

Practice Alert

Epilepsy management

September 2021 — updated May 2022

Key points

- Epilepsy is a condition of the brain that is more common among people with disabilities such as autism and intellectual disability. People with disabilities are also more likely to have severe and uncontrolled seizures.
- Providers should ensure participants have an epilepsy management plan that has been developed in consultation with a neurologist, specialist doctor or epilepsy nurse and reviewed at least every 12 months.
- Providers can also support participants with epilepsy by arranging training for their workers on seizure recognition, epilepsy first aid, seizure management and emergency response.

What is epilepsy?

Epilepsy is a common neurological condition characterised by abnormal or excessive brain activity that results in seizures.

There are two major groups of seizure:

- **Generalised seizures** impair consciousness. Generalised seizures include tonic clonic and absence seizures.
 - *Tonic clonic seizures* (previously called grand mal seizures) are convulsive seizures that cause loss of consciousness, collapsing, sudden muscle jerks, and repetitive stiffening and relaxing of muscles.
 - *Absence seizures* (previously called petit mal seizures) are brief seizures often mistaken for daydreaming or inattention. They are characterised by suddenly stopping activity, staring and unresponsiveness. Awareness is impaired for a very short time (often 2-10 seconds) and previous activity is usually resumed immediately. Some people will not be aware they have experienced an absence seizure.
- **Focal seizures** are typically non-convulsive and start in a small part of the brain and may or may not impair consciousness. Features vary greatly. There may be purposeless or repetitive movements, wandering, confusion, inappropriate responsiveness, or vocal sounds.

Focal seizures include **focal aware, focal with impaired awareness, and focal to generalised tonic clonic** seizures.

- *Focal aware seizures* – (previously called simple partial seizures) the person is aware of their surroundings but may not be able to talk or respond normally. They may simply experience sensations such as nausea, déjà vu, numbness or tingling. People with intellectual disability may have trouble explaining their experience during a seizure.
- *Focal impaired awareness* (previously called complex partial seizures) often involve the person appearing confused and engaging in unusual behaviours, such as fidgeting, mumbling or chewing. The person is unlikely to be aware or remember the seizure.
- *Focal to generalised tonic clonic seizures* – start as focal seizures but then evolve into a tonic clonic seizure (convulsion).

Why are people with disability at risk?

People with disabilities that affect the brain, such as autism or an intellectual disability, are more likely to have epilepsy compared to the general population. Although people with disability often have [more severe epilepsy than other people with epilepsy](#) and an increased risk of epilepsy-associated death; they may be less likely to receive adequate treatment for their epilepsy compared to the general population.

Seizure triggers

Triggers are specific situations that can either bring on a seizure or significantly increase the risk of a seizure. Common reported triggers include:

- Lack of sleep
- Missed or changed medication
- Fever or other illness
- Stress, physical or emotional
- Hormonal changes
- Dehydration
- Constipation
- Environmental factors (e.g. change in home environment, temperature, noise)
- Photosensitivity (flashing lights, gaming in a dark room)
- Growth spurts

Risks associated with epilepsy

The risks associated with epilepsy and recommended ways of managing or responding to these risks include:

- **Falls:** taking particular care and supervision of participants in the bathroom, kitchen and any room with hard surfaces.

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- **Burn-related injuries:** scalding can occur in the kitchen or bathroom during seizures. Minimise the risk of burns by reducing hot water temperature or supervising as appropriate.
 - **Aggression or agitation:** may occur as a seizure is ending when the person is confused.
 - **Risk of drowning:** ensure particular care and supervision is given to a person at risk of seizures when showering or bathing, or when swimming.
 - **Prolonged seizures:** prolonged or repetitive seizures without medical intervention may lead to status epilepticus (more than one seizure within five minutes or one lasting more than five minutes) and risk of suffocation. Prolonged seizures should be treated as a medical emergency. An ambulance should be called and, if prescribed, emergency medication should be administered as per the emergency medication plan.
 - **Sudden unexpected death in epilepsy:** there is an estimated 20-fold increased risk of unexpected death among people with epilepsy, compared to the general population.
 - Seizure detection alarms that can detect movement, falls or heart rate deviations for people who are at risk.

