

Only a doctor can diagnose and treat Epilepsy!



Keeping The Wheels Oiled by Hyphen

Until I went to university, my experience of people with E was almost non-existent. True, there was a boy a couple of years below me at senior school, who used to keel over on the playground every so often. His father taught at the school and was therefore easily obtainable whenever this happened, so I have to say that people didn't give him much thought, (apart from a small knot of sad bone-heads who thought the spectacle amusing, and eagerly awaited each attack: but then, I doubt that they've learned anything in the intervening 30 years or so?)

I arrived at my third year at uni having more or less forgotten that the condition existed, still less knowing anyone with it, then one evening things changed—subtly, not dramatically. I had been to a University Operatic Society rehearsal: (the company was called LopsOc: short for Light Opera Society—nothing to do with tree surgery or ritual amputations!) After the usual visit to the pub, we would gather in someone's room for coffee; that night there were not many takers, so I ended up entertaining one young acquaintance (female) to polite conversation and caffeine in my room: by the time she left, some three hours later, I had absorbed a detailed account of her family history, in which the word Epilepsy figured prominently, as both she and her younger brother have it. Interesting, I thought, though it never occurred to me that it is rare to hear such a frank disclosure of this condition, that many people are reluctant to discuss in front of comparative strangers. I realised much later that it was in fact a great act of trust.

A few months later, (by a complicated route, involving a 17th birthday party for a car and several spilled drinks,) this same young lady and I became the "Item" which we still are. At that time, though, Gigi's condition was something of which I was only peripherally aware, she had to take regular medication: but had been seizure-free for eight years and it did not seem to cramp her style significantly. Then one morning I was forced to become more "E-aware". It was the end of the summer term and everyone was preparing to go home. There had been a big, late party the previous evening and Gigi was staying over at my flat, as she often did. She had had a stressful couple of weeks awaiting news of her placement for the imminent year abroad: this had been resolved only the day before. I was setting out for a "make or break" job interview that morning, some 250 miles away. We were up early and there had been some (shall we say) "activity" beforehand. As she was getting washed, she uttered a sound unlike any I had ever heard... I was startled, I thought she had seen something that alarmed her. She stiffened, her eyes went blank and then went into convulsions... I carried her to the bed without her hitting the ground or anything else, and stayed with her. I was still in shock when she stopped, dozed a moment, then opened her eyes as if nothing had happened. The most disturbing thing was the way that she seemed to have lost all memory of anything that had happened in the past few days... I now know that this is part of her normal pattern, but it was new and terrifying then.

Since then, of course, I have seen her have quite a number of seizures, and helped deal with the aftermath of many more, so I have learnt to cope. After all, it's not me who has to go through the attack itself: all I can do is try to cushion the physical effects and help her to pick up the pieces. It doesn't sound like much, but she says it always helps.

So how has this circumstance affected our life as a couple, and my life in particular, over the past 25 years? We have to plan our social life carefully: it isn't wise for Gigi to be up too late too often without the opportunity to catch up on her sleep: the simple solution is that she should sleep in the... 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.

Only a doctor can diagnose and treat Epilepsy!

next morning.. That has never been a problem, as I have never been one to lie in and waste daylight! Also, alcohol, taken sensibly, isn't a problem.

One thing she has found a bind is that she has not been able to drive. Seemingly, every time she has expressed a desire to learn, she has been thwarted. I know she finds it frustrating, especially as she does not like to be totally dependent on me for transport, but we've lived pretty successfully with this for the 17 years that I have been driving, and if need be could manage the next 17. In any case, it isn't as though she had been allowed to drive before being diagnosed, and was now stripped of that.

Gigi has written elsewhere about the effects of E on our child-bearing and rearing but the very fact that we have children is tangible proof that our "private life" has not been extinguished by her condition. On occasion we have had to be careful to avoid particularly vulnerable times, and her medication has sometimes affected her interest in such matters. Also, we have avoided using 'The Pill' as Gigi has always been extremely wary of medicines that she feels may interfere with what she is already taking: she is always very alert about any medical substance and will check carefully whether it is compatible. However, without wishing to seem smug or slushy, we're fine, thank you...

I am a natural worrier, always on the alert for anything that might signal trouble: so far the only regular bone of contention has been that I often need to remind her to keep her supply of meds topped up: if I had £1 for every time I've heard "I'm running out of pills—I thought I had at least another four days' worth..."(Usually last thing at night, when neither doctor's nor pharmacy is going to be open the following day)...but in the main our day to day lives are not ruled by anxiety over Gigi's condition, though I know that I am inclined to be rather over-protective, which sometimes gets on her nerves.

I hope I have not made it sound as though I have spent the past X-number of years as an unpaid nurse. Far from it: I have needed a fair amount of looking after too, and received it unstintingly. In the past four years I have experienced a breakdown and a further episode of depression, (neither of them linked to my domestic responsibilities!) Without Gigi's care, love and understanding, I don't know where or what I would be. I have emerged from it with plans to change my career-path significantly, and have made decisions, which would have been impossible to contemplate without her support. The whole process has given her the opportunity to prove resoundingly that our relationship is a two-way thing.

We don't always agree, but God help anyone who tries to criticise either one within earshot of the other...as Shakespeare said, "though she be but little, she is fierce"!

Though we don't often get out alone together (kids, Opera rehearsals, Choir practices being the biggest barriers) we do enjoy each other's company and laugh a lot at the same things. At home we try to make the odd long mealtime a chance to talk and appreciate each other and our surroundings. I think most of those who know us would agree that we work well together and on the whole, deserve one another (in the positive sense!) Gigi never made any big secret of her condition, and I suppose that initial honesty may have unwittingly provided a secure basis for the relationship that was to develop. We've lasted almost 25 years and look set to last another 25. I wouldn't swap those years. Neither of us would.

Hyphen the Terrible.

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.