

Media Backgrounder

Epilepsy Foundation of Victoria

Background

The Epilepsy Foundation of Victoria is a state-based consumer support agency dedicated to enhancing the quality of life of people living with epilepsy in this state through information, education, advocacy, support services and research. The Foundation is a member of Epilepsy Australia and the Joint Epilepsy Council of Australia (JECA).

Epilepsy is a significant community problem. People living with uncontrolled epilepsy suffer from wide-ranging physical, psychological and social issues, as epilepsy impacts on every aspect of their lives and the lives of their families and carers. These include being disadvantaged in obtaining an education, loss of employment or limited employment prospects, social isolation, loss of enjoyment or participation in everyday life, relationship problems and, potentially, chronic depression.

The social stigma, coupled with the emotional and physical trauma associated with uncontrolled epilepsy, means that many people living with epilepsy suffer in silence, often for years. Many people with epilepsy avoid revealing that they have epilepsy to their employer, their friends, even their loved ones, for fear of rejection, loss of acceptance or opportunity, or of being shunned. These are very real fears, as stigma and ignorance still exist today.

Some facts about epilepsy:

- Epilepsy was ranked in the top five avoidable causes of death in young people (aged 5-29) in the Victorian Government's report *Avoidable Mortality in Victoria – Trends between 1997 and 2003*. It was number three in 5-9 year olds and 20th overall in the top causes of avoidable mortality, with a total of 356 deaths or 6.5 percent of total avoidable deaths.¹
- The number of people over 65 who will experience epilepsy is increasing with our ageing population.
- The cycle of disadvantage means people with epilepsy have lower rates of school and tertiary education completion, higher unemployment (three times the national average), higher dependency on social security and lower rates of marriage and home ownership.
- Using other Australian studies and the Australian Bureau of Statistics' population estimate in September 2008, it is estimated that between 8.8 and 20 per 1,000 people, or between 184,800 and 420,000 people, has epilepsy in Australia.² In Victoria, the number is therefore in the range of 45,760-104,000.

¹ *Avoidable Mortality in Victoria – Trends between 1997 and 2003*, Victorian Government Department of Human Services, Melbourne, Victoria. September 2008.

² Beran R (1983), *Epidemiological studies of epilepsy in Sydney, Australia*, a report prepared for the Federal Government of Health, Sydney. Sheehan R (1985), *Epilepsy and human rights*, Human Rights Commission Occasional Papers No 7, Canberra, AGPS. Brown K & Walker C (2006), *Developing an applied research agenda into the social effects of living with epilepsy*, Epilepsy Report, No 2, 23–27.

Funding shortfall

In the 2007-08 year, Epilepsy Foundation services were accessed by approximately 3,400 people, suggesting there are many thousands of people living with epilepsy, or closely linked to someone with epilepsy, who are not receiving services, either through lack of referral or awareness, or for other more emotional reasons associated with the perceived stigma of seeking help.

Epilepsy Foundation receives funding through the Victorian Government's Department of Human Services – Disability Services (DHS). This funding has strict disability criteria, which excludes the majority of people diagnosed with epilepsy. Much of our support is health-related, for which we receive no government funding.

Furthermore, the Foundation receives no government funding for under school-age children or people over the age of 65; disability funding only covers people between the ages of 5 and 65 (yet the Foundation nevertheless provides services to people of all ages).

What is epilepsy?

Epilepsy is often referred to as 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. This can be confined to just one part of the brain or can occur right across the brain. Communication between cells becomes scrambled and our thoughts, feelings or movements become momentarily confused or uncontrolled.

While seizures can be frightening, in most instances they stop without intervention. Once the seizure is over the person gradually regains control and re-orientates themselves to their surroundings, generally without any ill-effects. The majority of people diagnosed with epilepsy will have their seizures controlled with medication.

Who gets epilepsy?

Epilepsy can develop at any age, regardless of gender or ethnic group. Research suggests that up to three percent of Australians will develop epilepsy at some stage in their lives. Epilepsy was once considered a disorder of the young as it was believed that most people experienced their first seizure before the age of 20. However, authorities now identify people over 55 years as being the most vulnerable group. This rapidly growing demographic group is subject to the kinds of cerebrovascular, respiratory and cardiac events that can lead to epileptic seizures.

What causes epilepsy?

Many factors can contribute to the onset of epilepsy including acquired brain injury from brain disease and infections, accidental head trauma, drug/alcohol abuse and strokes. The majority of people who develop epilepsy have an underlying cause related to the functioning of their brain, such as brain malformations, chemical imbalances etc. Approximately 60 percent of the causes of epilepsy are not understood. There is so much that is not known about this major chronic illness that the World Health Organisation has added its weight to the contention that epilepsy is arguably the world's most stigmatised, misunderstood and under-resourced of all health conditions.³

Is epilepsy inherited?

