

Epilepsy Support Group Seminar Speech

Good morning ladies and gentlemen. First of all, I would like to thank the organisers for giving me this chance, of which I am much honoured, to be sharing my experiences with such a large international audience.

Well, experiencing the onset of epilepsy on our son at such a tender age of 2, was not an easy task to accept and handle. My husband and I had never seen anyone having a fit before. In fact, the first time it occurred, we thought that our son was having a nightmare or hallucinations of some sort.

However, on the second time we contacted our family doctor, who explained the condition and referred us to a paediatric consultant. The treatment chosen was Sodium Valproate and after some time this was changed to Carbamazepine. However both drugs did not stabilise or effectively control our son's condition.

Thanks God, currently he is quite well controlled by one of the recently developed drugs, Lamotrigine.

When one looks back, the first thing that comes to mind is the way that we felt about the impact of epilepsy—Why did it have to happen to our son? It would have been much easier to accept, if it had happened to either one of us—Why him then? Until then he had been a perfectly normal boy, making progress and learning quickly.

Moreover, his fits are of the tonic/clonic type or Gran Mal, which are very impressive and always occurred during sleep. On the onset of a fit the boy usually gave out a loud cry, but this was not always the rule. For my husband and me, this meant that we could not afford sleeping with our minds at rest during nights. At first we were even reluctant to leave our son to sleep in a separate room, for fear of not reaching him in time to stop the fit by treatment.

We constantly feared that he would die or get brain damage due to lack of oxygen during such fits.

Then, we installed a bedside radio transmitter by his bed and a receiver by ours, so that we could listen to him while he was asleep. We surely woke up to check on him at every sound we heard.

I also had to stop working away from home so as to have sufficient time to constantly provide him with physical presence and emotional support, which he really needed especially after an episode.

At school, Chris was completely normal, if not more intelligent than other children of his age. At the beginning of each scholastic year we usually contact his teacher and school administrator to inform them of the boy's condition and what to do in case he gets a fit.

In spite of all this, Ray and I have worked hard at trying to give our son the chance to lead as normal a life as possible. We have always allowed the boy to take part in any activity organised at school or by the Scout group that he still belongs to.

Chris is now twelve years old and like most boys of his age, he loves sports and fishing activities.

For Chris, I believe that the hardest thing to accept was to part with his scout colleagues every night on camp holidays to come and sleep at home. This he really hated to do, but we could not risk, as we knew well that lack of sleep and exhaustion triggered such episodes.

Another thing that hurt him was that unlike his elder brother, he was never allowed to sleep at his grandma's for fear that he might get a fit.

Well, everyone has bitter experiences in life, but the most important thing is to learn to accept and live through such situations, so that we can make the most of our time here. In life, the harder you are challenged, when you manage to overcome the fear, the stronger you become. The most important thing for us, as parents, to have had at such difficult moments, was the support that we received.

Given this opportunity, I would like to thank our families and friends, the Caritas Epilepsy Support Group and health care professionals at St. Luke's hospital, for their dedication towards providing the best support, advice and treatment possible. Thanks and keep up the good work!