

What is living with epilepsy really like?



People with epilepsy told Epilepsy Action about their challenges and needs in our recent discussion groups across Australia. Here we outline findings, hear from participants and give tips to address discrimination - a major issue people raised.

WHEN you're aiming to improve your services, there's no-one better to talk to than the people you support. With that in mind, Epilepsy Action began a series of discussion groups across Australia in January 2007. Our goal was to gain a current, accurate understanding of the needs and issues of people living with seizures, gathering information to develop services from their perspective.

What we did

We invited people with epilepsy, parents of children with epilepsy and carers to face-to-face and telephone discussion groups held in cities and regional centres. Each forum was kept small so issues could be explored in-depth. Topics covered included information, health, seizure management, daily living, recreation, learning, employment, community attitudes and emotional and social needs. We also looked at differences between states, plus specific needs in rural and remote areas.

Meanwhile one-on-one meetings gave us insight into the views of others working in the epilepsy field. We focused on the acute care sector, talking to specialists including General Practitioners, Neurologists and Paediatricians and exploring ways to better support people as they move between healthcare settings and daily life in the community.

Who participated?

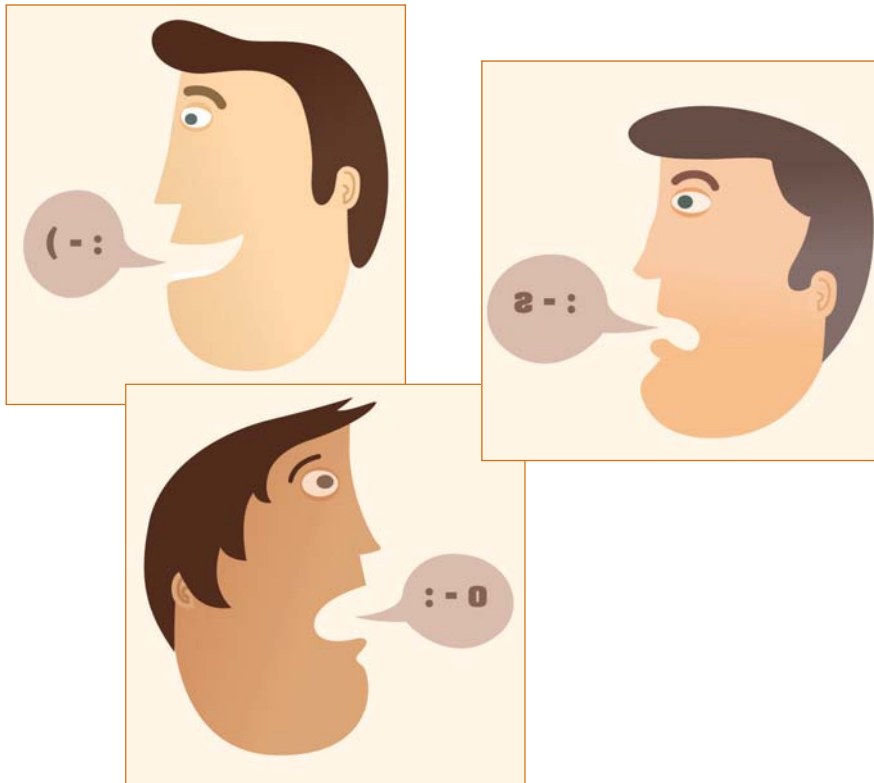
We held 32 discussion groups between February and June 2007:

1. 14 face-to-face sessions and 18 telephone forums
2. More than 200 participants to date
3. 29% men and 71% women
4. 56% had epilepsy
5. 27% had children with epilepsy
6. 11% partners
7. 6% other relationships, including siblings

What we found

Consumers identified varied issues, expressing these critical unmet needs:

- 1. Emotional and social needs including difficulties with family dynamics, relationship breakdowns, depression and isolation.**
 - Majority indicated poor confidence and self image.
 - Few had met anyone else with epilepsy.
 - High levels of distress were common, such as long-term anger, grief and loss.
 - Significant numbers reported family and friends did not understand.
 - Many felt acutely aware of stress as a trigger for seizures.
 - People concerned about the effect on children of witnessing seizures.
 - Anxiety and need to rest or recover created barriers to socialising.
 - Negative community attitudes towards epilepsy were a concern.
- 2. Daily living including need for respite and transport issues.**
 - Lack of appropriate respite or 'babysitting' prevented 'normal' life activity.
 - Loss of driver's licence severely restricted independence and created reliance.



