

Media Backgrounder

Epilepsy Foundation of Victoria

Our mission

The Epilepsy Foundation of Victoria is dedicated to enhancing the quality of life of people living with epilepsy through information, education, advocacy, support services and research.

Some facts about epilepsy and the Foundation

Epilepsy Foundation of Victoria is the Victorian epilepsy consumer support agency that supports people living with epilepsy across the state of Victoria. 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.

Epilepsy is a silent problem – 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, even today.

Some facts about epilepsy:

In Victoria:

- It is estimated that approximately 3 percent or 150,000 people living in Victoria will have epilepsy in their lifetime. However, the number of people who are significantly affected by epilepsy including, for example, family members and carers, will be approximately four times higher than this number, or 600,000 people.
- Up to 10 percent of people in Victoria will have a seizure in their lifetime, due to epilepsy or other health conditions. This represents 520,000 people who are directly affected or 2.08 million people indirectly, yet significantly, affected. Seizures from epilepsy make up the major proportion of total seizures.
- Epilepsy was ranked in the top five avoidable causes of death in young people (aged 5-29). (The Victorian Government's new report *Avoidable Mortality in Victoria – Trends between 1997 and 2003*.)

In Australia:

- It is estimated that up to 3 percent of Australians will have epilepsy during their lifetime (650,000). The number of people significantly affected by epilepsy in Australia is therefore estimated to be approximately 2.6 million.
- The number of people Australia-wide estimated to have a seizure in their lifetime, due to epilepsy or other health conditions, is 2.1 million people, or 8.4 million indirectly affected.

Our ageing population:

- The number of people who will experience epilepsy over the age of 65 is increasing in line with our ageing population.
- Recent US studies estimate 7 percent of people over the age of 65 will develop epilepsy. In Australia in 2007 there were 2.8 million people aged 65 and over. Within this age group approximately 196,000 people will develop epilepsy.

General facts:

- Epilepsy Foundation receives no government funding for under school-age children or people over the age of 65; the Foundation's disability funding only covers people between the ages of 5 and 65 (yet the Foundation nevertheless provides services to people of all ages).
- The cycle of disadvantage and marginalisation of people living with epilepsy means they have lower rates of school completion, lower rates of tertiary education completion, higher rates of unemployment (three times the national average), higher percentage of dependency on social security, lower rates of marriage and lower rates of home ownership.

The prevalence of epilepsy in Australia

One of our challenges is forming an accurate picture of the prevalence and impacts of epilepsy in Australia and, more particularly, in Victoria.

The Joint Epilepsy Council of Australia is seeking Australian Government funding to carry out the necessary research that will enable member organisations to properly estimate and plan for services in the future. This research would focus on important quantitative aspects including the incidence of people living with epilepsy, Sudden Unexpected Death in Epilepsy (SUDEP) and avoidable deaths attributable to epilepsy.

Furthermore, our longitudinal research needs cover the qualitative aspects of the condition, including epidemiological considerations and quality of life impacts across issues such as social inclusion and attitudes, housing, employment, education, mobility and the economic costs both to the person with epilepsy and the community.

This research will enable us to better plan for the future in tailoring our services to ensure they meet individuals' needs most effectively and to position Epilepsy Foundation to be able to meet the growing demand.

Using the most relevant and current research available, we have extrapolated what we believe is the likely picture of the prevalence of epilepsy in Australia today. The Joint Epilepsy Council of Australia conservatively estimates that as many as 600,000 Australians may presently suffer from epilepsy or will suffer from epilepsy at some time in the future.¹

¹ Joint Epilepsy Council of Australia (2006), *A national strategy for epilepsy in Australia*, the Epilepsy Foundation of Victoria, Melbourne.

Using other Australian studies, it is estimated that between 8.8 and 20 per 1,000 people in Australia has epilepsy.²

By applying the Australian Bureau of Statistics' estimate of the Australian population in September 2008 to the prevalence estimates, we estimate that the number of people with epilepsy in Australia is in the range of 184,800-420,000.³

In Victoria, the number is therefore in the range of 45,760-104,000. However, the number of people who are significantly affected by epilepsy including, for example, carers and family members, will be around four times higher than these figures.

