

EPILEPSY AND INTELLECTUAL DISABILITY

FACT SHEET



EPILEPSY AND INTELLECTUAL DISABILITY

It is estimated that 1 in 5 people with intellectual disability have epilepsy compared to 1 in 150 people in the general community.

Not only is epilepsy more common in people with an intellectual disability, but it can be harder to fully control seizures, and some people may need to take several different medications. This can increase chance of medication side-effects and make treatment costs higher



Living with epilepsy and intellectual disability

People who live with epilepsy and intellectual disability are more likely to have:

- More than one type of seizure
- Unusual or uncommon seizures
- More frequent or severe seizures, placing them at higher risk of injury and SUDEP
- Behavioural side effects from medication

All these factors can make diagnosing and managing the epilepsy more challenging.



Diagnosis

Getting the right diagnosis is important.

Diagnosing epilepsy in people with intellectual disability can be tricky. In fact, it's estimated that 1 in 4 people may be misdiagnosed.

This means many people don't receive the epilepsy care and support they need. A wrong or delayed diagnosis can impact quality of life and, in some cases, increase risk.

Getting an accurate diagnosis can make a big difference. It can lead to:

- The right treatment and better seizure control
- Improved health and quality of life
- A clearer understanding of the condition for family and support workers
- Fewer hospital visits
- Improved safety



Having an intellectual disability does not mean that person will have epilepsy, and living with epilepsy does not mean that person will have an intellectual disability.

IS IT A SEIZURE?

People with intellectual disability and epilepsy do not always have “textbook” seizures and it is easy to miss or misinterpret seizure activity in someone who has challenges with communication, behaviour or muscle control.

There are many different types of seizures, and some seizures can be difficult to recognise as such and are frequently misinterpreted as behaviour or other events. Daydreaming and unresponsiveness, confusion, unusual or inappropriate behaviour and temporary speech difficulties may all be signs of seizures.

Seizure mimics and medical events

Some events or medical episodes can be confused with, or mimic seizures. These can include:

- Repetitive movements
- Behaviours of concern
- Fainting
- Migraine
- Panic attacks
- Sleep disorders
- Movement disorders
- Functional seizures (FND)

It is important to be able to recognise what is a seizure and what is not.

Often this is difficult for even

an experienced healthcare professional, and this is where clear observation, documentation, and recording of seizures or events is useful.

Often people with intellectual disability have other medical conditions. These can influence or make epilepsy management more difficult.

Some of these other conditions may:

- Trigger seizures, such as diabetes (low blood sugar) or kidney disease (electrolyte imbalance)
- Mimic or be confused with seizures including involuntary or uncontrolled movements that can look like seizures (such as tics or repetitive movements)
- Require medication which can lead to more side-effects or can alter the effects of some epilepsy medications.

Observing and recording seizures

Good seizure observation, plus symptoms and behaviour before and after a seizure, can really help. This can identify patterns, seizure triggers and possibly other events.

Clear and accurate recording can contribute to better seizure management and improved quality of life.

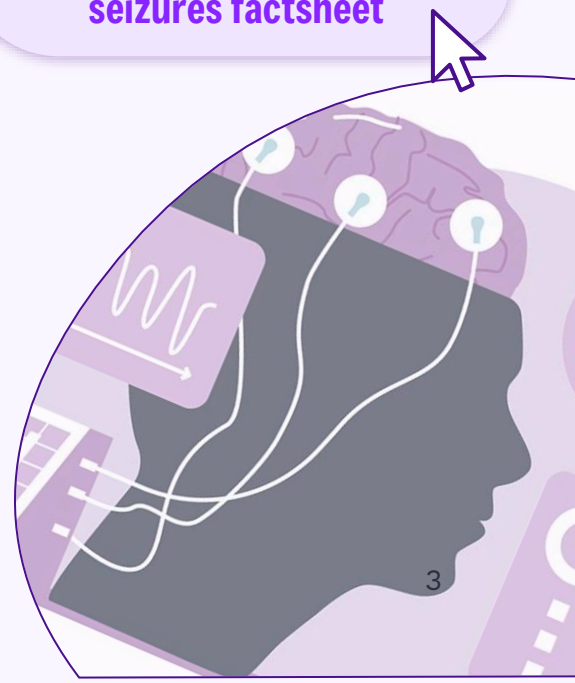
When recording seizures or other events, you need to know what to look for.

