JULIE’S STORY

From an early age I was prone to fainting. Assemblies and nativity plays would be the worst for me. I was always tired and lacked concentration. My mother was called into school to discuss this issue. The school felt it wasn’t normal for a child of 8 to have such a lack of energy. I was spending a large part of the day, “daydreaming”, as it was called, and they felt I should see a doctor. I was taken to see the local GP, who thought he could hear an extra heart beat. I was sent for blood tests and a chest x-ray. All proved negative. It was decided it was down to my age and I would grow out of it.

Life moved on a bit (1974) I was 10, and still blacking out. On occasion they were a bit worse, they had changed. Mum described it as “*more of a fit*”, luckily mum was a nurse so it wasn’t difficult to explain what happened. She couldn’t understand the terrible colour that I went, and the fact I appeared to look “*quite dead*”. On one occasion my mum actually gave me the kiss of life. She was convinced that I had died in her arms. After several more episodes I was referred to a neurologist at the local hospital. I had all the usual tests, blood, EEG and head x-ray all proved to be negative. All the same, a diagnosis was made: - “*Temporal Lobe Epilepsy*”.

From that day my life changed, and people changed towards me. I was the laugh in everyone’s joke, the weird girl at school who had fits. I lost all my privacy. No locking of the bathroom door was allowed, just in case. Sleepovers stopped because friend’s parents didn’t want the responsibility of looking after an epileptic. My parents had full control of my life, and I had no choices.

My school life suffered. The teachers felt I wasn’t going to achieve anything because of my lapse in concentration, my tiredness and my lack of energy. I was left to just achieve nothing and left school with next to no qualifications. I sought something I could control, and that was my own body and the food I put into it. Before long I had embarked on a radical diet, which took me to borderline anorexic. (1978)

Depression soon took over (1978); I had no freedom, a lack of qualifications and no future. My career choices were limited, I had no chance of becoming a nurse, policewoman, or joining the forces, not only because of my lack of education but because of my “*epilepsy*”.

My next trip to the hospital was to see a psychiatrist to treat my depression. Why was I depressed? A young girl of 16 with her whole life in front of her. The suddenly, “*I was attention seeking*”, “*it was my age*”, “*it was my hormones*”, “*I would grow out of it*”, “*have a baby that might help*”. These were all things I heard from the medical profession saying. I went away with pills and potions and no body listening to me or caring about my quality of life. It was after this I decided that if I was to have any sort of life I was to live a lie, so it was my decision NOT to tell anyone about my fits and I made my parents promise that it wouldn’t be discussed with anyone.

At 17 I was lucky to meet a man who is now my husband. I hid my epilepsy from him as I had vowed to do. However, events took over and the day came when he witnessed one of my fits. After a large whisky my GP took him to one side and said to him “*bigger men have walked away*”. I didn’t find this out until years later. Lucky for me he didn’t walk away but stuck by me “for better or worse”. He was prepared to take me on and all of my baggage. However, my one condition was that he didn’t tell anyone. Our wedding day came and went. Fit free thankfully! It was a bit of a blur as I was given extra drugs to control my nerves, the day in my life that is supposed to be a memorable one but one I can just about remember getting through. Once again life moved on. I was fit free for a while. so I began to drive, and decided to start a family, (I was told it might help with my fits). I was 21.

Julie Fear, Dorset

The nightmare started all over again. From the minute I got pregnant to the minute I gave birth, I was in and out of hospital, nobody knew if the baby would survive or be normal, lucky again for me I gave birth to a healthy 6lb baby girl. I didn't enjoy the baby days, always in the back of my mind was, was I going to have a fit and injury her in the process? What would happen if I was bathing the baby or carrying her, on my own with her, who would find me, who would take care of the baby? All the pleasures of a normal mum were taken away from me because of the fear. I did go on to have 2 more children, each time I thought it might get easier, the fear might subside and the fits might stop but it didn't and a Doctor told me having a baby would help as the trigger they felt was hormones!