In the 2007-08 year, Epilepsy Foundation of Victoria provided support services for approximately 3,400 people and education and training for more than 30,000 people, clearly highlighting the vast unmet need for services.

Avoidable deaths

The Victorian State Government's new report on avoidable mortality in Victoria provides some alarming statistics about epilepsy⁴. Epilepsy ranked 20th overall in the top causes of avoidable mortality (during the period 1997 to 2003), with a total of 356 deaths or 6.5 percent of total avoidable deaths. Most alarming is the ranking for young people – epilepsy is ranked in the top five avoidable causes in the age groups from 5 to 29.

In the report, epilepsy was ranked:

- As the third leading cause of avoidable deaths in the age range 5-9 years of age
- As the fourth leading cause of avoidable deaths in the age range of 25-29 years of age
- As the fifth leading cause of avoidable deaths in the age ranges of 10-24 years of age
- In the top 10 leading causes of avoidable deaths in the 30-34 and in the 35-39 age range.

Health priorities such as heart disease, asthma and cancer receive millions of dollars in funding each year. As a leading cause of avoidable deaths, as well as a major contributor to numerous ongoing psychosocial problems that are associated with chronic illness, epilepsy in Victoria and, indeed Australia, is massively under-funded.

Funding shortfall

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

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.

³ Australian Bureau of Statistics census reports, 2007.

⁴ *Avoidable Mortality in Victoria – Trends between 1997 and 2003*, Victorian State Government Department of Human Services, Melbourne, September 2008 p5.

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.

In the 2007-08 year, the Epilepsy Foundation received \$866,000 in government grants. However, this funding represents only 20 percent of our total funding needs at current demand levels, with the 80 percent funding shortfall being covered through fundraising efforts. Our combined income does not allow us to meet all the current needs of our clients, much less the growing demand due to the ageing population.

Many would be unaware that epilepsy can, in fact, strike unexpectedly for the first time in people over the age of 65. With our ageing population, the number of people with epilepsy can only be expected to rise each year, creating even greater demand for our services.

Furthermore, and regrettably, current funding does not cover the needs of children under the age of five or older people over the age of 65, two unique groups with specific needs, which represent a significant proportion of those who seek our services.

While we know that there is a significant unmet need in the community (whether through lack of awareness of our services, or a perceived stigma associated with having epilepsy or with seeking help for epilepsy), we do not have the capacity to expand and service more people. Hence, currently we do not market our services as this would lead to a demand which we are just not capable of meeting at current funding levels.

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 is a common condition in our community and can develop at any age, regardless of gender or ethnic group. Research suggests that up to 3 percent of the Australian population 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.

Do we know what causes epilepsy?

Many factors can contribute to the onset of epilepsy including acquired brain injury from such things as 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. At present approximately 60 percent of the causes of epilepsy are not understood. We do not know why many people have recurrent seizures. There is so much that is not known about seizures and about this major chronic illness we call epilepsy 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.**⁵

While it is estimated that up to 12 percent⁶ of the population will have a seizure at some time, we only talk about them as having epilepsy if the seizures are recurring and unprovoked. There are seizures that are not epileptic such as those that result from diabetes and a range of other health conditions.

Is epilepsy inherited?

We are learning more each day about genetic factors. While we can be encouraged by the breakthroughs that are happening in genetic medicine and the genetic insights that are being developed around epilepsy, we also have to admit that in the majority of cases there is simply no known cause. 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.

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 but if it could be it might offer great hope for a solution. As genetic medicine moves forward in leaps and bounds for other conditions, we hope that epilepsy is not left behind. 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 our key purpose. The reasons why people seek our services vary widely and depend on many factors: age and stage of life, individual needs, the unique problems or issues a person may be facing and their personal goals and aspirations for the future. Unfortunately, there are still substantial numbers of people who are unaware of our services.

