

## Article

*Epilepsy Awareness Week 11-17 May 2009*

### Knowledge reduces the fear of epilepsy

Pat Cashin and his daughter Elizabeth know only too well the feelings of isolation, fear and anxiety that often accompany a diagnosis of epilepsy as both have the debilitating condition, having been diagnosed with different types of epilepsy at different stages in their lives and in different circumstances.

While there is a family history of epilepsy on the maternal side of Pat's family, it was still a shock when Elizabeth was diagnosed with tonic clonic seizures some six years ago.

Elizabeth started having severe seizures at the age of 15. They were tonic clonic seizures, meaning they affect the whole of her brain and cause the stiffening and jerking muscles commonly recognised as epilepsy. She has also experienced myclonic seizures as well as simple and complex partial seizures, which affect part of her brain, and absence seizures, which cause her to become 'vague' for a few minutes.

A very bright and articulate girl, Elizabeth says her seizures were incredibly disruptive and were largely uncontrollable for many years until a change of medication a few months ago has brought them under better control.

"The medications are harder to deal with than the seizures. It has taken a lot of time and patience to get the right combination of drugs. The side-effects have been terrible too, including mood changes, weight gain (I gained 22 kilos within the first six months, which was very hard to bear) and severe tiredness. The memory loss is frustrating, particularly as I am now studying."

Amazingly, Elizabeth's epilepsy is now sufficiently under control to be able to study for a Nursing and Arts Degree at Australian Catholic University in Melbourne.

"You have to set yourself goals and I had to just hope that I would get better. There was a time when I wasn't sure I was going to be seizure-free and whether I would be able to study or not. I am grateful for the University's support – they have been very understanding and helpful."

Pat's journey with epilepsy began only six months ago and has been very different to Elizabeth's. Last November he had a serious car accident on a main road in Ballarat involving his own vehicle and three others, caused by a black-out as a result of an epileptic seizure.

"I have no recollection of just before, during or several minutes after the accident," he says. "I 'came to' in the car in a tremendous amount of pain. I was covered in blood and found out later I had bitten right through my lip. I had also broken my sternum and wrist."

"When I got out of hospital I went to my own GP who did a series of diagnostic tests. I ended up with a neurologist in Melbourne who told me I had epilepsy. While it was a shock in one sense, it was a relief as it answered certain questions as to why I had no knowledge of the accident and, if I had hit three cars, why I did not wake up after the first one."

About a month after the accident Pat had recovered sufficiently to be able to return to work, in the funeral director business he owns with wife Therese, although there has been a legacy of injuries that are still healing today.

“I suffered memory loss – basic things like my own mobile number or the names of people I have known for years – and had trouble with job functions like programming the stereo,” he says. “Now five months on, I’m much better with multi-tasking and my memory is slowly improving.”

Pat and Elizabeth have both found the support of the Epilepsy Foundation of Victoria very helpful in their personal journeys with epilepsy.

“In the funeral business, I sometimes see parents who have lost children through epilepsy. As a parent of a child with epilepsy too, that has sometimes been very hard to deal with. I’ve been able to talk that through with the counsellor and basically unload my feelings,” says Pat.

Elizabeth agrees saying, “When I was first diagnosed, the situation flabbergasted me. The doctors were saying things in terminology that was beyond me, that was not in my own language. Because I couldn’t comprehend it, I couldn’t connect with it and became completely detached from it. The Foundation provided really good support and advice when I needed it.”

This week is Epilepsy Awareness Week (11-17 May). Unlike many people who avoid telling people they have epilepsy, Pat and Elizabeth were pleased to have the opportunity to talk about their experiences. Both agreed there needs to be more knowledge of epilepsy in the community, to dispel the myths and reduce some of the stigma that still exists.

“You become very aware of the prejudice and fear and how confronting epilepsy is both to health professionals and many people in society. That puts the person with epilepsy back so far with their confidence,” Pat explains. “We have not really moved on from the fear of 100 years ago.”

Elizabeth agrees. “Seizures themselves take so much control out of your life already. It’s a human, natural thing to want to have some element of stability, structure and control of your life and when you have a seizure it throws everything out of control. So every time people say “you can’t do this because you are ‘epileptic’” they take away even more from you, like your self-esteem. At the end of the day, they are just seizures, but people completely overreact.”

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 spasms, 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](http://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.*

## **Ends**

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