Epilepsy Action Australia

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EPILEPSY AND THE NDIS

FACT SHEET

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EPILEPSY AND THE NDIS

The National Disability Insurance Scheme (NDIS) is a way of providing support for Australians with disability, their families and carers.

Epilepsy's functional impact is often far-reaching and can affect many aspects of daily life, from cognitive abilities and physical health to social interactions and work or school performance.

- Cognitive challenges can include memory problems, difficulty with attention and concentration, and language difficulties.
- Physical challenges may be fatigue, sleep disturbances, and mood changes, all of which can affect daily activities and quality of life.

What epilepsy supports are funded?

Epilepsy supports are what we call disability-related health supports.

NDIS will only fund these supports if they directly relate to your disability and help you carry out activities involved in daily life.

They may fund epilepsy supports if your disability means you can't monitor or manage your epilepsy on your own. NDIS may fund epilepsy supports like:

- training for a support worker to help you follow your Epilepsy Management Plan (EMP)
- training for a support worker to follow your Emergency Medication Management Plan (EMMP) if you need medication when you have a seizure
- a support worker to monitor your seizures
- a nurse to monitor seizures if you have complex health and disability needs
- time for your support worker to go to training, for your specific support needs
- assistive technology for example, alarms or seizure monitors
- support coordination, if you don't have a local area coordinator, family, or carers to link you with epilepsy support services.
- **Click Here to see our training options**

Am I eligible?

To be eligible, you must:

- Have a permanent impairment that significantly affects your ability to take part in everyday activities, or have a developmental delay
- Be aged under 65 years when you first apply to enter the NDIS
- Be an Australian citizen or hold a permanent visa or a Protected Special Category visa.

! To find out if you are eligible, go to the NDIS website and complete the eligibility checklist

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DETERMINING YOUR ELIGIBILITY

NDIS has six functional domains to assess your capacity and determine eligibility for support

These are:

Mobility (using public transport, seizure related risks, falls or injuries, house modifications),

Learning (learning new things, memory, planning and concentration issues),

Communication (letting others know needs, help with talking, following instructions),

Self care (looking after self, personal hygiene, shower safety, taking medication),

Social (social interaction, making and keeping friends, talking to particular people), isolation), and

Self management (making decisions, lifestyle changes, avoiding triggers).

You may also want to submit a carers impact statement as part of your NDIS application. It can demonstrate the everyday difficulties experienced by the you and your family or caregivers, and to validate how much care and support you need. This can help strengthen your application because it provides a clear, practical picture of the supports that are needed.

Consider what limitations the person experiences every day because of their disability

! If I am not eligible, will Epilepsy Action Australia still assist me?

Yes. Epilepsy Action Australia will continue to deliver services regardless if you have NDIS funding or not. We offer a range of services including:

- Information and education for individuals, families, schools, employers, community groups
- Emergency medication training
- Epilepsy Management Planning
- A range of self-management tools
- Assessment of epilepsy related safety needs and equipment
- Accredited and non-accredited online courses
- Peer support opportunities

☑ **If you meet eligibility criteria**, you can apply by filling out the Access Request Form with supporting evidence from your treating health professionals. The supporting evidence should be recent and in the form of letters, assessments, reports or a supporting evidence form. **Use this to describe how epilepsy affects your daily life, including any challenges, risks, or barriers you face, and the type of support you're requesting.**

☒ **If your eligibility request is declined,** you'll receive specific feedback about what's missing.

You can reapply as many times as needed.

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NDIS PLANNING

If you are eligible, your first step will be developing a personal plan that reflects your needs and goals.

The plan will start with a meeting with NDIA about what you need, want and can also include input from your family or carers.

Following this meeting, your plan will be sent to you, listing the funding and supports provided. They will let you know the next steps and how long it will take to receive your approved plan. For more click here

For more information about preparing for the planning meeting, click here

These NDIS Booklets explain the whole process

EPILEPSY RELATED SUPPORTS: THINGS TO CONSIDER

Informal supports in your network

These people provide me with the most *informal* support:

- Partner or spouse
- Parent
- Children
- Close family member
- Grandparent
- Friend
- Neighbours
- Volunteer

Does your primary carer (who provides you with the most care and support):

- Live in your house?
- Live elsewhere?

Community participation

I currently access these community services (library, gym, shops, peer support group)

I would like to access:

What is important to me? What are my goals?