My youngest, Naomi, is just like me in every way. She is a day dreamer, and she lives in her own little world. I hoped she would not be like me in one way (the fits). When she was about 2 years old, the day came that I had hoped I would never see. Naomi had her first fit. Naomi was playing with her older sisters rolling off of the sofa when she let out a strange cry. Immediately I knew something was wrong. When I got to her she was deathly white, blue around the mouth, her eyes were right up into her head and her head was tilted right back. I tried to move her but she was making a grunting noise. In blind panic I picked her up and ran with her to a neighbour. I wanted someone to help me save her! My neighbour called the GP, who admitted her into hospital. After a long chat with the pediatrician, explaining what I saw, a diagnosis of reflex anoxic seizure (RAS) was made. I had never heard of this condition so I needed to find out more, as I wasn't going to get any information from my GP or Pediatrician

Soon after Naomi's first attack I watched a TV programme on Epilepsy. As I have the condition, I watched it. To my surprise Reflex Anoxic Seizure were mentioned. A book had been written to accompanied the program, and for more information, immediately I sent for the book. Each day I waited for the postman and at last it arrived. There in the book was a telephone number for a support group for families of sufferers of reflex anoxic seizures. I couldn't wait to phone. It was fantastic! At last I had made contact with someone who understood how I was feeling, and could give me all the information and the advice I needed (1995).

Time moved on and things became tough, for my husband and parents. My daughter and I continued to have blackouts, not knowing where or when it was going to happen. Life changed yet again. My other 2 children had to grow up fast and be responsible for me and their little sister when no one else was around and that caused problems. My eldest daughter started to suffer with behavior problems and was very aggressive towards me she was only 8 and looking back I can see she had a lot to cope with. By the age of 10 she was being treated for depression and was under a psychiatrist, which added more pressure to the family and still the medical profession did not understand the impact of RAS and epilepsy was having. I believe that because the doctors didn't understand the condition, they choose to ignore it.

We battled on. After one particular episode my husband called the GP. He thought I wasn't actually going to make it. Just before I went unconscious I had complained of a pain in my chest, and he believed I was having a heart attack. Again, I was put back on to medication. However, something made us think. My husband spotted similarities between my fits and Naomi's RAS. Between us we plucked up the courage to approach the GP and ask if I could possibly see a specialist to check if it was really epilepsy! I also got back in touch with the support group after several years to see if there were any changes in the support group and to ask if in fact adults were now being diagnosed with RAS. To my surprise, "*yes, they had discovered adults had in the past been misdiagnosed with epilepsy and they had in fact got the adult form of RAS - reflex syncope*".

Armed with all the new information my appointment arrived and we saw a neurologist at our local hospital. What a disaster. I was laughed at and told to put my head between my knees and to stop all my medication. I wasn't offered any test to prove or disprove my previous diagnoses, just to stop wasting his time. I needed to know what I had and what treatment was available, the patient group gave me details of an adult specialist which I then approached my GP for a referral. After waiting 5 months for an appointment for a consultation and a further 9 months for tests in September 2003 I was finally diagnosed with "Vaso Vagal Syncope", 29 years after being diagnosed and treated for epilepsy.

Where am I now? I have got my diagnosis. I don't have to take that awful medication. Surely that is the end of the chapter?

No! It is not! Neither my life nor my daughter's life has changed one bit. I have lost all those precious years, and every memorable event in my life was ruined. I still have attacks, and my daughter still has attacks. We have been offered no treatment to give us some quality of life. My career opportunities are the same and will be the same for my daughter. The stress on the family is the same, my husband worries each time he goes to work about what he is going to find on his return and my 2 other daughters still have responsibility of me when there is no one else around. This is a life sentence. I have little or no faith in the medical profession because of my treatment over the years and fear for my daughter's future unless we are listened too. I have been given treatment for my depression, cognitive therapy and drugs, but nothing will change for me until the underlying problem is dealt with. I still suffer extreme bouts of tiredness, lack of energy and confidence. I am only able to work 18 hours a week, on the recommendation of the Occupational Health doctor. This still has an adverse effect on me and I spend the afternoon and evenings sleeping. I ask, is this the way a woman of 40 should be living in 2004?

We are not alone. There are many families like mine. They will also who have to find their own specialists and hospitals. They also have to just get through each day at a time until there is some hope some thing will change. I am nearing 40 and can see my life remaining the same for the next 40. It's just an existence, not a life. I want something better for my daughter.

Julie Fear, Dorset