⁵ WHO Global Campaign: Out of the Shadows, 1997.

⁶ Dr Wendyl D'Souza, Neurologist, *Mary Davis Oration*, 2008.

Our services can essentially be described as the provision of:

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

The way we provide these services depends very much on individual needs – our services are tailored in response to the person’s expression of their own goals and aspirations. We spend time with people to learn about their life and family situation and gain an understanding of what they want to achieve, and then determine how best we can help.

A diagnosis of epilepsy should not mean that life has to stop. One of our primary aims is to see people managing 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. Importantly, we work with people to help them regain their confidence so that they can continue to do the things they love or 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. This is a time when there can be a great deal of anxiety and confusion along with feelings of anger, sadness or frustration. Our early intervention helps people make a healthy adjustment to living with epilepsy, often preventing the development of chronic problems such as depression.

There is a widespread lack of understanding about epilepsy in the community and social stigma persists as a consequence.

We believe that an effective way to reduce the stigma and dispel the myths associated with epilepsy is through awareness and education. One of our long term goals is to have someone in every household and every workplace understand basic first aid for seizures.

Our information service helps to reduce the anxiety surrounding epilepsy by easing the fear of the unknown, helping people understand the facts and demystifying the misconceptions about what epilepsy is, and is not. We ensure that people living with epilepsy have access to as much current information about the causes, treatments and impact of epilepsy as they need and want, 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.

Library service

The Epilepsy Foundation Library includes more than 2,500 books, audio visual materials, CDs, journals and extensive information files containing current and retrospective literature for adults and children on many subjects associated with both the study of, and living with, epilepsy. It is the most comprehensive epilepsy collection in the Southern Hemisphere and of considerable value to the community, to the medical and other health professions, and to researchers engaged in the study of epilepsy.

Our Librarian endeavours to assist with all information queries, whether they are made in person or by telephone, letter or email. Most books and audio visual materials are available for loan to members of the Foundation and our online catalogue is available for browsing. All clients, members of the public, research workers, students and medical professionals are welcome to visit the library to make use of its facilities.

Support services

Our support services are at the heart of our work with people with epilepsy – it is through our professional counsellors' one-on-one consultations with adults and children and their ability to build relationships with those who use our services that we are able to make a real difference to people's lives.

Support services are provided in a number of ways. These can include, for example, 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, counselling or working with the person to re-establish their confidence in gaining or regaining employment or engaging in social or recreational activities. Services can be provided periodically to address changing life situations, or on an ongoing basis. The Epilepsy Foundation also provides counselling support to families in times of grief.

Camps for children, adults and families

Our annual family and adult camps are an opportunity to share experiences, problems and ideas, and to undertake activities that for most would be commonplace. The camps provide a safe and secure outlet for individuals, both children and adults, living with epilepsy and their families to talk with others experiencing the same issues and share coping strategies and their hopes for the future. It is often the first opportunity for a child, and even adults, living with epilepsy to meet and interact with another person living with the same condition.

Education and training

Our education and training program is a key element of our community awareness-raising work, on what it means to have epilepsy, how to live with the condition and how to manage if an employee or student has epilepsy.

Our seminar program includes *Understanding and Managing Epilepsy, Men and Epilepsy and Women and Epilepsy*, as well as parent and carer education days and a childhood epilepsy seminar. We also conduct talks at schools, which often relate to a particular student with epilepsy. This work is designed to assist school staff to manage the needs of the student and to provide a safer, happier and more accepting environment for all concerned. We conduct an in-school epilepsy awareness event, Trivia Challenge, which reaches more than 28,000 students, their teachers and families. Training is provided in places of employment, to assist business owners and supervisors to better support an employee with epilepsy in the workplace.

We also run training workshops within community residential units operated by the Department of Human Services and other community providers, to arm those caring for people with epilepsy with knowledge and information. Some of our training staff provide epilepsy training in the TAFE sector to students undertaking disability and aged care studies.