Epilepsy is a common disorder and frequently within an extended family more than one person may have seizures. Sometimes there is a family history of seizures including febrile (fever-caused) seizures, epilepsy, or seizures in childhood that later went into remission. Some abnormal genes have been identified as being responsible for some epilepsy syndromes; three genes have been discovered (two in Australia) for some of the rarer, more severe epilepsy syndromes.

³ WHO Global Campaign: Out of the Shadows, 1997.

While epilepsy is not understood to be an inherited disorder there is growing evidence that there are some families that have a marginally increased risk. In most cases a specific pattern of inheritance of epilepsy within the family cannot be determined. Unlike the simpler genetics of many conditions involving dominant and recessive genes, the genetics involved with epilepsy are far more complex. Some of the most important work in epilepsy and genetics is being done in Australia.

About Epilepsy Foundation's services

Providing quality, relevant and valued client services that make a difference to people's lives, and providing them in a timely way along the person's journey with epilepsy, is the Foundation's key purpose. The reasons why people seek our services vary widely and depend on many factors: age, stage of life, individual needs, the unique problems or issues a person may be facing and their personal goals and aspirations for the future.

Our services can essentially be described as the provision of:

- information
- counselling and support
- education and training
- advocacy – group and individual
- research.

Services are tailored in response to each person's goals and aspirations. We aim to help people to manage their epilepsy in a way that enables them to live, study and work as they normally would and participate in the activities they enjoy, no matter what age they may be. Many people with epilepsy are able to play sport, swim, go to the movies and, under certain circumstances, drive a car. We work with people to help them regain their confidence so they can continue to do the things that matter most to them.

Information services – Our initial contact with a new service user is usually by telephone, often immediately after the person or their child has been diagnosed with epilepsy. We ensure people with epilepsy have access to current information about the causes, treatments and impact of epilepsy to optimise management of their condition and improve their quality of life. We also provide valuable information services to those in the community working with people with epilepsy, which enhances their capacity to provide appropriate services.

Support services – Our support services, provided by professional counsellors, are at the heart of services and make a real difference to people's lives. Support services are provided in a number of ways including counselling on how to deal with epilepsy for those newly diagnosed with the condition, liaison with schools or employers on behalf of the person with epilepsy, helping a person to engage in social or recreational activities, or grief counselling.

Camps for children, adults and families – Our annual family and adult camps provide a safe and secure opportunity for individuals, both adults and children, to share experiences, problems and ideas, and undertake activities that for most would be commonplace.

Education and training – Our education and training program is a key element of our community awareness-raising work, and focuses on what it means to have epilepsy, how to live with the condition and how to manage if an employee or student has epilepsy. We run an extensive seminar and workshop program including *Understanding and Managing Epilepsy*, *Men and Epilepsy* and *Women and Epilepsy*, parent and carer education days and childhood epilepsy seminar. We conduct an in-school epilepsy awareness event, Trivia Challenge, which reaches more than 28,000 students, their teachers and families each year. Training is provided in places of employment, to assist business owners and supervisors to better support an employee with epilepsy in the workplace.

Research – Epilepsy Foundation is leading the psychosocial research efforts into epilepsy in Australia. It has set up a world first research participant register with a view to conducting a long term longitudinal study into living with epilepsy.

Involvement in epilepsy clinics – Epilepsy Foundation has five counsellors who work in partnership with neurologists specialising in epilepsy in seizure clinics at the major hospitals in Melbourne and in some regional cities. These counsellors are immediately on-hand after a patient is diagnosed with epilepsy to provide support and empathy during what is often a traumatic time for the patient. Our counsellors also visit clients when they are in hospital for various investigations or surgery.

Accommodation service – We assist people to stay near their loved ones so they can be on-hand while they access medical services in Melbourne. Our service involves linking people with accommodation facilities such as quality local motels located conveniently near the major hospitals and, where appropriate, providing accommodation subsidies.

Regional services – Our counsellors provide state-wide services including counselling, information, advocacy, education and training and clinic support.

Advocacy – We advocate on behalf of all people living with epilepsy at all levels of government and to the wider community. Individual advocacy involves supporting our clients to ensure they are not disadvantaged in any community setting such as the workplace or school. We aim to ensure minimal restrictions and maximum opportunity for growth and fulfillment. Information and education are essential strategies for removing barriers to full participation and opportunity.

National Help Line – A National Help Line (1300 852 853) has been set up by Epilepsy Australia. People with epilepsy can ring this number anywhere in Australia and be put through to the epilepsy organisation in their state or territory.

Volunteers – Like many not-for-profits, the Epilepsy Foundation relies heavily on its volunteers, who assist with a range of activities including running our Opportunity Shops, administrative tasks, providing clerical support as well as helping our Client Services and Fundraising departments with events such as our family and adult camps, Superfits recreational group and Trivia Challenge.

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