asked me all about what had happened. Talking it through with him I said although I originally thought it was concussion, how did she get concussed when she fell back onto a carpet covered wooden floor. Considering she was already crouched down she didn't have far to fall I thought it extremely unlikely she could have hurt her head doing so.

The doctor finally returned and said x-ray okay. Told him about my theory of a seizure. But he told me that when someone is concussed the brain gets shook up which probably led to her loss of consciousness and dismissed what I said. We were given a list of what to look for regarding concussion and duly sent on our way with a letter for our general practitioner. Rather than hand the letter in I decided to make an appointment to see a GP to discuss it.

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 GP was not prepared to listen to my theory and insisted it was concussion. I said "Okay I accept that it is concussion but just in case I am right and it was a seizure what exactly am I supposed to do if it happens again?" GP gave a great sigh and said if it happens again make sure she is safe and get in touch with us straight away. His whole manner was one of total disbelief that it would ever be necessary. Three weeks later it happened again on a Saturday morning.

This time my husband was at home and he was panicking a bit." What are you going to do?" he asked me. I was all cool calm and collected, "I am going to do what they told me to do" I replied "I am going to phone the GP's. I walked over to the phone and dialled the number. When I was connected I started to say why I was calling when a voice from the other end said "Is that you Peg?" Mrs cool calm and collected had phoned her next door neighbour by mistake, I finally phoned the surgery explained to the receptionist what had happened and that I was told to phone in if it did. She took my phone number and said she would get back to me after speaking to the GP. In a short space of time phone went and it was my favourite GP he asked how she was and I told him she had now gone to sleep and I was letting her sleep. He said obviously she was over it and he couldn't really achieve anything by coming to see her but would I make an appointment with reception to see him on Monday as we need to discuss this.

Went to see him on the Monday was a bit frightened he would put her on medication without any proper checks but he didn't. He said that it sounded to him like Epileptic seizures and he didn't intend to give her medication because he wanted her to see a Neurologist first. He did say that it was quite common for children to start having Epileptic Seizures with the onset of puberty (my daughter was 10). He said he hoped she wouldn't have anymore before the neuro appointment. A couple of weeks later the appointment letter arrived for the following week. A day or two before the appointment she had her third seizure.

This seizure happened just before Christmas my husband and I were decorating a room when there was this loud crash. We rushed into the lounge and our daughter was having another seizure. In falling she had knocked over the TV. I knelt beside her and was immediately aware of the smell of peanuts. I thought she had been eating peanuts and could well choke on them if she had a mouth full. We didn't know what to do. Didn't know if we should do the unforgivable and prise her mouth open to remove the peanuts or wait to see if she was likely to choke on them and then prise her mouth open. In the end we just waited in a panic not able to make up our minds to do anything. She came round and when questioned about eating peanuts she had no recollection of peanuts at all. Later the mystery was solved when I went into the kitchen and saw that she had obviously made herself a peanut butter sandwich.

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Eventually the day of the appointment arrived. Firstly she had an EEG and afterwards we saw the neuro. He confirmed that she has pattern sensitive epilepsy and told us that a habit she had of fluttering her eyes was in fact petit mal. We had just assumed it was a habit formed and because she was teased at school about it she had in fact made it worse by becoming more aware of it. He suggested that we try to discourage her from doing it as he said she enjoyed (subconsciously I assume) the feeling it gave her. She had had this habit for several years and I felt very guilty about not doing anything about it. But it is always easy to be wise after the event isn't it. This was the first time I had heard of petit mal. She was given Sodium Valproate (Epilim). At first we went quite regularly to see the neurologist. But eventually the visits lessened.

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My husband looked into the medical reports on Epilim and at the time it was considered a good treatment for Epilepsy. The report stated that there was a possibility that it could have an effect on the liver and it could also cause weight gain. It wasn't considered to be a great risk. The problem of effect on liver would be quick to show up so we were pleased that she was given that drug rather than a barbiturate drug that would make her sleepy. In the early days I was terrible, I saw danger everywhere. The neurologist said to let her participate in sports but that when she went swimming an adult must be made aware that she was subject to Epileptic seizures. I was afraid to let her out of my sight. Always having the tendency to want to be one step behind her. I wouldn't let her ride her bike on the main roads. The neuro told me she was less likely to have a seizure whilst she was concentrating on what she was doing and to let her ride her bike. I ignored his advice because I thought I knew her better than him and I knew the way she went off into her own little world where concentration on what she was doing just didn't happen. When she had a bath she wasn't allowed to lock the door and had to sing whilst in the bath so that we would know she was alright. The times she must have got so sick of hearing "I cant hear you singing!" The fear does lessen over time but never goes away. She is an adult now and married. We are proud of her for what she has achieved over the years and the fact that despite set backs she reached the goals she had set for herself.

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