

Living with Epilepsy & 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, seizure freedom is less likely and sometimes many medications are taken. This can mean a higher chance of unwanted side-effects and higher treatment costs.

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.

People who live with epilepsy and intellectual disability are more likely than those without intellectual disability to have:

- More than one type of seizure
- Unusual or uncommon seizures
- Complex types of epilepsy
- Longer or more severe seizures, placing them at higher risk of injury and SUDEP
- Behavioural side effects from medications

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

Diagnosis

Diagnosis of epilepsy for people with intellectual disability is complex and it is estimated that as many as 1 in 4 people with intellectual disability are misdiagnosed. Because of this, many go without appropriate epilepsy management. Misdiagnosis can affect quality of life and in some instances, expose the person to unnecessary risk.

People with intellectual disability and epilepsy do not always have “textbook” seizures and it is easy for an untrained worker to miss or misinterpret seizure activity in someone who has challenges with communication, behaviour or muscle control. Some types of seizures can easily be mistaken for behaviours or mannerisms that may be seen in someone with intellectual disability.

An accurate diagnosis is important because it means there is:

- Correct management of the seizures and consequent improved health and quality of life
- Better understanding of the condition for caregivers and family leading to more appropriate seizure management
- Fewer hospital admissions and doctors’ visits
- Improved safety

Is it a seizure?

There are many different types of seizures and some seizures can appear like the person is 'just staring' or experiencing behavioural changes or repetitive movements.

There are also several events, medical episodes or actions that can be confused with, or mimic seizures.

Some of these include:

- Repetitive movements
- Behaviours of concern
- Fainting
- Migraine
- Panic attacks
- Sleep disorders
- Movement disorders
- Psychogenic non-epileptic seizures



It is important to be able to differentiate what is a seizure and what is not. Often this is difficult for even an experienced healthcare professional, and this is where clear observation and documentation of seizures or events is extremely useful.

Recording events on electronic devices can also be valuable. Sometimes video EEG testing is necessary to record an event which allows simultaneous EEG and video recording.

Other medical conditions

Often people with intellectual disability have other medical conditions. These can make epilepsy management more difficult. Some of these other conditions may:

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

Observing and recording seizures

Good seizure observation, plus events and behaviour before and after a seizure, can help with diagnosis and treatment. This can pick up patterns, seizure triggers and possibly identify 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 behaviours, signs or symptoms that can occur. Sometimes this can be simply a change in mood. A seizure can have up to 3 phases:

1. The actual start of a seizure which is often called an 'aura' or 'warning' (not everyone has this)
2. The seizure itself
3. The recovery period after the seizure



Observing and recording seizures continued...

Try to note what happens in each phase of the seizure – before, during and after. Sometimes it is not always easy to separate the phases. Write down what happens as soon as you can. Our [Observing and Reporting Seizures](#) factsheet has more detail

Seizure triggers you may not expect

Sometimes seizures are random and 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 *common 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

For some people living with intellectual disability ‘seizure triggers’ can also prompt ‘behaviours of concern’.

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. Epilepsy Action has a free, user-friendly online seizure diary, [click here](#)

Challenges

Cognitive or learning difficulties might make it difficult for a person to understand their epilepsy. The person may:

- Not be able to tell you they are about to have a seizure. This can cause a lot of anxiety and possibly result in behaviours of concern
- Not be able to tell you about medication effects or unwanted side effects. Some medications can affect alertness, thinking, moods and make someone feel nauseous or unwell
- Find it difficult to self-manage their epilepsy, such as 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 and does not know how to express themselves, this can lead to ‘behaviours of concern’. This can be challenging as some ‘behaviours of concern’ look like some seizure types.



Poor tolerance to diagnostic tests.

Most tests used to diagnose epilepsy require the person to remain calm and still for a lengthy period. The 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 or impossible. Which makes diagnosing, recording, monitoring and therefore managing the epilepsy more difficult.

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:

- What the person likes and doesn't like
- How they usually communicate
- What to do to help them calm down
- 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. Appropriate and accurate diagnosis and management are essential to reduce the impact.

Further information:

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

[Living with Epilepsy and Disability](#)

[Minimising the Risk](#)

[Epilepsy Essentials](#)

[Common seizure triggers](#)

References:

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