

Epilepsy and the NDIS

NDIS registered provider

www.epilepsyqueensland.com.au

Some people with epilepsy do not identify as having a disability, and therefore, believe they are not eligible for supports under the National Disability Insurance Scheme (NDIS).

However, you may be eligible for the NDIS if you meet the eligibility requirements available on the NDIA website. You need to evidence the impact that epilepsy has on your/your loved ones life.

There are many sources of support a person with epilepsy may access – including, support from family and friends, mainstream services – such as through the health and education system, and now, another option is support from the NDIS.

Accessing the NDIS

To access support through the NDIS, a person with epilepsy will need to be eligible as assessed against the NDIS Access Checklist and subsequently complete the Access Request Form.

All potential NDIS participants are required to complete Part A: General Information and Part B: Diagnosis of Conditions.

Epilepsy can have a profound impact on a person's ability to function on a daily basis and actively engage in community and mainstream services. However, it is not currently recognised as a condition that allows for a streamlined process when entering the scheme. Therefore, potential NDIS participants will be required to complete Part C, providing evidence of the impact of the condition.

The required documentation and evidence requirements for Part B and Part C can be found on the National Disability Insurance Agency (NDIA) website at: https://www.ndis.gov.au/people-with-disability/access-requirements/completing-your-access-request-form/evidence-of-disability.

Accessing the NDIS – already receiving funded state based supports

People who are already accessing state based disability supports will not be required to resubmit evidence for eligibility, as this information will be transferred from the state to the NDIA.

You may wish to contact your local Service Centre to update your personal details and ensure all information is current. For information regarding functional impairment, this should be within 12 months.

Preparing for the NDIS Planning Meeting EQI have a Workbook that has been developed to assist people prepare for the NDIS Planning Conversation with the NDIA. Please contact us to obtain a copy of this workbook. We can assist you with completing this, or you can work on it on your own

Below, is a list of the types of supports and services EQI believe people with epilepsy should be seeking in their NDIS plan.

Epilepsy Queensland consider these supports to be "reasonable and necessary" for people living with epilepsy and requiring support across various areas of their life to enhance their independence and be active and contributing members of their community.



- 07 3435 5000 or 1300 852 853 (outside brisbane)
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| | Epilepsy Related Needs | Example of Goal | Suggested areas where this may fit into the NDIS Plan? | |
|---|---|--|--|--|
| | Development of an Epilepsy Management Plan | To improve the knowledge, skills and confidence of people providing informal and formal supports to me in order to understand the type of epilepsy that I have, my triggers, what it looks like before, during and after my seizures, and how to keep me safe. | Capacity Building Improved Daily Living Therapeutic Supports | Epilepsy Queensland is a Registered Provider with the NDIS. Contact us on 07 3435 5000 or |
| | Development of the Epilepsy Emergency Management Plan. This is only relevant to people who require the Emergency Administration of Midazolam | To improve the knowledge, skills and confidence of people providing informal and formal supports to me in order to understand the type of epilepsy that I have, my triggers, what it looks like before, during and after my seizures, and how to keep me safe. | Capacity Building Improved Daily Living Therapeutic Supports | |
| | Training for family, carers or other people supporting the individual with Understanding Epilepsy and Emergency Administration of Midazolam (if required) | To improve the knowledge, skills and confidence of people providing informal and formal supports to me in order to understand the type of epilepsy that I have, my triggers, what it looks like before, during and after my seizures, and how to keep me safe. | Capacity Building Improved Daily Living Therapeutic Supports | |
| | Aids & equipment designed to keep people with epilepsy safe & develop their independence – e.g. protective headgear, monitoring equipment, cooling devices, seizure dogs, seizure mats, falls detection devices, medication dispensing aids | To have suitable equipment and aids that assist me to live safely and enhance my independence and inclusion | Capacity Building Improved Daily Living Capital Supports Assistive technology Depending on the assistive devices required, you may be allocated initial funding for an OT assessment to identify your needs. From here, you can submit the quote to NDIS for consideration and approval. This will then be added to your plan. | 1300 852 853 to find out more about how we can assist you. |
| 4 | Aids for everyday living – this may be in relation to mobility, personal care or continence – e.g. wheelie walker, shower chair, handrails | To have suitable equipment and aids that assist me to live safely, enhance my independence and engage in social and mainstream activities of my choice | Capacity Building Supports Improved Daily Living Capital Supports Assistive technology Core Supports Continence Assistance with daily life (supports) | |

