

Epilepsy Foundation services



Information and resources

The Epilepsy Foundation's Information Line operates Monday to Friday between 9 am and 4 pm.

The Information Line is staffed by Epilepsy Support Workers with expertise in how epilepsy affects health, wellbeing and daily living issues incorporating person-centred, self management strategies.

Available resources:

- epilepsy information sheets
- Epilepsy Management Plan templates
- *Epilepsy: Know Me, Support Me* - detailed resources and best practice guidelines for people with a disability, their family and people working in the disability sector
- Epilepsy Smart Schools - resources for school children, families and schools (www.epilepsysmartschools.org.au).

These resources can be found on our website www.epilepsyfoundation.org.au

Education and training

The Epilepsy Foundation offers evidence based person-centred training programs. Our training programs increase awareness and understanding of epilepsy in the community.

Past participants have told us that they feel more confident in recognising seizure activity and providing person-specific support after completing our training programs designed for families, schools, communities and the workplace.

People living with epilepsy experience better outcomes through improved epilepsy knowledge, epilepsy management plan development, seizure first aid response and training in emergency medication administration.

For more information on training available visit www.learning.epilepsyfoundation.org.au

Support services

Epilepsy Support Workers are available to assist people living with epilepsy and their families and support networks.

Epilepsy Support Workers can provide:

- advice and information about epilepsy
- advice about risk management and living well with epilepsy
- individualized support for people living with epilepsy who require assistance with accessing supports and community resources
- development of tailored epilepsy management plans.

People are able to self-refer to our services. We also accept confidential referrals from health professionals.

NDIS support

The Epilepsy Foundation is a registered NDIS provider. NDIS participants will need to have the Epilepsy Foundation in their NDIS plan if continued support from the Foundation is needed.

Supports include:

- assistance with checking eligibility for the NDIS and the registration process
- pre-planning services to assist in deciding what goals the NDIS plan should contain
- epilepsy specialist assessment and support
- development of Epilepsy Management Plans
- education and training for families and support organisations
- occupational therapy assessments to identify the impacts of epilepsy on daily life.

For more information go to: www.epilepsyfoundation.org.au/ndis-you/

No one should go it alone

Peer support

A number of peer support groups are run throughout the year for families, young people and adults living with epilepsy.

Our website, Facebook page and blog provide opportunities for people living with epilepsy and their families to connect with others and share their stories.

Australian epilepsy research register

The Epilepsy Foundation manages the Australian Epilepsy Research Register (AERR) for people and families living with epilepsy. The research focuses on the social and psychological impacts of living with epilepsy.

Participation is voluntary, anonymous and free of charge.

To become involved, go to: www.epilepsyfoundation.org.au/australian-epilepsy-research-register/

Contact us on 1300 761 487 or email on epilepsy@epilepsyfoundation.org.au

For more information on any of these services, or if you have any questions, please contact the Epilepsy Foundation on 1300 761 487 or email epilepsy@epilepsyfoundation.org.au

If you have a hearing or speech impairment, please call 1800 555 660 (local call charges apply).

To communicate with us in a language other than English, please call the Translating Interpreter Service on 13 14 50.

The Epilepsy Foundation is a registered charity and depends on the support of donors, volunteers and other interested people. If you would like to support our work, now or in the future, please telephone (03) 8809 0600 or visit www.epilepsyfoundation.org.au

Epilepsy myths versus truths

Myth: Epilepsy is contagious.

Truth: *You cannot catch epilepsy from another person. However most people will experience a seizure at some point in their life.*

Myth: You can swallow your tongue during a seizure.

Truth: *It is physically impossible to swallow your tongue.*

Myth: You should force something into the mouth of someone having a seizure.

Truth: *Absolutely not! The correct first aid is simple. Just gently roll the person on one side and put something soft under their head to protect from injury.*

Myth: You should restrain someone having a seizure.

Truth: *Never use restraint! The seizure will run its course and you can not stop it.*

Myth: Only kids get epilepsy.

Truth: *People of all ages can have epilepsy with those over age 60 diagnosed almost as often as children aged ten and under.*

Myth: People with epilepsy should not be in jobs with responsibility or stress.

Truth: *People with the condition have the same range of abilities and intelligence as the rest of us. Some have severe seizures and cannot work; others are successful and productive in challenging careers.*

Myth: You cannot die from epilepsy.

Truth: *Epilepsy is a very serious condition and individuals do die from it. Around 300 people per year die from epilepsy.*

Myth: Thanks to medication, epilepsy is a solved problem.

Truth: *Epilepsy is a chronic medical condition that for many people can be successfully treated. Unfortunately, treatment doesn't work for everyone and there's a critical need for more research.*