- ☐ To maintain or change my living arrangements
- ☐ To maintain family relationship & activities
- ☐ To have access to community/social activities
- ☐ To sleep independently in my own bed
- ☐ To be able to live independently
- ☐ To maintain/gain employment, study or volunteering opportunities
- ☐ Maintain/improve my health & wellbeing

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EPILEPSY RELATED SUPPORTS: THINGS TO CONSIDER

Symptoms

Epilepsy and the impact of seizure medication give me the following symptoms:

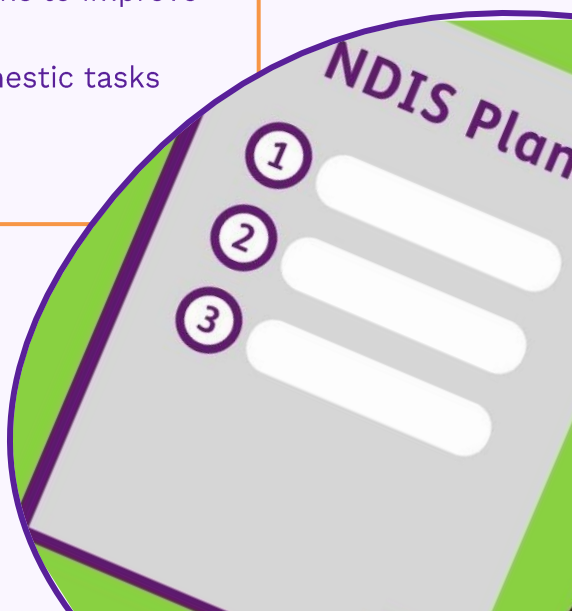
- Memory difficulties
- Concentration difficulties
- Tiredness, fatigue
- Anxiety, stress
- Depression
- Problems with learning
- Pain
- Ongoing seizures
- Weakness
- Poor coordination/balance problems
- Other:

These symptoms make it difficult to:

- Travel alone on public transport
- Be home alone
- Maintain the house or yard
- Find and keep work
- Take part in sport or exercise
- Do shopping
- Complete schooling or education
- Other:
- Live independently
- Prepare meals
- Look after my children
- Have social outings
- Drive
- Have holidays
- Go to school, excursions or camps

To lessen the impact of epilepsy on my independence in daily life, I need:

- ☐ Epilepsy training for my family, carers, school, community organisation or employer
- ☐ Support with Epilepsy Management Planning
- ☐ Peer support with other people with epilepsy
- ☐ Assessment of safety needs and equipment such as head protection, seizure alarms or monitors
- ☐ Supports to manage seizure triggers such as sunglasses, temperature regulating clothing
- ☐ Epilepsy Nurse support and advice
- ☐ Home modifications to improve safety
- ☐ Support with domestic tasks
- ☐ Respite services
- ☐ Other



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NDIS PLANNING MEETING

So, you now have your meeting date. Here are some examples of what you will be asked in your first NDIS planning meeting.

- **Your personal details**: You will need to have ID with your name, age and address, plus bank account details that you want the funds to be sent to. You'll also be asked about your epilepsy and other health conditions or disabilities, so *take any health reports or assessments.*
- **Your community and mainstream supports**: You will be asked about different areas of your life, what support you currently have. This may include family, friends or neighbours as well as health services, community groups or help at school.
- **Your everyday activities**: This is an opportunity for you to discuss what services, support or equipment might make your activities or tasks easier. *Do you work, study or volunteer? What does your average day look like? Do you need any help at home?*
- **Supports and assistance**: You will be asked what support, or equipment will help remove barriers, or make you feel safer, and about any safety concerns. *Think about what assistance or equipment would make your life easier, and are there any barriers preventing you from doing things you want to do? What are your main challenges or obstacles? Do you need help to take care of yourself or your home?*
- **Think about your goals:** What outcomes you want to achieve with your NDIS supports? This is an opportunity to talk about your future goals and what you want to achieve. This includes short term (immediate and essential needs) as well as long term goals that may be worked on over the period that the plan is in place. *Goal examples may include, fostering independence, learning new skills, accessing education, and increasing community participation.*

Read your plan carefully because if you are not happy, you have the right to ask for an internal review.

For more information about the internal review process visit How to Review a Planning Decision

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WHO CAN HELP?

Role of Local Area Coordination (LAC)

LAC's can help you to understand and access the NDIS, create and implement a plan and review your plan.

For more about LAC's Click Here

Early Childhood Early Intervention (ECEI) Partners

The ECEI approach supports children under 6 years who have a developmental delay or disability or children younger than 9 years with disability and their families. For more Click Here

Support Coordination

A support coordinator will work with you to build and the skills you need to understand, implement and make full use of your plan. For more about Support Coordinators, Click Here

Where can I find out more about the NDIS?

The NDIS website has lots of information and resources available to help you navigate the NDIS and determine how it will work for you. You can access the website here and there are many useful downloadable factsheets here

!

Support for families and carers

Families and carers are partners in the support of people with a disability, and the NDIA aims to work with these crucial supports to maintain family wellbeing.

Click Here to find out how NDIS can help families and carers

You can also call the NDIS info line on 1800 800 110

We ndis Registered NDIS Provider

Epilepsy Action Australia is a registered NDIS provider, delivering epilepsy training and individualised services to meet each person's needs.

Click Here to see training options

Contact us:

Phone: 1300 37 45 37

Email: epilepsy@epilepsy.org.au

Book a telehealth appointment with an epilepsy nurse

Visit our website

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