Factors that may contribute to risks include inadequate epilepsy medication, poor recording of epilepsy management, inadequate seizure monitoring, support staff not being aware or confident of best practice in responding to seizures, and lack of access to medical reviews or specialist consultations.

Supporting participants

Providers can work with participants who have epilepsy to:

- ensure epilepsy medication is given as prescribed
- recognise and address seizure triggers and risk factors that may reduce the likelihood of a seizure occurring
- implement strategies to reduce or eliminate the risk of injuries during seizures
- watch for changes in behaviour that may indicate a seizure, such as falling, unresponsiveness, confusion, purposeless or uncharacteristic movements or behaviours
- maintain a detailed record of seizures, including the time and duration, triggers that may have preceded the seizure and behaviours before, during and after the seizure
- consult with a neurologist, specialist doctor or epilepsy nurse to develop an individualised **epilepsy management plan**, and **emergency medication plan** (where prescribed)
- develop, implement and review protocols that guide decision-making when administering emergency (PRN) medication and when an ambulance is required
- identify and discuss individual sudden unexpected death in epilepsy (SUDEP) risk factors through completing the [SUDEP and Seizure Safety Checklist](#) with a specialist epilepsy nurse or treating doctor.

Epilepsy Management Plans

Providers can support participants by ensuring an **epilepsy management plan** is developed for all participants with epilepsy, in consultation with a neurologist, specialist doctor or nurse.

An epilepsy management plan enables providers and workers to understand the participant's support needs to manage their epilepsy, how to respond to seizures and individualised emergency response procedures.

Epilepsy management plans may outline:

- epilepsy diagnosis
- description of seizures including type, duration and usual frequency of seizures
- medication and dosages currently taken
- seizure triggers and management
- other health conditions and medications currently prescribed
- person-specific seizure first aid
- when to call an ambulance
- post-seizure monitoring and response
- emergency medication plans where appropriate should be prescribed/written by a doctor (in consultation with participant/carers and/or NDIS provider)
- risk and safety factors
- documentation.

Participants can seek support to develop Epilepsy Management Plans (and Emergency Medication Plans) from their neurologist, specialist doctor, specialist epilepsy nurses or through epilepsy support organisations. Further information is available in the resources section below.

Epilepsy management plans should also be reviewed at least once every 12 months, or at each review by the neurologist, specialist doctor or epilepsy nurse.

Epilepsy treatment

Medication is usually prescribed if a person has been diagnosed with epilepsy. Providers should ensure participants are supported to take their epilepsy medication as prescribed.

Providers should support participants with epilepsy to arrange a review by their neurologist or specialist doctor at least yearly, or more often if seizures are not well controlled.

Participants should be supported to seek a neurologist or specialist doctor review as soon as possible if:

- they are not responding to anti-seizure medication
- their seizures are not controlled
- they are experiencing unwanted side effects from their medication
- they have any concerns about their epilepsy treatment.

If the participant is admitted to hospital, ensure hospital staff are aware of what epilepsy medication is prescribed and that a copy of the participant's Epilepsy Management Plan goes with them. On discharge from hospital, providers should support participants to follow up on recommendations, including neurologist or specialist doctor review where indicated.

The [Practice Alert: Transitions of care between disability services and hospitals](#) provides guidance on supporting participants when they are admitted and discharged from hospitals.

Training

Providers can support participants with epilepsy by arranging training for their workers so they are able to meet participants' support needs. The training can cover seizure recognition, epilepsy first aid, seizure management and emergency response.

Where a participant is prescribed emergency medication, it is important that workers are trained to safely and correctly administer those medications.

Steps to take during and after seizures

Participants with epilepsy may experience seizures while receiving supports and services from providers. While there are two major groups of seizures, individuals have many symptoms meaning that one person's seizure frequently appears very different from another person's seizure.

Therefore, the type of seizure, how to support the person during a seizure, and specific emergency procedures will be unique for each person. This information should be detailed in the participant's Epilepsy Management Plan.

Support participants during a seizure with specific emergency procedures detailed in their Epilepsy Management Plan.

However, some general approaches to responding to a person's seizures are recommended. These include:

Focal (impaired awareness) seizures

During the seizure: gently guide the person away from obstacles or situations that may increase the risk of falling or serious injury. Seizures usually last between 30 seconds and three minutes.

