

Living With Epilepsy:

Diagnosis, Treatment and Home Support Services



Disability support services for epilepsy

What is epilepsy?

Epilepsy refers to a group of brain conditions that make someone have seizures over a period of time. These seizures are caused by disruptions to the brain's electrical activity, and can last from a few seconds to several minutes. Some people are born with epilepsy while others develop it later in life.

Not everyone who has a seizure has epilepsy. Seizures can be **caused** by other conditions such as fever and diabetes.

Symptoms of epilepsy

The most common symptom of epilepsy is repeated seizures. If you are witnessing someone having a seizure, see **seizure first aid**.

There are many different **types of seizures**. The most recognised type (generalised tonic clonic seizures) causes unconsciousness and jerking or strange body movements. Absence seizures can be harder to identify due to the person remaining conscious but going 'blank' for a few seconds. Absence seizures often start in childhood and can be mistaken for daydreaming.

Diagnosis and treatment

It is important to seek medical help if you or someone you care for experience repeated seizures, unexplained moments of 'blankness' and memory loss, or strange feelings or movements in the body.

Your doctor will ask about symptoms and family medical history to diagnose epilepsy. It can be helpful to keep a **seizure journal**, and bring someone who has seen your seizures to the doctors appointment.

The doctor may order a range of tests and **brain scans**, and refer you to a brain specialist (neurologist). The doctor will work with you to rule out other possible causes, and/or identify what kind of epilepsy you might have and what treatment is best. They may also suggest you speak to NDIS registered providers for optimum support services.

Epilepsy treatment and supports

There are a **range of treatments** for epilepsy, including medication, therapeutic approaches, or surgery if seizures are severe and not responding to other treatments. These treatments should be discussed with your healthcare professional and taken into account when selecting your home care packages and considering the assistance of disability services.

Your treating doctors might suggest lifestyle changes to avoid triggers and try to reduce the risks associated with unexpected seizures. For example, you may need to avoid driving or operating heavy machinery. However, with the correct home care services, you can be assured of supported independent living for optimal wellbeing.

You will need to discuss various treatment options with your doctor, and it may be helpful to maintain the same physician for regular consultations — **find a general practitioner (GP) near you**.

If you have just been diagnosed with epilepsy, there is information available on **living with epilepsy**, including what people with epilepsy **wish they'd known** when they

were diagnosed, how it might **affect your lifestyle**, and information about **pregnancy and epilepsy**. There are also a range of **NDIS support service providers** to ensure you have access to the best services.

You should discuss any concerns or changes to your epilepsy treatment or management with your GP.

Epilepsy support and Claro

Claro provides a range of **disability and allied health supports** tailored to your needs.

Whether epilepsy affects your everyday tasks like cleaning and shopping, or you need more complex support with personal care or overnight assistance, we can work with you to find the right support.

We also partner with **Plena Healthcare** to provide allied health services you might need, like nursing, occupational and physiotherapy, speech pathology, dietetics, podiatry and behavioural support.

While we continue to grow our team and the services we can offer across Australia, we currently offer supports to clients over 18 years old. **Get in touch today** to find out what services we offer near you.

Fill out our **quick and easy enquiry form** and we will contact you to talk about the right support options for you.

Caring for someone with epilepsy

If you care for someone with epilepsy, you will likely need to respond to their seizures at some point (known as seizure management nursing). You may want to keep a **seizure management guide** handy for you and other people involved in your loved one's care.

Caring for someone with epilepsy also involves long-term management. It is important to take a person-centred approach when discussing these measures with doctors. That means involving the person with epilepsy in conversations about their care, supports, and goals, and making sure management plans respect their wishes.

Epilepsy Management Plan (EMP)

One important aspect of living with epilepsy is to develop an **Epilepsy Management Plan (EMP)**. This is a document you create with people in your life who are involved with your care or might be required to care for you during a seizure at some point, like your workplace, school or gym.

Your EMP helps others understand your type of epilepsy, and how you would like to be supported by them during and after a seizure. An EMP has to be signed off by a doctor.

You should update your EMP regularly, or if any aspect of your epilepsy or preferred care changes.

The NDIS and epilepsy

If your epilepsy has a permanent and significant impact on your daily life you might be eligible for the National Disability Insurance Scheme (NDIS). The NDIS provides funding for **disability-related supports and services**.

You will need to provide **evidence of your disability** to apply for the NDIS. Your GP can help you gather this information and **apply for access**.

If you access the NDIS, you will need to start **preparing for your first NDIS planning meeting**. Think about the areas of life impacted by your epilepsy, and take a look at **supports funded by the NDIS**. This might give you an idea of the supports to discuss during your planning meeting, like training an NDIS-funded worker to support you in implementing your EMP.

Living with epilepsy can be a big adjustment. If you need support or have questions about managing epilepsy, you can contact your doctor or epilepsy support and advocacy organisations:

- **Epilepsy Action Australia**
- **Epilepsy Foundation**
- **Epilepsy Australia**

Resources

- **Epilepsy, Health Direct**
- **Understanding Epilepsy, Epilepsy Action Australia**
- **Epilepsy Treatment, Epilepsy Australia**
- **Managing Epilepsy, Epilepsy Action Australia**
- **Living with Epilepsy, Epilepsy Foundation**
- **Seizure Types and Nursing Management, Ausmed**
- **Seizure Nursing Management Guide, St John Ambulance**
- **Epilepsy and Seizure Management Tools, Epilepsy Foundation**
- **Introduction to disability services and the NDIS**
- **Applying for Access to the NDIS**
- **The NDIS in each state**