



**KNOW ME  
SUPPORT ME**

# Your epilepsy support and NDIS

Preparing for your NDIS meeting

# Your epilepsy support and NDIS

If you have been accessing Epilepsy Foundation services in the past, or think you might in the future you must get all of the supports written into your plan. If they are not included in your plan the Epilepsy Foundation may not be able to provide services due to a loss of funding.

As epilepsy is unique to each person and the impact of epilepsy on an individual and their family can often be more than the seizure itself.

This checklist has been designed to:

- Help you prepare for a planning session with a NDIA planner
- Identify what impacts epilepsy has on your life
- Identify possible supports needed to help you achieve your goals

Epilepsy Foundation staff can help you prepare for your meeting with NDIS, including support to complete this document if required.

## NDIS planning checklist

### STEP 1

#### How does epilepsy impact you?

When thinking about your epilepsy, what makes it hard to achieve your goals?

##### Health and wellbeing

- Feeling tired and fatigued, or sleep issues
- Memory, thinking, planning and concentrating
- Coordination
- Pain
- Feeling depressed, anxious or stressed
- Seizure triggers (e.g. heat, stress)
- Fear of having a seizure or dying from a seizure
- Side effects of medication
- Frequent or prolonged seizures
- Fear of discrimination and stigma

##### Daily living and home

- Feeling unsafe at home (due to the physical environment, lack of adequate support or inability to perform tasks safely)
- Injuries as a result of my seizures
- My family (or those I live with) don't understand my epilepsy or know how to support me during a seizure

##### Relationships and accessing the community

- Feeling lonely and isolated
- Disclosing epilepsy to my school, employer or friends
- Concerns about participating in social and leisure activities
- My support staff don't understand my epilepsy or know how to support me during a seizure
- Lack of transport options

##### School and learning

- My school doesn't understand my epilepsy
- My school doesn't know how to support me during a seizure
- Participating in school activities like swimming and camps

##### Volunteering and work

- I feel unable to work due to my epilepsy
- My employer doesn't understand my epilepsy or know how to support me during a seizure.

### STEP 2

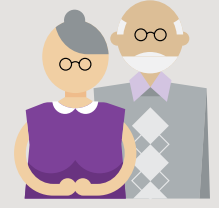
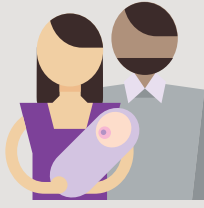
#### What is most important to you?

Thinking about the areas that you have ticked, which are the issues that are most important to you?

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2. ....
3. ....
4. ....
5. ....

Thinking about these issues, what are your goals?

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Participant's name:

Date:

### STEP 3

#### What Epilepsy Foundation services have you previously received?

- Support and advice on the InfoLine
- Epilepsy Management Plan development and review
- Midazolam training for family
- Midazolam training for others (school staff, day program or CRU staff )
- Occupational therapy assessment and equipment advice
- Specialist epilepsy assessment and support
- Epilepsy education (school staff, day program or CRU staff)

#### Support groups

- YES group (ages 12-24 years)
- AWEsome group
- Regional support groups
- Women's Epilepsy Network (WEN)
- Parents group
- PAUSE (Older parents and carers group)

#### Getaways

- Adult getaway
- Women's Epilepsy Network (WEN) Getaway
- Family respite weekend

Epilepsy is a chronic health condition and a disability under the *National Disability Insurance Act 2013* both on its own and with other disabilities

Is your Epilepsy Management Plan up to date?

Does your medication require review?

### STEP 4

#### Epilepsy Foundation services to consider for your NDIS plan

##### Specialist epilepsy assessment and support

Learn and understand more about the impact of epilepsy on your life. Develop an Epilepsy Management Plan which details how you would like to be supported during a seizure and discuss other strategies for managing your epilepsy.

##### Occupational therapist assessment/aids and equipment

Identify issues with independence and safety in the home and community, and develop strategies or identify equipment or aids to manage these.

##### Epilepsy education, training and advice for families and staff

Epilepsy education and training for you, your family or your support workers about understanding and managing your epilepsy, and training around the safe administration of emergency medication.

##### Transitioning to school or tertiary education

Assistance and advice for families and children transitioning to kindergarten, primary, secondary or tertiary education. Support is available to facilitate inclusion in the classroom, excursions, camps, swimming etc.

##### Employment and Volunteering

Assistance and advice for adults returning to or entering the workforce who are concerned about their epilepsy.

##### Social and interpersonal skill development

Support and strategies to help manage personal, interpersonal or social issues that may arise from living with epilepsy.

##### Social, recreation and community activities, groups, weekends away

A variety of social groups, events and getaways are offered where you can meet other people with epilepsy.

### STEP 5

#### What Epilepsy Foundation services would you like to go into your NDIS plan?

- Epilepsy Management Plan development or review
- Midazolam training for family
- Midazolam training for support staff
- Occupational Therapy assessment
- Specialist epilepsy assessment and support
- Epilepsy education (e.g for carers or support staff)
- Assistance with school transitions
- Assistance with employment/ volunteering issues
- Support groups
- Getaways

Supports from other providers I might need:

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\* NDIS does not fund school training. Schools can access funding through the relevant department in each State or Territory.

If you would like to know more about these supports please contact us on **1300 761 487**.

## Your epilepsy support – next steps

To find out more about our supports, to request assistance with completing this document or to find out more about your eligibility for NDIS contact the Epilepsy Foundation:

**Telephone: 1300 761 487**

**Email: [intake@epilepsyfoundation.org.au](mailto:intake@epilepsyfoundation.org.au)**

**[www.epilepsyfoundation.org.au](http://www.epilepsyfoundation.org.au)**

Take this document to your NDIS Planning meeting

Take a friend/advocate with you to the NDIS meeting

Take supporting documentation such as current EMP, neurologist/doctors letters, allied health assessments, equipment needs

## Choice and control

For participants with a disability who need to identify good service providers and learn more about their epilepsy, refer to the *Epilepsy – know me, support me; Better Practice in the Disability Sector* resource which sets national standards in managing epilepsy.

For parents of primary and secondary aged children who need to identify good education settings, use the *Epilepsy Smart Schools – educate me, include me* resource which sets standards in managing epilepsy.

These resources can be accessed via [www.epilepsyfoundation.org.au](http://www.epilepsyfoundation.org.au)



## The impact of epilepsy is not just seizures

This is what others usually see when a person has epilepsy

### Seizures

Below are some of the other possible impacts of epilepsy that people may experience because of their seizures and which can often impact a person more than the seizure itself.

### Memory

For some people with epilepsy, memory can be a significant challenge

### Stigma

A person can experience stigma due to a lack of community awareness and understanding of epilepsy

### Tiredness/fatigue

Due to seizure activity (including during sleep) people can be tired and find it difficult to concentrate

### Medication

Side effects from medication may cause tiredness, difficulties with concentration or mood/behaviour changes

### Self-esteem

The unpredictable nature of seizures can have a negative effect on a person's confidence and self-esteem

### Depression and anxiety

Up to 50% of people living with epilepsy experience depression or other mental health illnesses

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The information contained in this publication provides general information about epilepsy. It does not provide specific advice. Specific health and medical advice should always be obtained from a qualified health professional.

The images in this publication show models who do not necessarily have an epilepsy diagnosis and are for illustrative purposes only.

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**Epilepsy Foundation Information Line 1300 761 487**  
**[www.epilepsyfoundation.org.au](http://www.epilepsyfoundation.org.au)**