- Public transport difficulties occurred through fear of seizures and misunderstanding of others.

3. Information needs including availability, appropriateness and timing.

- Serious lack of information experienced at time of diagnosis.
- Information from internet, libraries etc was inconsistent, difficult to sort.
- Concern that General Practitioners lacked depth of epilepsy knowledge.
- Current health status impacted ability to seek and process information.
- Lack of age-appropriate information was an issue, especially for children and youth.

4. Employment issues including long-term unemployment, discrimination and disclosure issues.

- High unemployment or underemployment experienced by people with epilepsy or their carers.
- People struggled to balance need for disclosure (for safety) with fear of intolerance, discrimination.

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- Many felt anxious about job performance.
- Participants lacked confidence in negotiating flexibility e.g. frequent breaks, short days with employers.

5. Medical specialists and health personnel experienced a range of issues.

- Concern felt about issues relating to both patients’ psychological wellbeing and social life.
- Pathways were inadequate to refer people from acute care settings such as hospitals or medical centres to community care for help with daily living.
- Referrals also prevented by lack of knowledge about available community services e.g. ‘charity’ support versus professional non-medical services.

Strength through sharing

Sydney couple Anne and Graeme Woods support each other. But that didn’t keep them from the Epilepsy Action forum in Epping. “It was just good to unload your feelings, how you cope with your epilepsy,” says Anne, who began having absence seizures as a child, but wasn’t diagnosed with epilepsy until her 20s. “I used to get into trouble at school for daydreaming.”

Anne, 39, who has since had three tonic clonic seizures in her sleep, met Graeme, 45, on her first visit to an epilepsy support group in 1997. “We’re both very supportive of each other through the times we’ve not been well,” says Graeme, a horticulturalist who works for the local council. For Graeme, those times have been all too frequent. His first tonic clonic seizures hit when he got encephalitis as a result of measles at age four. Being assaulted in 1985 prompted complex partial seizures (one of which saw him bundled into a police paddy wagon on suspicion of drug or alcohol intoxication). Then, in 1997, five years after temporal lobectomy surgery successfully treated his epilepsy, a fever contracted from mosquito bites led to his first nocturnal seizure. Despite all this, “I continue to focus on a positive outlook on life,” says Graeme, “and don’t dwell on my condition.”

Typically, Anne and Graeme went to the forum, not only for what they could get, but also what they could give. The couple who donate to support services for people with epilepsy, presented ideas for raising public awareness. “The more the public are aware, the more it breaks down the stigma,” says Anne. “If anyone had told me that staring could be a type of seizure, I wouldn’t have believed it.”





Learning experience

Dialling into an Epilepsy Action telephone discussion group, Jane had just one thought: “Knowledge is power!”

Jane Flower’s 18-year-old son Jonathan has had seizures since age two but was only formally diagnosed with epilepsy last year. Jonathan, who also has an intellectual disability after contracting meningitis at 10 months, “is totally dependent on me for transport and my life is tied in with his,” says Jane, 49, who lives with her husband and their only child near Bunbury, three hours south of Perth.

Jane was initially apprehensive about the telephone forum, which an Epilepsy Action researcher hosted from Melbourne. But once participants warmed up and recognised each other’s voices, “it was really nice to hear the point of view of someone who suffers from epilepsy, what they experience.”

One frustration for Jane is Jonathan’s inability to remember. Although “I don’t know where his epilepsy stops and his intellectual disability comes in,” through the two-hour forum, “I found out memory loss is common with epilepsy, so I’m more sympathetic now.”

