

Media Release

Knowledge reduces fear of epilepsy

Shirley O'Bree knows only too well the feeling of social isolation that often accompanies a diagnosis of epilepsy, having been on the receiving end of much ignorance about her condition over the years.

"In the past, when I told people I have epilepsy, they would literally take a step back with a 'don't give it to me' attitude, as if it were contagious," Shirley says, "and people just don't know how to deal with the situation when someone near them has a seizure."

Shirley has focal epilepsy, which means she mostly has mild seizures that cause her to become vague or lose consciousness for a short time. This is in contrast to the tonic clonic seizures more commonly understood, where the person falls to the floor and experiences uncontrollable muscle spasms, although Shirley has had a few of these more serious seizures throughout her life.

Shirley was first diagnosed at the age of 14 after several focal seizures at school which, she says, made her "feel funny" and a tonic clonic seizure which literally threw her out of bed.

"It wasn't so much of a shock when the doctor at the hospital told me I had epilepsy," she says, "because not much was known about epilepsy then, so we didn't know what to expect. I didn't know anyone else at school or in the district who had epilepsy."

Epilepsy has had an effect on many aspects of Shirley's life, often related more to her worry about the impact on others, especially her family, than on herself. One of the biggest factors was her inability to drive. "I never wanted to risk potentially hitting a pedestrian or causing anyone any life damage. I didn't want to have to live with that as well as with the epilepsy, so I have never held a licence," she says.

Sadly, Shirley also gave up playing sport and swimming in her mid-teens. When she was young and before her diagnosis she used to swim a lot but her brothers and sisters were always asked to watch out for her when she was in the water. She felt that they couldn't enjoy themselves so she gave it up.

It has not been all bad news as Shirley, now 64, has managed to work, get married and raise two healthy children while also finding great support from the Epilepsy Foundation of Victoria, which helped her along the way.

She first started accessing the Foundation's services when she met counsellor, Lisa Rath, in the mid-1980s at the Eaglehawk Community Centre, now known as Community Health Bendigo. Shirley says Lisa has been very helpful in providing advice and support and setting her up with a support group.

"Lisa is very knowledgeable and she has been someone to talk to and confide in; her advice has been invaluable over the years. She makes you feel that you are not alone and that others are experiencing the same thing. The support group was helpful in knowing that others understand how you feel."

Epilepsy Awareness Week takes place from 11-17 May 2009, an opportunity for people like Shirley to tell their stories. Unlike many people who avoid telling workmates, friends and sometimes even family members they have epilepsy, Shirley was pleased to talk openly about her condition and do her bit to dispel some of the myths.

“There is still not much awareness of epilepsy in the community. I had a seizure outside a school one day and one of the teachers called an ambulance. By the time the ambulance arrived I had come out of it and there was no need to go to hospital. You really only need to call an ambulance in certain circumstances.”

Husband John agrees some knowledge is useful. “It is helpful to get to know some of the signs, so you know what to do if someone near you has a seizure,” he says, remembering a time when Shirley had a seizure in a shop and people walked past her without stopping to help. “Generally, the public doesn’t know, understand or want to get involved, even today.”

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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16 April 2009