NDIS Quality and Safeguards Commission

Practice Alert

Epilepsy management

November 2020

Key points

- Epilepsy is a condition affecting the brain that is more common among people with disability. It causes several types of seizures depending on what part of the brain is affected.
- People with intellectual disability and epilepsy are at increased risk of severe and uncontrolled seizures compared to other people with epilepsy.
- Providers should ensure participants have an epilepsy management plan that has been developed in consultation with specialist doctors and revised at least every 12 months.

What is epilepsy?

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

There are two major types of seizure:

- **Generalised seizures** impair consciousness. Generalised seizures include tonic clonic and absence seizures.
    - *Tonic clonic seizures* (previously called grand mal seizures) commonly involve falling, convulsing, screaming, tongue biting, or loss of bladder control.
    - *Absence seizures* (previously called petit mal seizures) are often mistaken for daydreaming or inattention. They are characterised by staring, unresponsiveness and suddenly stopping activity. Awareness is generally impaired for a very short time (often 2-10 seconds) and normal activity is resumed immediately.
- **Focal seizures** start in a specific part of the brain and may or may not impair consciousness. There may be a variety of non-intentional movements or vocal sounds which may resemble

behaviours associated with other disorders. The person is unlikely to be aware of them and distraction is unlikely to reduce or suppress them.

- *Focal aware seizures* – the person is aware of their surroundings but may not be able to talk or respond normally. Patients 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.
- *Focal to bilateral tonic clonic seizures* – start as focal seizures but are often indistinguishable from generalised tonic clonic seizures

Seizure triggers

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

- Lack of sleep
- Missed medication
- Fever or other illness

Recommended ways to support NDIS participants with epilepsy

- Ensure epilepsy medication is given as prescribed.
- Watch for changes in behaviour that may indicate a seizure, such as falling, unresponsiveness, confusion, non-intentional behaviours.
- Document the details of suspected seizures and discuss with a GP as soon as possible. The GP can then refer the participant to a neurologist or other specialist for further assessment.
- Ensure an epilepsy management plan is developed for all participants with epilepsy, in consultation with a neurologist or specialist doctor. Epilepsy management plans should cover seizure type, first aid, emergency plan, risk and safety factors, and when an ambulance is required.
- All participants with epilepsy should have a medical review of their epilepsy management plan every 12 months, or more often, depending on how well their epilepsy is controlled.
- Refer the participant to specialist services for further assessment within 4 weeks if their seizures are not controlled, or their medication might be causing side effects.
- Work with the participant to recognise and address seizure triggers that may reduce the likelihood of a seizure occurring.
- 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.
- Implement strategies to reduce the risk of injuries during seizures.
- Organise training for staff in seizure recognition, epilepsy first aid, and seizure management and emergency response.
- If the participant is admitted to hospital, ensure hospital staff are aware of what epilepsy medications are required.

Steps to take during and after seizures

Focal (awareness impaired) 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: when 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 away from the person that could cause injury. Seizures usually last between 30 seconds and three minutes.

After the seizure: If the person is unconscious, check their airways and breathing, lie them on their side, place something soft under their head, and stay with them until they regain consciousness.

Call an ambulance if:

- a seizure lasts 3 minutes or more
- the person is unconscious
- another seizure starts shortly after a previous seizure
- the person has an injury
- it is thought to be the person's first seizure
- the person also has diabetes or is pregnant
- the person has breathing difficulties after the seizure
- it is specified in their Epilepsy Management Plan.

Risks associated with epilepsy

- **Falls:** Particular care and supervision of participants in the bathroom, kitchen and any room with hard surfaces is required.
- **Burn-related injuries:** Scalding can occur in the kitchen or bathroom during seizures. Minimise the risk of burns, such as by reducing hot water temperature or supervising as appropriate.
- **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 tools such as smart watches or pressure mattresses can be used for people who are at risk.
- **Risk of drowning:** Ensure particular care and supervision is given to a person at risk of seizures when showering or bathing, or when swimming. Seizure detection such as smart watches or baby monitors may be useful to alert to or detect seizure activity.

- **Aggression:** May occur as a seizure is ending when the person is confused.

Factors that may have contributed to deaths 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.

Epilepsy treatment

Medication may be prescribed if a person has been diagnosed with epilepsy. Refer participants who do not respond to antiepileptic medication or experience adverse side effects to specialist epilepsy clinics within four weeks for further assessment.

Providers should develop an **epilepsy management plan,** which must be endorsed by a GP, and ensures that providers and support workers understand the person's care needs to manage their epilepsy and how to respond to seizures.

Epilepsy management plans should outline:

- Epilepsy diagnosis
- Description of seizures including type, duration and usual frequency of seizures
- Medication and dosages currently taken
- Seizure triggers
- Other medications currently prescribed
- Person-specific seizure first aid
- Other co-occurring medical conditions
- When to call an ambulance
- Post-seizure monitoring
- Emergency medication management plan where appropriate (must be endorsed by a doctor)
- Risk and safety factors
- Seizure chart.

Further information and templates are on the Epilepsy Foundation Australia website.

Participants with epilepsy should be reviewed by a neurologist or specialist doctor at least yearly, or more often if seizures are not well controlled.

Provider obligations

As an NDIS provider, you have obligations under the NDIS Code of Conduct, the NDIS Practice Standards, as well as your conditions of registration, that relate to the delivery of safe, quality supports and services, and the management of risks associated with the supports you provide to NDIS participants.

Responsibilities of providers and carers:

- An epilepsy management plan should be developed for each participant with epilepsy in consultation with a medical practitioner.

- Staff should have completed medication-specific training to be able to administer emergency medications such as midazolam.
- Providers and carers should identify and minimise exposure to seizure risk factors.
- Staff should be knowledgeable in seizure types, seizure triggers and symptoms, impact of epilepsy on the person, and seizure management procedures.
- Staff should monitor and record seizures.
- Providers should have protocols that guide decision-making when administering PRN medication and when an ambulance is required.

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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, and 9.00am to 5.00pm in other states and territories Monday to Friday, excluding public holidays.

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