

Life Without Barriers (LWB) provides disability support to many people with epilepsy and non-epileptic seizures.

## What is Epilepsy?

Epilepsy is a disorder of brain function that takes the form of recurring convulsive or non-convulsive seizures. Epilepsy is not just one condition; rather, it is a diverse family of seizure disorders.

10% of the population are at risk of experiencing a seizure during their lifetime, while 3-4% will go on to be diagnosed with Epilepsy.

<sup>1</sup>Epilepsy is diagnosed if someone has:

- At least two unprovoked (or reflex) seizures
- One unprovoked (or reflex) seizure and a probability of further seizures happening
- Diagnosis of an Epilepsy

**Note:** 'reflex' means the seizure was not provoked by anything obvious e.g. a temperature / head injury.

Detailed information explaining Epilepsy can be accessed via the link below:

<http://www.epilepsyaustralia.net/epilepsy-explained/>.

All staff providing support with Epilepsy should be encouraged to complete the [LWB eLearning module](#) – Epilepsy and Seizure Management.

## What are non-epileptic seizures?

Not all seizures have Epilepsy as a cause. Some people experience symptoms that are similar to that of an epileptic seizure but without the unusual electrical activity in the brain. When this occurs, it is known as a non-epileptic seizure (NES). These seizures are very real to the person experiencing them, and they have no conscious or voluntary control over them. Outwardly, these seizures resemble epileptic seizure types and can occur at any age.

Information relating to NES can be found here:

<https://epilepsyfoundation.org.au/understanding-epilepsy/seizures/types-of-seizures/psychogenic-non-epileptic-seizures-pnes/>

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<sup>1</sup><https://www.epilepsy.org.au/about-epilepsy/facts-and-statistics/>

## Supporting People with Epilepsy or NES

### At Engagement

During the Engagement process, people identified with epilepsy or NES will be asked to choose their preferred risk management strategy concerning how their Epilepsy or NES will be supported.

The choices are:

- The person will self-manage their epilepsy or NES and agrees to LWB following general emergency response only if required (this option is available for people receiving lifestyle support only and reflected in the Engagement form).
- The person will use an existing Epilepsy or seizure management plan completed by their General Practitioner (GP) or Neurologist
- For Epilepsy only - the person will use [NDIS LWB 5542 Epilepsy - Management Plan](#) and arrange for it to be completed by their GP or Neurologist.

Where LWB has responsibility for Epilepsy or NES Support (including SIL settings) environmental considerations must also be addressed to ensure the person is safe including:

- Temperature controls for hot water supply
- Use of sliding doors in toilets where practical – or a door that can be unlocked from outside
- Modification of shower recesses to remove sharp edges, remove the hob and soap dishes.
- Attaching a long chain to bath plugs for easy water drainage and establishing supervision requirements for people whilst using the bath
- Purchasing furniture with rounded edges or padding any sharp or pointed edges with foam or rubber
- Ensuring shower screens and doors and panels with glass are made from safety glass or plastic – or ensuring safety film is applied to any plain glass.

Where a person we support requires Epilepsy or NES support, and their regular seizure activity requires mapping; or a diagnosis of Epilepsy is yet to be confirmed, the [NDIS LWB 5543 Seizure Activity - Observation Tool](#) should be used to gather information in preparation for the GP or Neurologist review.

Where a person we support has a seizure, and they are not diagnosed with Epilepsy or do not have an NES Management Plan, call an ambulance immediately.

### During Service Delivery

When supporting a person with Epilepsy or NES, staff must ensure the following is in place:

- The person is reviewed regularly (at least annually) by a medical professional – either a Neurologist or their GP. The person’s epilepsy or NES support requirements, such as medication and seizure activity, must be addressed and should include blood tests for monitoring of medication levels.
- The doctor documents the person’s Epilepsy or NES support requirements in an appropriate Management Plan outlining:
  - their usual seizure type
  - routine medication
  - when to give PRN
  - when to call an ambulance
  - support with dentures (if applicable)
  - supervision requirement during showering / bathing
  - water temperature requirements
  - supervision requirements
    - while swimming
    - when sleeping
    - any monitoring devices
  - strategies for accessing the community
  - protective equipment required

For epilepsy only - Ideally, the [NDIS LWB 5542 Epilepsy - Management Plan](#) should be provided to the doctor electronically via USB or email to complete. As a precaution, also take the [PRN Protocol](#) template and provide it if required. LWB does not maintain a template management plan for NES - this will need to be developed by the treating doctor.

