



# Are you supporting someone with epilepsy to prepare for the NDIS?

NDIS registered provider

[www.epilepsyqueensland.com.au](http://www.epilepsyqueensland.com.au)

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

However, epilepsy is a chronic health condition and recognised as a disability under the National Disability Insurance Act (2013), both on its own and as part of other disability types.

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 for the person accessing the NDIS and Part B: Diagnosis of Conditions.

Whilst many people recognize that epilepsy can have a profound impact on an individual's ability to function on a daily basis and actively engage in community and mainstream services, 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 NDIA website at: <https://www.ndis.gov.au/people-with-disability/access-requirements/completing-your-access-request-form/evidence-of-disability.html>.

## Preparing for the NDIS Planning Meeting

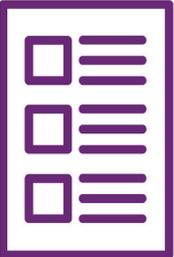
Your role in supporting a person to prepare for their NDIS Planning Meeting, is vital in ensuring the person can clearly articulate their support needs, including, their needs in relation to epilepsy.

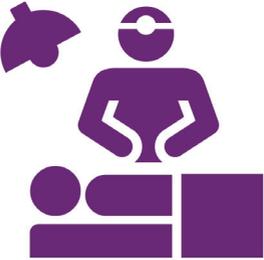
**Below, is a list of the types of supports and services people with epilepsy should be seeking in their NDIS plan.**

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)  
✉ [ndis@epilepsyqueensland.com.au](mailto:ndis@epilepsyqueensland.com.au)  
📮 po box 1457 coorparoo bc qld 4151



	Epilepsy Related Needs	Example of Goal	Suggested areas where this may fit into the NDIS Plan?
	<p>Development of an Epilepsy Management Plan</p>	<p>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.</p>	<p><b>Capacity Building</b> Improved Daily Living</p>
	<p>Development of the Epilepsy Emergency Management Plan. This is only relevant to people who require the Emergency Administration of Midazolam</p>	<p>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.</p>	<p><b>Capacity Building</b> Improved Daily Living</p>
	<p>Training for family, carers or other people supporting the individual</p>	<p>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.</p>	<p><b>Capacity Building</b> Improved Daily Living</p>
	<p>Aids and equipment designed to keep people with epilepsy safe and develop their independence – e.g. protective headgear, monitoring equipment, cooling devices, seizure dogs, seizure mats, falls detection aids, medication dispensing aids</p>	<p>To have suitable equipment and aids that assist me to live safely and enhance my independence and inclusion</p>	<p><b>Capacity Building</b> Improved Daily Living</p>
	<p>Aids for everyday living – this may be in relation to mobility, personal care or continence – e.g. wheelie walker, shower chair, handrails</p>	<p>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</p>	<p><b>Capacity Building Supports</b> Improved Daily Living <b>Core Supports</b> Continence Assistance with daily life (supports)</p>

	Epilepsy Related Needs	Example of Goal	Suggested areas where this may fit into the NDIS Plan?
	<p>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.</p>	<p>My home environment is safe and enables me to be independent / enhance independence</p>	<p><b>Capital Supports</b></p> <p>Home modifications</p> <p>Assistive technologies</p>
	<p>Access social groups and activities, which incorporates sharing lived experiences with people with epilepsy</p>	<p>Meet new people by accessing social groups in the community, with the potential to engage with other people with epilepsy</p> <p>A person's goal may also extend to be an active participant in a social group, such as host, organizer etc.</p>	<p><b>Capacity Building</b></p> <p>Increased Social and Community (Skill development)</p> <p><b>Core Supports</b></p> <p>Assistance with Social and Community Participation</p>
	<p>Therapy supports to increase independence and facilitate functional improvement through adjustment, adaption and building capacity to participate in the broader community</p> <p>To access therapies to support global developmental delays and help manage behaviours</p>	<p>To increase independence and inclusion by engaging with a variety of therapies,</p> <p>This may be in relation to:</p> <ul style="list-style-type: none"> <li>- Memory, cognitive impairment</li> <li>- Managing stress/anxiety</li> <li>- Movement</li> <li>- Communication</li> <li>- Developmental delay</li> <li>- Behavior support and management</li> <li>- Confidence</li> </ul>	<p><b>Capacity Building</b></p> <p>Improved Daily Living</p> <p>e.g. Therapy Services from an OT, Speech therapist, Psychologist etc.</p> <p><b>Capacity Building</b></p> <p>Improved Relationships</p> <p>e.g. Behaviour Support including social skills development, managing emotions etc.</p>
	<p>Support to maintain the capacity of family/carers to provide informal supports.</p> <p>This was previously referred to as respite.</p>	<p>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</p>	<p><b>Core Supports</b></p> <p>Assistance with Daily Living</p> <p>Short term Accommodation and Assistance</p> <p>NDIS Price Guide – Vic, NSW, Qld, Tas – valid from 1<sup>st</sup> July 2017, p. 27 and 40</p>

Whilst the above goals relate specifically to the supports required to manage the person's epilepsy and enhance their quality of life, below are a list of other suggested goals, that relate more holistically to the person's life.

**As a general guide, we suggest you support the person to think broadly about their life and about their goals, incorporating:**

- Health and wellbeing
- Identity 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

**This is not an exhaustive list, however, provides some examples to think about, as they relate to the person you are supporting to develop their NDIS plan.**

Examples relevant to children:

- To attend school/social/sporting activities independently
- To attend sleep overs with friends and family
- To sleep independently and safely
- To play safely in the playground with other kids
- To try a new hobby

Examples relevant to adults:

- To maintain my home and garden
- To find and maintain a job or volunteer work
- To move out of home, or to live independently
- To access social opportunities or try a new hobby
- To develop my skills in managing my lifestyle e.g. completing various forms, organizing appointments /events etc.
- To learn how to manage my own finances
- To 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](mailto:ndis@epilepsyqueensland.com.au) or 07 3435 5000 or 1300 852 853 if outside Brisbane.

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 po box 1457 coorparoo bc qld 4151