Before the seizure – Sometimes even for a whole day or two, you may notice a change in behaviour or other symptoms. This may simply be a change in mood.

During & after the seizure – Seizures can have up to 3 stages.

1. Some people may have an ‘aura’ or ‘warning’
2. The seizure itself
3. The recovery period after the seizure

[See Observing and Recording seizures factsheet](#)



CHALLENGES

Seizure triggers you may not expect

Sometimes seizures are unpredictable while others can be triggered.

Circumstances or events that can “set off” seizures are called seizure triggers.

Don't underestimate what can be a trigger for a seizure.

Apart from commonly reported triggers such as:

- Sleep deprivation, excess stress, illness and missed medication,

Less common triggers may also include:

- Pain, constipation, temperature or weather changes, high levels of emotion such as upset or overexcitement, low blood sugar, dehydration, startle – such as a loud noise, boredom

Keeping a daily diary of seemingly minor or unrelated things, may provide valuable information over time and help to distinguish between seizures and other events or behaviours.



Communication

Someone with intellectual disability might not understand their epilepsy or what is happening. They may:

- Not be able to tell you they are about to have a seizure. This can cause a lot of fear and anxiety.
- Not be able to tell you about medication effects or side effects. Some medications can affect alertness, thinking, moods and make someone feel nauseous or unwell
- Find it difficult to understand the importance of taking their medication on time, getting enough sleep, or managing stress
- Find it hard to know what their seizure triggers are and how to avoid them.

If the person becomes frustrated or anxious or unable to express themselves, this can lead to ‘behaviours of concern’. This can be challenging as some ‘behaviours of concern’ can look like seizures.



Poor tolerance to medical tests

- Most tests used to diagnose epilepsy require the person to remain calm and still for a lengthy period.
- Testing also means a trip to hospital, being wired up to various machines and generally being surrounded by a lot of new people and technology.
- This can be confusing or frightening for someone living with an intellectual disability and a lack of cooperation can make testing challenging, which, in turn, makes diagnosing, recording, monitoring and therefore managing the epilepsy more difficult.



Knowing the person is key

KNOWING THE PERSON IS KEY

The key to identifying seizure activity is to know the person you are supporting as well as possible, so you can recognise when things are 'out of the ordinary' and potentially a seizure. It is important to know:

1. What the person likes and doesn't like
2. How they usually communicate
3. What to do to help them calm down
4. When things are out of the ordinary

Poorly controlled epilepsy can be a chronic, disabling and socially isolating condition which significantly affects quality of life.



Accurate diagnosis and management of seizures are essential to reduce the impact

Further information

Epilepsy Action Australia has several [short online courses](#) specific to supporting someone living with epilepsy and disability including:

1. [Living with Epilepsy and Disability](#)
2. [Epilepsy: Minimising the Risk](#)
3. [Observing and Recording Seizures](#)
4. [Supporting People with Epilepsy and Intellectual Disability](#) (bundle of 1-3)
5. Our fundamental course, which includes seizure first aid is [Epilepsy Essentials](#)
6. If you need to administer emergency medication for seizures, we have an [Emergency Medication](#) course

See our [Training Brochure for Disability Organisations](#) for more information

Contact us on:

Phone: 1300 37 45 37

Email: epilepsy@epilepsy.org.au

[Book a telehealth appointment with an Epilepsy Nurse](#)

Visit our website



Disclaimer: This information is given to provide accurate, general information about epilepsy. Medical information and knowledge changes rapidly and you should consult your doctor for more detailed information. This is not medical advice, and you should not make any medication or treatment changes without consulting your doctor.