- The Epilepsy or NES Management Plan is current, has been uploaded to CIRTS and has been reviewed during the past 12 months and again anytime the person’s seizures change, or their condition deteriorates.
- Routine Medications are prescribed in the person’s Compact Medication Chart.
- PRN Medications are documented within the PRN Protocol and the completed Protocol is uploaded to the person’s CIRTS record.
- All seizures are recorded in the [NDIS LWB 5542a Seizure Activity - Recording Chart](#) and the completed chart is uploaded to CIRTS.
- An annual summary of seizures is recorded within the [NDIS LWB 5542b Seizure Activity – Annual Summary – Recording Chart](#) and the completed chart is uploaded to CIRTS.
- The person is supported by staff and/or family who know them well and can provide information about their health and seizure activity during health reviews.
- Seizure Charts, the Epilepsy or NES Management Plan, any PRN Protocols and results of blood tests are made available to the GP or Neurologist during reviews.

- Where the person is prescribed Midazolam as an emergency PRN to treat seizures, all staff providing [Midazolam Administration](#) must complete LWB HIDPA Training and a Workplace Skills Assessment conducted by a nurse or doctor (Appropriately Qualified Health Professional) with each person they support.
- Risk Management strategies relating to Epilepsy or NES and Health are documented within the person's [NDIS LWB 5001 Client Profile](#).
- Tracking of health reviews including Epilepsy or NES Management is completed within the [NDIS LWB 5502 Health and Wellbeing Plan](#).

Disability related health support funding is available via the NDIS for Epilepsy supports which include Epilepsy seizure monitoring and Epilepsy monitoring through assistive technology.

Where the person has experienced no seizures in the last 10 years and has not been prescribed or administered seizure medicines during the last 5 years, their Epilepsy should be considered as resolved and does not require an Epilepsy Management Plan. If the person does experience a seizure, call an ambulance, or if they exhibit signs or experience any symptoms of Epilepsy, they should be reviewed immediately by their GP.

## Responding to a seizure

In the event of a seizure, always follow instructions within the person's Epilepsy or NES Management Plan. However, if you do not know the person or are unable to access the plan, follow the steps below.

### When the seizure starts:

- Stay calm and remain with the person.
- Note what time the seizure starts.
- Protect the person from injury – remove any hard objects from the area.
- Place something soft under the person's head and loosen any tight clothing.
- Stay and observe the person during the seizure.
- Roll the person onto one side as soon as possible to maintain a clear airway. A person cannot 'swallow their tongue' but the tongue can move back to cause a serious block to breathing.
- Call an ambulance if necessary

### While the seizure continues:

- Stay with the person and protect them from harm until the seizure ends naturally.
- Maintain the person's privacy and dignity as far as possible.

- Call an ambulance if necessary.

**After the seizure stops:**

- Note what time the seizure stops.
- Reassure them, calmly talk to the person until they regain consciousness – usually within a few minutes.
- Observe the person's breathing pattern.
- During the recovery period, continue to monitor the person for confusion, agitation, drowsiness, headache or other pain.
- Provide care to prevent inhalation of fluid or foods during the recovery period.
- When the person is fully awake, assist them to wash and change clothing if needed.
- Complete the person's Seizure Chart and other daily records.

**Call an ambulance (Dial 000) if:**

- You are in doubt about responding to the seizure.
- The seizure lasts more than 5 minutes, or some other time interval specified for this person by the treating doctor.
- The person does not respond to emergency medication.
- Food, water or vomit cannot be removed from the person's mouth.
- The seizure occurs in water.
- The person has been injured.
- A second seizure occurs before complete recovery from the first one.
- The person has breathing difficulties or goes blue in the face.
- The person has diabetes.
- The person is pregnant.

For further information about providing First Aid during a seizure, and access to a Seizure First Aid Poster, click the link below:

<http://www.epilepsyaustralia.net/seizure-first-aid/>

## Review

Health Care Plans are important for ensuring the health and safety of the people we support. All Health Care Plans must be developed by a Health Professional who understands the person's individual needs. To ensure plans remain relevant, each Health Care Plan must be reviewed at least annually, or more often if the person's needs change. The Health Professional who develops the plan should also detail any signs that, if

observed by staff, indicate an immediate review should take place. LWB Disability Support Staff must also monitor the person's health in the context of the STOP AND WATCH principles outlined in the [NDIS LWB 5501 Health and Wellbeing - Procedure](#). Health Care Plans can only be reviewed a maximum of six (6) times before a new plan must be developed. Additionally, Health Care Plans can only be reviewed by the Health Professional who developed the plan, or by another professional with equivalent qualifications. If the treating Health Professional has changed since the plan was originally developed, the new Health Professional may choose to develop their own plan for the person.

## **Further advice**

The NDIS Quality and Safeguarding Commission has produced a Practice Alert that explains the risks associated with epilepsy, how to support people with epilepsy and provider obligations.

[Practice Alert: Epilepsy Management](#)