After the seizure: if the person is confused, reassure them and maintain communication with them.

Generalised absence seizures

Recognise that a seizure has occurred, repeat any information they may have missed during the seizure and reassure and stay with the person.

Tonic clonic seizures

During the seizure: move furniture or items that could cause injury away from the person. Seizures usually last between 30 seconds and three minutes.

After the seizure: if the person is unconscious, or has something in their mouth that can block their airways such as food, drink or dentures, lie them on their side, place something soft under their head and stay with them until they regain consciousness.

Call an ambulance if:

- it is specified in the person's epilepsy management plan or emergency management plan
- a seizure lasts 5 minutes or more
- the person is unconscious
- another seizure starts shortly after a previous seizure
- the person has an injury that requires further medical assistance
- it is the person's first seizure
- the person has diabetes or is pregnant
- the person has breathing difficulties after a seizure

Provider obligations

NDIS Code of Conduct

Providers and workers must comply with the [NDIS Code of Conduct](#) when providing supports or services to NDIS participants.

The NDIS Code of Conduct requires all NDIS providers and workers who provide NDIS supports or services to NDIS participants to, among other things:

- provide supports and services in a safe and competent manner with care and skill
- promptly take steps to raise and act on concerns about matters that may impact the quality and safety of supports provided to people with disability.

NDIS Practice Standards

If you are a registered NDIS provider, you must comply with the [NDIS Practice Standards and Quality Indicators](#) as part of your conditions of registration. The NDIS Practice Standards relate to the delivery of safe, quality supports and services, and the management of risks associated with the supports you provide to NDIS participants.¹

The NDIS Practice Standards that are most relevant to this alert include:

- **Access to supports:** each participant can access the most appropriate supports that meet their needs, goals and preferences.
- **Human resource management:** each participant's support needs are met by workers who are competent in relation to their role, hold relevant qualifications, and who have relevant expertise and experience to provide person-centred support.

¹ Please note that the applicable NDIS Standards vary according to the provider type, the classes of supports provided and whether the provider is in the transition period (see sections 25-29B of the [NDIS \(Provider Registration and Practice Standards\) Rules 2018](#) for more information about transitioned providers).

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- **Incident management:** each participant is safeguarded by the provider's incident management system, ensuring that incidents are acknowledged, responded to, well-managed and learned from.
 - **Independence and informed choice:** each participant is supported by the provider to make informed choices, exercise control and maximise their independence relating to the supports provided.
 - **Information management:** each participant's information is managed to ensure that it is identifiable, accurately recorded, current and confidential. Each participant's information is easily accessible to the participant and appropriately utilised by relevant workers.
 - **Management of medication:** each participant requiring medication is confident their provider administers, stores and monitors the effects of their medication and works to prevent errors or incidents.
 - **Responsive support provision:** each participant accesses responsive, timely, competent and appropriate supports to meet their needs, desired outcomes and goals.
 - **Risk management:** risks to participants, workers and the provider are identified and managed.
 - **Safe environment:** each participant accesses supports in a safe environment that is appropriate to their needs.
 - **Support planning:** each participant is actively involved in the development of their support plans. Support plans reflect participant needs, requirements, preferences, strengths, and goals, and are regularly reviewed.

Resources

The [National Epilepsy Line](#) is funded by the Australian Department of Health and provides a phone and email service to support people living with epilepsy, their families and carers.

Epilepsy first aid

[First Aid - Epilepsy Action Australia](#)

[Seizure First Aid | Epilepsy Foundation](#)

Epilepsy Management Plans and Emergency Medication Plans

[Epilepsy Management Plans and Emergency Medication Plans, Epilepsy Foundation](#)

[Seizure Management Planning, Epilepsy Action Australia](#)

[Emergency Management Plan - Epilepsy Queensland](#)

Further information and training

[SUDEP and Seizure Safety Checklist](#)

[Epilepsy Essentials Course](#)

[Epilepsy Action Australia](#)

[Epilepsy Australia Ltd](#)

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General enquiries

Call: 1800 035 544 (free call from landlines). Our contact centre is open 9.00am to 4.30pm in the NT, 9.00am to 5.00pm in the ACT, NSW, QLD, SA, TAS and VIC Monday to Friday, excluding public holidays.

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