

## **Epilepsy Supports**

**Quick summary:** The Australian health system provides treatment for epilepsy for everyone. We can only fund epilepsy supports if they're related to your disability. We may fund epilepsy supports if your disability means you can't monitor or manage your epilepsy on your own.

We may fund a support worker or nurse to help monitor your seizures when they happen. We may also fund someone to help carry out your Epilepsy Management Plan (EMP) if you have a seizure. If you need medication, we may fund supports to help you carry out your Emergency Medication Management Plan (EMMP).

**Note:** when we say 'your plan' we mean your NDIS plan. If you're looking for information about Community Connections, go to Our Guideline – Community connections.

If you're looking for information about your child's early connections, go to <u>Our Guideline</u> – Early connections.

## What's on this page?

#### This page covers:

- What do we mean by epilepsy supports?
- What help can you get to manage your epilepsy through the health system or other services?
- How do we decide what epilepsy supports we fund?
- What types of epilepsy supports do we fund?
- How do you get disability-related epilepsy supports in your plan?
- What happens once you have epilepsy supports in your plan?

#### You might also be interested in:

- Disability-related health supports
- Mainstream and community supports
- Assistive Technology

## What do we mean by epilepsy supports?

Epilepsy supports are what we call disability-related health supports. We can only fund these supports if they directly relate to your disability and help you undertake activities involved in day-to-day life.<sup>1</sup> Learn more about <u>what we mean by disability-related health supports</u>.

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Epilepsy supports help you monitor or manage your epilepsy if you can't do this on your own because of the functional impact of your disability. This means, because of your disability you are unable to, or it's hard for you to manage your epilepsy yourself.

If you have epilepsy you should talk to your doctor first. They can link you to health services that are paid for through Medicare. You can continue to access health services from Medicare, even when you're an NDIS participant. Learn more about the <a href="help you can get">help you can get</a> through the health system or other services.

As an NDIS participant, we may fund supports to help you manage your epilepsy. Like all supports we fund, epilepsy supports must meet the <u>NDIS funding criteria</u>.

Epilepsy is a medical condition that affects the brain and causes seizures. It's diagnosed by a medical specialist. The number and type of seizures caused by epilepsy varies greatly between people.

Epilepsy affects people differently. Your epilepsy may not have a big impact on your life. You may be able to manage your epilepsy with medication and services provided through the health system. Or your epilepsy may have a big impact on your life. It may affect your education, employment, lifestyle, health, social and family life.

We may fund support to help you manage your epilepsy if your disability means you can't do this on your own. The support might be:

- assistive technology, for example alarms or seizure monitors
- a support worker or nurse to monitor your seizures.

Epilepsy supports are one of the disability-related health supports we may fund. Learn more about other <u>Disability-related health supports</u>.

## What help can you get to manage your epilepsy through the health system or other services?

Everyone who has epilepsy can get help to manage it through the health system, or other services whether or not they have a disability. Under the NDIS, we can't fund a support if it's more appropriately funded or provided by another service. If you can get support for your epilepsy through the health system or another service, we can't fund it.

Government and community services must ensure all Australians, including people with disability, have access to their supports. We call these supports mainstream and community supports. The NDIS was set up to work alongside government and community services, not replace them. Learn more about <u>Mainstream and community supports</u>.

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#### What services do epilepsy support organisations provide?

The <u>Epilepsy Foundation</u> has information, education and training for anyone living with or caring for someone with epilepsy. Each state and territory also has an epilepsy support organisation. Most people will manage their epilepsy through the general health system and their local epilepsy support organisation.

The <u>Epilepsy Foundation</u> recommends you have an Epilepsy Management Plan (EMP). And if you're prescribed emergency medication an Emergency Medication Management Plan (EMMP).

#### **Epilepsy Management Plan (EMP)**

An Epilepsy Management Plan is a lifestyle plan you create with your family or carers. You can share this plan with your school or employer, your service providers, and your sporting or social clubs. It can help other people understand and respond to your epilepsy support needs.

