

Overview

Epilepsy itself is not an intellectual disability. Epilepsy, however, is more common in people who live with intellectual disability than for the rest of the population and it is estimated that 1 in 5 people with intellectual disability have epilepsy.

Not only is epilepsy more common in people with an intellectual disability, seizure freedom is less likely and multiple medications are often prescribed. This can mean a higher chance of unwanted side-effects and higher treatment costs.

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 atypical seizures
- Complex types of epilepsy
- Longer or more severe seizures, placing them at higher risk of injury

All these factors 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 proper epilepsy management. This misdiagnosis can exacerbate their disadvantage in all aspects of life and, in some instances, can expose the person to unnecessary risk.

People with intellectual disability and epilepsy do not always have “text book” seizures and it is easy for an untrained worker to miss or misinterpret seizure activity in someone who has challenges with communication, controlled behaviour or motor control. Some types of seizures can easily be mistaken for behaviours or mannerisms that may be experienced by 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 carers 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 seizure including some that appear like the person is ‘just staring’ or experiencing repetitive movements. Because of the variety of seizures there are a number of 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

Fact Sheet: Living With Epilepsy and Disability

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, but clear observation and documentation of seizures or events is extremely useful for diagnosis. Recording on electronic devices is also valuable. In difficult cases, sometimes video EEG testing is necessary to record an event whilst having simultaneous EEG and video recording.

Other medical conditions.

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

Some of these other conditions may:

- make the seizures happen more frequently, such as diabetes or kidney disease
- may mimic or be confused with seizures
- include involuntary or uncontrolled movements that can look like seizures (such as tics or repetitive movements)
- require additional medications which can lead to more side-effects or can alter the effects of some epilepsy medications.

Observing and documenting seizures

When recording seizures or other events, you need to know what to look for. Seizures can be broken down into 4 phases:

1. Behaviours, signs or feelings that can occur hours to days before a seizure
2. The actual start of a seizure which was previously thought of as an 'aura' or 'warning'
3. The observable seizure itself
4. The recovery period after the seizure

Try to note what happens in each phase of the seizure - before, during and after the event. Write down what happens as soon as you can.

Good seizure observation and recording, plus the events and behaviour before and after the seizure, have a vital role in helping the neurologist with diagnosis. This can pick up patterns, seizure triggers and possibly identify other events. Clear and accurate recording can significantly contribute to better seizure management and improved quality of life.

See Seizure Smart - Observing and Reporting Seizures factsheet for more detail <https://www.epilepsy.org.au/wp-content/uploads/2017/08/Fact-Sheet-Observing-and-Recording-Seizures.pdf>

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 triggers like sleep deprivation, heightened stress, illness and missed medication, some seizures can be triggered by:

- pain,
- constipation,
- temperature or weather changes
- a specific food,
- high levels of emotional such as upset or overexcitement

For some people living with intellectual disability these same 'seizure triggers' can trigger '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.

Common seizure triggers <https://www.epilepsy.org.au/strong-foundations/epilepsy-management/identifying-triggers/>

Challenges

Communication

Where a person has cognitive or learning difficulties, they may find it hard to understand things about their epilepsy and may find it hard to communicate.

The person may:

- not be able to tell you if they feel like they are about to have a seizure. This can generate 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 have effects on alertness, thinking, and moods and can also make someone feel nauseous or unwell.
- find it hard to understand what to do to help self-manage their epilepsy, such as the importance of taking their medication on time, getting enough sleep or managing stress.
- find it hard to understand and remember their seizure triggers and to avoid them.

If the person becomes frustrated or anxious and does not know how to express themselves, this can lead to using 'behaviours of concern' to try and communicate. This is challenging because some 'behaviours of concern' can look like some types of seizures.

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 touched and wired up to various machines and generally being overwhelmed with a lot of new people and technology. This can be confusing or frightening for someone living with an intellectual disability and lack of cooperation can make testing challenging or impossible.

This makes diagnosing, recording, monitoring and 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 disabling, chronic and socially isolating condition and significantly affect 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 <https://www.epilepsy.org.au/product/living-with-epilepsy-and-disability/>

Minimising the Risk <https://www.epilepsy.org.au/product/epilepsy-minimising-the-risk/>

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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.

