

Article

Epilepsy Awareness Week 11-17 May 2009

Knowledge reduces fear of epilepsy

Judy and Graham Hewson know only too well the feelings of isolation, fear and anxiety that often accompany a diagnosis of epilepsy after being told five years ago their son Joshua, then just four years of age, has the condition.

“I can still picture it,” says Judy, referring to the first time Joshua, the youngest of their three boys, had a terrifying seizure and the first of many trips to the hospital. “He was lying on the floor and I thought he was dead. My Mum is a trained nurse and yet she freaked. A friend actually found him – she is a carer at a nursing home and was fantastic. We had called the ambulance, but the doctor came from up on the corner and he cancelled the ambulance and we took him in by car.”

Judy says there is no history of epilepsy on either side of the family, but Joshua’s experiences with the condition over the past five years indicate that there are many different forms of epilepsy. “They have never told me what sort of epilepsy he has, but it is hard to pinpoint as he has had a range of different seizures. His first one was a tonic clonic seizure with the jerking; he also has seizures where his whole body trembles, sometimes he stares and then his mouth will tremble.”

“He was having about two a month initially, but we are just in the middle of a medication change at the moment and he has only had two this year.”

Judy says with time she has learned to manage Joshua’s seizures and has researched epilepsy on the Internet, but she has not always been so at ease. His problems are compounded by the fact that he has autism and mutism. “It was a disappointing diagnosis and I got upset but you just deal with. With the seizures he is having now I am more relaxed, I know I can do this. But when he was first diagnosed it was very scary.”

“Joshua is also autistic so he does not verbally communicate. He is not the kind of little boy who can say how he feels and we still don’t know if he gets any warnings before a seizure.”

Joshua goes to Barwon Valley Special School, which according to Judy he loves. “He has speech therapy there. He has had about three seizures at school and they are great with him.”

Judy says the Epilepsy Foundation of Victoria has played a big part in helping her come to terms with Joshua’s epilepsy and overcoming her fears.

“They have been great. I have spoken with Jan Burns many times. There’s the sense that there’s someone there to help you and you can call her at any time for support, or to ask different questions.”

“We have just attended the epilepsy camp this year. It was brilliant, fantastic. Listening to people’s stories there, I realised I have nothing to worry about!” she says with a wry smile.

“We learned that like us, other parents are cautious and do keep a closer eye on the child with epilepsy, than on their other children. I learned a lot about the medication that these children take – some are on four or five drugs, while Joshua is only on one. In talking to this group on the Saturday night there were lots of tears and laughter and it was great.”

“We have also borrowed two different types of the bed monitors, which alert us to the fact that Joshua is having a seizure during the night. So far he has only had one at night.”

This week is Epilepsy Awareness Week (11-17 May). Unlike many people who avoid telling people they have epilepsy, Judy was pleased to have the opportunity to talk openly about her journey with Joshua’s epilepsy and do her bit to dispel some of the myths.

“There is a lot of ignorance in the community about epilepsy,” Judy says. “I try to explain, especially to children, that it’s like you have electrical wires and the wires aren’t touching properly, and he’s having little fires in his head.”

“The two older boys look out for Joshua and will let me know if they think he’s having a seizure. They are far more aware of epilepsy and what to do when someone has a seizure than most kids would be because they have been brought up with it.”

Graeme Shears, chief executive officer of the Epilepsy Foundation of Victoria explains the condition. “Epilepsy is a disorder of brain function that takes the form of recurring seizures. Our every thought, feeling or action is controlled by brain cells that communicate with each other through regular electrical impulses. A seizure occurs when sudden uncontrolled bursts of electrical activity disrupt this regular pattern,” he said.

“Epileptic seizures can range in type and severity from seizures where, for example, a child might simply appear vague or distracted for a short time, right up to the more commonly-held perception of seizures where a person might fall to the ground and experience severe body convulsions, known as tonic clonic seizures.”

“However, for 80 percent of people with epilepsy, medication controls their seizures well, and they are able to live normal lives and work, drive a car, swim and do all they things they usually would.”

It is estimated that up to 104,000 people in Victoria will have epilepsy during their lifetime. Surprisingly, many older people will have their first seizure over the age of 65, so our ageing population means many more people are likely to experience epilepsy in the future.

The Epilepsy Foundation of Victoria provides services including counselling, support, information and advice, as well as advocacy and research, and wants to raise awareness of epilepsy to reduce the stigma in the community.

“Our services are about working with individuals to help them manage their epilepsy better in the way that matters most to them – whether that means ensuring they are seeing a specialist neurologist, providing up-to-date information and counselling or linking families with others who have epilepsy for support,” says Graeme Shears.

“We want to raise awareness of epilepsy and reduce the social stigma attached to it, so that people have a better chance of being accepted in the community and getting on with life in a positive way.”

“We aim to have one person in every household understand the appropriate first aid to give to someone having a seizure,” he says.

People with epilepsy or their families can call the Epilepsy Foundation of Victoria for assistance on 9805 9111 or the National Epilepsy Helpline 1300 852 853 for the cost of a local call, or visit www.epinet.org.au

Epilepsy Awareness Week will take place from Monday 11 May to Sunday 17 May 2009. The aim is to raise awareness of epilepsy and seizure first aid and to reduce the stigma in the community.

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