After almost completing a TAFE certificate in horticulture, Jonathan is keen to work in the industry. But a lack of an understanding employer - and public transport near home - is a challenge.

“We haven’t really come across [discrimination] as a barrier,” says Jane, “but in the back of my mind I was sure it probably would be.” Jane found others could empathise. “They’d all experienced some discrimination and difficulties interacting in the community,” she says. “It was quite an eye-opener.”

And afterwards? “I don’t think relieved is the right word,” says Jane, “but... it felt like you weren’t alone.”

Next steps

People with epilepsy and their carers face significant unmet needs. To design more effective services, Epilepsy Action will address the following areas in the next two years:

- Build pathways for referring to Epilepsy Action, bridging the gap between medical professionals such as Neurologists and General Practitioners.
- Employ staff of different specialities to address epilepsy’s impact on all areas of life.
- Offer professional counselling and peer-support opportunities.
- Develop tools to assess people’s needs and evaluate how well we meet needs so services can be improved as required.

For more information on our service developments see pg 12.

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Think positive

A tragic car accident took the life of Nerise Harper's six-year-old son James on Mother's Day in 2002 and left her with catastrophic injuries – including brain damage. Before then Nerise, now 39, was a straight-A English student and classically-trained opera singer who held down three jobs and played, among other instruments, piano, guitar, saxophone and clarinet. Though she eventually returned to university and graduated, these days Nerise's biggest 'A' is for attitude. "What are you going to do? Lay in your bed and be disabled?" asks Nerise, who was diagnosed with temporal lobe epilepsy two years ago. "You can sit there and whinge and moan or you can get off your bum and do something about it."

It was this philosophy that attracted Nerise to the Epilepsy Action forum in Adelaide, which she attended with her partner Mark. "I wanted to know how much of my life epilepsy might impact," says Nerise, "what I'd need to do and who I'd need to tell." Nerise, who spent a year in hospital after the accident, was first alerted to her epilepsy one night two years ago when, engrossed in her favourite TV show, *All Saints*, she fell asleep in her dinner. "I didn't wake up until the music at the end," she says. "I had casserole on my forehead."

While Nerise "definitely got more information about epilepsy" from the forum, fellow participants learned from Nerise too. "Don't let epilepsy blind your life to what virtue you can find," she says.



Discrimination – what to do

Many forum participants across Australia felt they'd experienced discrimination because of epilepsy. But how do you know its discrimination? And is it worth making a complaint?

What is discrimination?

Discrimination occurs when a person with a disability - or their relative, friend, carer, co-worker or associate - is treated less fairly than someone without a disability. The federal Disability Discrimination Act protects the rights of people with a disability. It aims to ensure that everyone has an equal opportunity to participate in and make a contribution to Australian life. The law prevents people discriminating against you in areas including:

- Employment, such as getting a job or applying for a promotion.
- Education at school, university, TAFE.

- Access to public premises like shops, libraries or hospitals.
- Getting goods and services, including taxis, banks, legal services.
- Accommodation whether renting units or houses or buying/selling land.
- Activities of clubs or associations, such as joining a sports club or RSL.
- Commonwealth Government laws and programs, like voting.
- Playing sport.

Who is covered?

The Act's broad definition of 'disability' includes physical, intellectual, psychiatric, sensory, learning and neurological disabilities such as epilepsy.

Why complain?

While it's illegal, discrimination can only be addressed if people report it. Only you can take that step, although support is

available to guide you through the process.

"We receive hundreds of complaints but few lodged by people with epilepsy," says Graeme Innes, Human Rights and Disability Discrimination Commissioner. Innes encourages people not to be afraid to complain. A successful complaint "doesn't just have a positive effect for that person, it has a flow-on effect so people with that disability won't be treated in the same way again," he says.

Making a complaint

Call the Human Rights & Equal Opportunity Commission Complaint InfoLine on 1300 656 419 for advice on what constitutes discrimination and the simple steps to make a complaint. The website www.hreoc.gov.au/ is also a comprehensive source of information.

Source: Human Rights & Equal Opportunity Commission