

Article

Epilepsy Awareness Week 11-17 May 2009

Knowledge reduces fear of epilepsy

Trudy and Warwick Strauch know only too well the feelings of worry and anxiety that come with a diagnosis of epilepsy having learned that two of their four children have the condition, along with other intellectual disabilities.

Their youngest son James was first diagnosed with epilepsy at the age of six months. Trudy and Warwick had only just managed to get James' frequent seizures under control nine months later, after trialling several different medications, when their oldest daughter Chevonne also began having seizures at the age of six.

"When James first started having seizures it was a bit of a shock, but because there were so many things it could have been and we were so worried while we waited for test results, when we finally got the diagnosis it was more of a relief. We knew what it was and could deal with it."

"When Chevonne started having seizures, we had been through it with James and even though she had a different type of seizure, we knew straight away what was happening. That made it a bit easier."

Trudy explains her children's experiences with epilepsy. "James had infantile spasms, a serious form of childhood epilepsy, which caused developmental delays. After a lot of medication, including having hormone injections as a baby, we finally got control of his seizures and he was able to go off the medication for a short while."

"We then noticed James was having different seizures. He was diagnosed approximately four years ago with absence seizures. He is now being weaned off the medication as he has been seizure free for three years, and we will see how he goes."

James' health problems are compounded as he also has autism and selected mutism, which means he only talks at home and not outside of the home environment.

"James' communication problems are the hardest to deal with because he doesn't talk at all but he goes to a special school, Kalianna Special School, which is great," Trudy explains. "They are very understanding and he communicates with his face and eyes, so he can get across what he wants. As he gets older we will have to look into some sort of communication device as we expect it will become more difficult for him."

Trudy says Chevonne was in Grade 1 when she was first diagnosed with a different type of seizure to those that James was experiencing.

"It was only a few weeks after we got James' seizures under control when she started having complex partial seizures. She had scarring in the memory centre of the brain so she had surgery at the Royal Children's Hospital three years ago whereby the verbal memory centre was removed."

“After the surgery, her symptoms changed and she now she has a different type of epilepsy – she has night time seizures and is back on medication which is helping.”

Chevonne also has a mild intellectual disability which was discovered after her seizures began, however, now aged 19, she is able to work and holds a part time job at Calico Country as a machine operator and also spends two days a week at Peter Harcourt Day Services.

Trudy has a very matter-of-fact approach to coping with her two children’s needs saying, “It just becomes part of everyday life. There are a lot of families out there that are worse off than us.” However, she did notice that some friends found it hard to handle James’ seizures and there were often curious reactions from onlookers.

“When James was a baby I noticed a few friends found it hard to deal with his seizures because there are only certain times when we step in and help him. It was hard for them to understand why we were seemingly not helping him – they couldn’t cope with that, but we were used to it.”

“There was an incident when we were queuing for Santa one year and James had a seizure. We simply took him out of the queue and let others go through until he was okay and then we got back in line. A few people asked questions about what was going on and we had to explain to them that James has epilepsy.”

Trudy and Warwick have been accessing the Epilepsy Foundation of Victoria’s services through Lisa Rath, one of its counsellors. Trudy says Lisa has been very helpful in providing advice and support and linking her with other parents of children with epilepsy and in providing support that goes beyond what an extended family can provide. She has also attended workshops and seminars to hear a neurologist speak.

“The Foundation has been there providing advice and support along the way. Lisa has been great. She has put us in contact with other families and vice versa so we could ring each other and talk about our experiences. We could also call her at any time if we were worried about anything or unsure about what the doctor said, or about the medication.”

“We had the sense that this person really knows what she is talking about, she knew exactly what we were going through and was there to provide support. Our family members are great but if you are not dealing with it all the time you don’t truly know what it’s like.”

“We have also borrowed videos from the library that show the different types of seizures,” she says.

The children’s epilepsy hasn’t stopped the Strauch family from doing normal things. Importantly all of the older children, including Chevonne, had a role to play in looking after James when he had a seizure and were aware of what to do.

“We had three older children when James was a baby, so we couldn’t just stay at home,” says Trudy. “We cope with family life as normally as we can. Each of the girls were included in looking after James and we never hid that from them. One would stroke his head, another would wait for the ambulance, and so on. So they grew up with it and were never shut out.”

Trudy believes that helping the children to understand about epilepsy and involving them in it meant that they knew exactly what to do and were not frightened by it. She says there needs to be more of this awareness in the community.

“People think that having seizures is all about the typical tonic clonic seizure – if they are not on the floor and jolting around they can’t see that it’s a seizure,” says Trudy. “They don’t realise there are different types of seizures with different symptoms, nor do most people know what to do if someone is having a seizure. There needs to be a lot more awareness in the community about epilepsy and how to deal with it.”

“It is very traumatic for the family initially but when you live with it you deal with it and it no longer has that shock factor that other people have when they see someone having a seizure.”

Epilepsy Awareness Week takes place from 11-17 May 2009, which is an opportunity for people like Trudy to tell their stories.

Graeme Shears, chief executive officer of the Epilepsy Foundation of Victoria explains more about the condition. “Epilepsy is a disorder of brain function. Our thoughts, feelings and actions are 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 says. “For 80 percent of people with epilepsy, medication controls their seizures.”

It is estimated that up to 104,000 people in Victoria will have epilepsy during their lifetime; many will have their first seizure over the age of 65.

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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