Research

The 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. Many of the more difficult cases develop into much longer support relationships.

Many of our counsellors also visit clients when they are in hospital for various investigations or surgery. Our in-patient work at hospitals such as St Vincent's, the Alfred, Royal Melbourne and the Austin is proving an invaluable service to patients and is highly valued by their health care professionals. Our expert knowledge of the social aspects of epilepsy and our advice on managing and living with the condition often lessens the anxiety surrounding a diagnosis of epilepsy and helps to demystify the facts.

We maintain excellent links with the Royal Children's Hospital, which refers patients to the Epilepsy Foundation. We support the hospital's ketogenic diet treatment program by supplying scales for families to borrow while they are trialling this treatment for their child with uncontrolled epilepsy and by providing detailed information on the diet.

Accommodation service

Epilepsy Foundation assists 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 mainstream accommodation facilities such as quality local motels, which are located conveniently near the major hospitals and where appropriate providing accommodation subsidies.

Regional services

Our counsellors provide a state-wide service that encompasses the range of services provided from our Camberwell office including counselling, information, advocacy, education and training and clinic support. This work is facilitated by our office in Geelong and our outreach programs.

Advocacy

Our advocacy work is both at a group level and an individual level. At a group level, we advocate on behalf of all people living with epilepsy at all levels of government and to the wider community. Individual advocacy primarily 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. Our five opportunity shops in the metropolitan region require a considerable number of volunteers to run effectively each day. In addition, volunteers assist with a range of administrative tasks and provide clerical support at the head office as well as helping our Client Services and Fundraising departments with events such as our family and adult camps, the Superfits recreational group and annual Trivia Challenge.

The sector in Australia

The epilepsy sector is structured as follows:

- The International Bureau for Epilepsy (IBE), based in Ireland, is the peak international body of which JECA is the full Chapter member in Australia and Epilepsy Australia is an associate member. The IBE addresses social problems such as education, employment, insurance, driving licence restrictions and public awareness. The IBE also works in close liaison with the International League against Epilepsy (ILAE), an organisation of medical professionals involved in the medical and scientific issues of epilepsy.
- Epilepsy Australia is Australia's peak consumer-led epilepsy body and the national coalition of Australian Epilepsy Associations.
- Joint Epilepsy Council of Australia (JECA) is an organisation set up to provide a truly national voice, and designed to incorporate the state of New South Wales (Epilepsy Action), which is not part of the Epilepsy Australia coalition. Epilepsy Action has a constitutional right to JECA membership but is not a current financial member.
- The Epilepsy Foundation of Victoria is a state-based organisation and is a member of Epilepsy Australia and JECA. Epilepsy Foundation of Victoria provides resources to support other state service providers and plays an active role in the activities of Epilepsy Australia and JECA.
- Other Epilepsy Australia organisations include: Epilepsy Queensland Inc, Epilepsy Association of Western Australia, The Epilepsy Centre (Epilepsy Association of South Australia and the Northern Territory), Epilepsy ACT and Epilepsy Association of Tasmania.
- Epilepsy Society of Australia (ESA) is a professional organisation of clinicians, scientists and technologists involved in the diagnosis, treatment and research of epilepsy in Australia. ESA is the Australian chapter member of the ILAE.

The IBE International Conference, the *Asian & Oceanian Epilepsy Congress*, will be held in October 2010 in Melbourne. The Epilepsy Society of Australia and Joint Epilepsy Council of Australia are the local members of the organising committee and are working collaboratively to ensure the success of this prestigious event.

Contact details

Epilepsy Foundation of Victoria
818 Burke Road
Camberwell Vic 3124
Tel: 9805 8111
Fax: 9882 7159

For further media information contact:

Julie Stephens, Stephens Public Relations
Tel: 03 9391 4603 0413 119 673

Graeme Shears, Epilepsy Foundation of Victoria
Tel: 9805 8111
Email: gshears@epilepsy.asn.au

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