

Only a doctor can diagnose and treat Epilepsy!

Epilepsy Support



Being a Parent with Epilepsy by Gigi

Family Planning. With the accent on the Planning if you are a would-be mother on AEDs. In my humble opinion the neuro should have tackled the subject as a matter of course, when he realised that I was getting married. No matter, though; on a daily diet of 600mg of Epilim (sodium valproate), I certainly wasn't about to start a family without thorough consultation. What were the risks, what were the options?

As far as they knew at the time, (in 1986, without the luxury of the Net!) Epilim was 'reasonably' safe. Certainly, it doubled the risk of giving birth to a child with a neural tube defect (spina bifida, hydrocephalus), I was told, but this was, in any case, a very small risk. Unconvinced by this 'reassurance', I determined to embark on the lengthy process of cutting down my meds, hoping to achieve a drug-free pregnancy - it was, after all, a very long time since the last seizure, and my condition was well controlled. This, as it turned out, was a little optimistic. When I got down to 100mg a day, which was after about 12 months, I had my one and only collapse ever in a work situation. What now?

Balancing the risks is crucial. Advice from any quarter is of value. It may confuse, but it really is better to be informed. Personally, I opted for an extremely well-monitored pregnancy on a minimal dose of 200mg Valproate a day...with lots of folic acid to supplement what the medication was leeching from my body.

I was fortunate in sailing through a very 'normal' pregnancy, without problems such as sickness and high blood pressure, so I felt in control (as I realise many do not), and the seizures stayed at bay. I was so relaxed that I even planned and achieved a drug-free, suture-free labour. But it is after the birth that decisions start to mount up, and I was as exhausted and bewildered as any other new mother at this extraordinary new responsibility. Did the benefits of breast feeding outweigh the risks of drug transference to our new arrival? I found out that the incidence of drugs in breast milk was less marked than I had imagined, decided to feed my baby myself and did so successfully for a long time. Was it safe to spend long periods of time at home alone with the baby? I tried to ensure that it was my least vulnerable time of day that found me alone with our child; I developed a good network of friends so that I might avoid isolation. The main difficult period was the few months during which I seemed to get little or no sleep, and my husband was a total star. He it was

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who got up at night to bring our son to me for a feed. He was the one who spent hours pacing up and down a room to lull the baby to sleep. A committed and loving partner really does make life easier.

The second pregnancy was less idyllic, though I approached it in exactly the same way. Firstly, a mix-up at my GP surgery meant that I was given incorrect information and did not know I was pregnant until the eleventh week (so was furious because I had not been able to optimise my folic acid intake from the start; it was not given as a matter of course in those days). When I was perhaps 35 weeks gone, I had a fright when I lost some water and had to be kept in hospital briefly for observation. I was put on a ward where nearly everybody was being induced, some painfully and unsuccessfully, and so was reminded that not everyone was as lucky as I had been.

One quite difficult issue for our family has been that of immunisation. My mother was convinced that my brother and I, both E-sufferers, had started to show signs of epilepsy when we were inoculated against whooping cough, and I was very worried about allowing my children their jabs. Both sons, when aged 12 months, received the controversial early joint measles/mumps/rubella vaccine; however, by the time a 'booster' was introduced at around school age, the younger was presenting some indications of high-spectrum autism; I decided enough was enough and he did not receive the booster shot. Since then his problem has been shown to be a language processing one, which loosely resembles the difficulties with language experienced by young autism sufferers (though there are no other autistic pointers), but there is absolutely no evidence that it has been caused either by my own condition or by the drugs I require to treat it. In fact both the boys (nearly 14 and nearly 10 at the time of writing) are healthy, happy, highly intelligent, a joy to be with and dearly loved by all their carers and peers. Not only that, but they are mature in their attitude to E, can explain it simply and unselfconsciously to others, and have proved that they can deal with a seizure rapidly and sensibly.

As I have said, I consider myself hugely lucky - so many other things could have gone wrong - but I am living proof that the great challenge and delight of parenting is available to the mother with epilepsy. I have had to believe in my instincts about my own body and needs and those of my sons all along the way - am continuing to do so as they develop - and access to information has been vital in giving me that confidence. Inform yourself, ask questions, be a nuisance. Make choices. Being a parent does not necessarily mean being completely in control - but you need at least to be able to convince the children that you are!

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