Your Epilepsy Management Plan is not a medical document, but your doctor must approve it. We might ask you to share your Epilepsy Management Plan with us, so we can understand your epilepsy support needs.

#### **Emergency Medication Management Plan (EMMP)**

If your seizures are hard to control you may be prescribed medication to take when you do have a seizure. If you're prescribed medication you and your doctor should prepare an Emergency Medication Management Plan. This plan describes:

- the name of your medication
- how much you take and how often
- instructions about how you take it
- any emergency procedures.

Learn more about Epilepsy Management Plans and Emergency Medication Management Plans at <u>Epilepsy Foundation</u>.

### What supports can you get through Medicare?

Medicare helps all Australians with the costs of their healthcare. You can access Medicare to help pay for services to manage chronic health conditions, such as epilepsy. This includes funding for services to test for and diagnose epilepsy. You might be eligible for a Medicare funded <a href="Chronic Disease Management Plan">Chronic Disease Management Plan</a>.

Learn more about Medicare.

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#### What about support through the Pharmaceuticals Benefits Scheme?

The Pharmaceuticals Benefits Scheme (PBS) funds epilepsy medication. If you need medication to manage your epilepsy, your doctor will prescribe what you need.

Learn more about the Pharmaceuticals Benefits Scheme (PBS).

## How do we decide what epilepsy supports we fund?

All NDIS funded supports must meet the NDIS funding criteria.

Generally, we can fund epilepsy supports for you if you need them ongoing and they're related to your disability. We'll need evidence to support this, such as reports or assessments from a qualified health professional.

Epilepsy supports are one of the disability-related health supports we may fund.

Learn more about How do we decide what disability-related health supports we fund?

## What types of epilepsy supports do we fund?

If your disability means you can't manage your epilepsy, we may fund epilepsy supports like:

- training for a support worker to help you follow your <u>Epilepsy Management Plan</u>
  (EMP)
- training for a support worker to follow your <u>Emergency Medication Management Plan (EMMP)</u> 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.

## What if you need someone to help monitor your seizures?

If you need to be monitored for seizures because of your disability we may fund a support worker or nurse to help you. We'll only do this if your family or carers can't help.

If you need someone to monitor your seizures, we'll need evidence from your doctor or treating physician. The evidence will need to describe who can safely provide the support. It should say whether this can be a family member or carer, a support worker or a nurse.

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We'll then look at your current supports. For example, you might already have a support worker to help you with self-care or daily living activities. They may be able to be trained to provide your epilepsy supports and seizure monitoring. Or you might need additional hours of support.

If support workers will provide monitoring and support for seizures we can fund their training to meet your specific needs.

#### What is delegated care?

Delegated care means a registered nurse or health treatment team authorises a trained worker to provide support for more complex tasks such as help to complete your epilepsy management plan. This is called 'delegation and supervision of care'. It allows a registered nurse to delegate nursing tasks to an appropriately trained person. The support worker or enrolled nurse must have training from the registered nurse or health team before giving you this type of support.

We'll look at whether you need a registered nurse to carry out your epilepsy care according to your Epilepsy Management Plan (EMP) and Emergency Medication Management Plan (EMMP). Or, whether a support worker or enrolled nurse can safely support you with direction and supervision by a registered nurse.

We'll look at all the information you've given us to decide what level of support you need. This will include the number of hours we'll fund.

## What if you need support with your epilepsy management plans?

We don't fund support to help you create your Epilepsy Management Plan (EMP) or Emergency Medication Management Plan (EMMP). There are epilepsy support organisations that can help you do this.

Learn more about What services do epilepsy support organisations provide?

If you can't link with an epilepsy support organisation because of your disability, we may fund a support coordinator to help you. We'll only do this if you don't have a local area coordinator, family or carer to help you.

If you need help to link with an epilepsy support organisation, talk to your my NDIS contact or support coordinator.