| | Epilepsy Related Needs | Example of Goal | Suggested areas where this may fit into the NDIS Plan? | |
|---|---|--|---|---|
| | House modifications to improve safety and enhance independence e.g. air conditioning (some people's seizures are triggered by heat), shatter proof glass, outward opening doors, doors unlocked from the outside etc. | My home environment is safe and enables me to be independent / enhance independence | Capital Supports Home modifications Assistive technology | Epilepsy Queensland is a Registered Provider with the NDIS. Contact us on 07 3435 5000 or 1300 852 853 to find out more about how we can assist you. |
| * | Access social groups and activities, which incorporate sharing lived experiences with other people with epilepsy | Meet new people by accessing social groups in the community, with the potential to engage with other people with epilepsy A person's goal may also extend to be an active participant in a social group, such as host, organiser etc. | Capacity Building Increased Social and Community (Skill development) Core Supports Assistance with Social and Community Participation | |
| | Therapy supports to increase independence and facilitate functional improvement through adjustment, adaption and building capacity to participate in the broader community To access therapies to support global developmental delays and help manage behaviours | To increase independence and inclusion by engaging with a variety of therapies. This may be in relation to: - Memory, cognitive impairment - Managing stress/anxiety - Movement - Communication - Developmental delay - Behavior support and management - Confidence | Capacity Building Improved Daily Living e.g. Therapy Services from an OT, Speech therapist, Psychologist etc. Capacity Building Improved Relationships e.g. Behaviour Support including social skills development, managing emotions etc. | |
| | Support to maintain the capacity of family/carers to provide informal supports. This was previously referred to as respite. This may include: emotional and behavioural supports/counselling | To increase my confidence and independence by attending various social activities (day and overnight) without my parents and learning to adjust to different social settings | Core Supports Assistance with Daily Living Short term Accommodation and Assistance (NDIS Price Guide – Vic, NSW, Qld, Tas – valid from 1st July 2017, p. 27 and 40) Capacity Building Improved Relationships e.g. behaviour support Capacity Building Improved Daily Living e.g. Psychology | |

Whilst the above goals relate specifically to the supports required to help manage epilepsy and enhance an individuals quality of life, below are a list of other suggested goals, that relate more holistically.

As a general guide, we suggest individuals think broadly about their life and about their goals, incorporating:

- Health and wellbeing;
- Identity, culture and values;
- Doing things and going places the person enjoys, including transport considerations;
- Trying new things;
- Meeting new people and making new friends;
- Having a valued status in the community e.g. work, volunteer, study, friendships, connections with others;
- Developing and maintaining independence and safety;
- Use of assistive technology that will enhance independence, safety and lifestyle.

Furthermore, below is not an exhaustive list, however, provides some examples of goals to think about, as they relate to the person developing their NDIS plan.

Examples relevant to children:

- Attend school/social/sporting activities independently;
- Attend sleep overs with friends and family;
- Sleep independently and safely;
- Play safely in the playground with other kids;
- Try a new hobby.

Examples relevant to adults:

- Maintain my home and garden;
- Find and maintain a job or volunteer work;
- Move out of home, or to live independently;
- Access social opportunities or try a new hobby;
- Develop my skills in managing my lifestyle e.g. completing various forms, organizing appointments /events etc.;
- Learn how to manage my own finances;
- Learn how to manage my NDIS funding and supports.

Epilepsy Queensland is committed to supporting people as they transition to the NDIS. If you have any questions in relation to eligibility, epilepsy related needs or services or want more information on our approved registration groups - please do not hesitate to contact us at: ndis@epilepsyqueensland.com.au or 07 3435 5000 or 1300 852 853 if outside Brisbane.

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