## What if you need assistive technology?

Most people will be able to get what they need to manage their epilepsy through the health system or other services. Learn more about What help can you get to manage your epilepsy through the health system or other services?

Assistive technology to help manage your epilepsy can include things like:

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- a seizure monitor alarm system
- a seizure mat for a bed
- an oximeter.

We'll only fund assistive technology if you can give us evidence that:

- having the assistive technology means it will reduce your need for other supports, for example, less need for a support worker or nurse<sup>2</sup>
- you'll be able to be more independent<sup>3</sup>
- other mainstream health services don't fund the assistive technology and you need the support because of your disability.<sup>4</sup>

You'll need to give us evidence to show the assistive technology meets all the <u>NDIS funding</u> <u>criteria</u>.

Learn more about Assistive technology.

#### What supports can you get for children?

Children with epilepsy need support from parents and carers, doctors, schools and communities. The <u>Epilepsy Foundation</u> has information about supports for children with epilepsy. This includes things like dietary management, support for families, education and schooling.

Generally, we expect families or carers to look after the daily support needs of children, including managing their health. We may fund your child's epilepsy support if the support is more than you are able to provide as a parent or carer. The support must relate specifically to your child's disability. Like all supports we fund, supports for children need to meet the NDIS funding criteria.

# How do you get disability-related epilepsy supports in your plan?

## Do you need to provide us with evidence?

Yes. To get epilepsy supports in your plan, you need to give us evidence that helps us understand the disability related supports you need. Talk to your my NDIS contact or support coordinator to work out what evidence we need. Learn more about the evidence we need before we create your plan.

You can give us any new information or evidence about your support needs when you get it or anytime we talk to you.

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In your planning meeting we'll ask you, your parent or carer about your disability and how your disability affects your ability to manage your epilepsy by yourself. We'll ask about what epilepsy supports you currently have, and what supports you might need. We'll also ask who you get your supports from, and how often you get them.

We'll also look at any other information about your epilepsy support needs. This may include reports from your allied health professional, your doctor or specialist.

We'll use this information to decide if epilepsy supports meet the <u>NDIS funding criteria</u>. If they do, we'll work out the amount of funding to make sure you get the disability-related epilepsy supports you need.

### What if you don't agree with our decision?

If we decide epilepsy supports don't meet our <u>NDIS funding criteria</u>, we can't include them in your plan.

We'll give you written reasons why we made the decision.<sup>5</sup> You can <u>contact us</u> if you'd like more detail about the reasons for our decision.

If you don't agree with a decision we make about your request for epilepsy supports, you can ask for an internal review of our decision. <sup>6</sup> You'll need to ask for an internal review within 3 months of getting your plan. <sup>7</sup> Learn more about <u>reviewing our decisions</u>.

# What happens once you have epilepsy supports in your plan?

Once we approve the funding in your plan, you can start using your epilepsy supports. Your plan will describe how you can use your funding to get epilepsy supports. We will also talk to you at your plan meeting.

If you need help to use the funding, talk to your my NDIS contact or support coordinator.

You might also like to look at our guideline about Your plan or the Using your plan webpage.

For more information, you can also look at What happens once you have disability-related health support funding in your plan?

## **Reference List**

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<sup>&</sup>lt;sup>1</sup> NDIS (Supports for Participants) Rules r 7.4.

<sup>&</sup>lt;sup>2</sup> NDIS (Supports for Participants) Rules r 3.1(f).

<sup>&</sup>lt;sup>3</sup> NDIS (Supports for Participants) Rules r 3.1(f).

<sup>&</sup>lt;sup>4</sup> NDIS (Supports for Participants) Rules rr 3.5, 7.4.

<sup>&</sup>lt;sup>5</sup> NDIS Act s100(1).



<sup>&</sup>lt;sup>6</sup> NDIS Act s 100.

<sup>&</sup>lt;sup>7</sup> NDIS Act s 100(2).