

Ten things you should know

1. Epilepsy, while a common neurological condition, carries with it serious risks and consequences.
2. People living with cognitive disability have a 25 percent chance of also being diagnosed with epilepsy.
3. Characteristics and behaviours associated with a person's cognitive disability, as well as difficulty tolerating certain investigations, can sometimes make it more complex and lengthy to diagnose epilepsy.
4. People living with a cognitive disability and epilepsy may have more severe, difficult to control seizures and an increased risk of preventable death.
5. There is a number of risk factors to consider when a person lives with epilepsy and a cognitive disability.
6. Treatments for people living with a cognitive disability and epilepsy can sometimes be more complex due to other medical or health conditions.
7. People living with a cognitive disability often need help from their circle of support to manage their prescribed anti-seizure medication (ASM) and epilepsy management strategies.
8. A person-centred approach when providing support should be taken. This lets the person be actively involved in discussions and decisions which take into account their life experience, values, culture, interests, beliefs and goals.
9. If a person has communication difficulties it is important that doctors and other healthcare professionals understand this and change the language and approach they take when meeting with their patient.
10. Mental health issues can sometimes be overlooked in people living with epilepsy and a cognitive disability, because the person may have difficulty communicating their feelings, concerns, experiences and fears.

What does this mean for the person?

Diagnosing epilepsy in a person living with a cognitive disability can sometimes be challenging, complex and take a long time.

The person's cognitive disability may mean that they have particular characteristics or mannerisms specific to them, but changes in behaviour could be symptoms of an underlying medical condition such as epilepsy.

The person may find it hard to give a history or describe behaviours that could indicate seizure activity. It is important that people in their circle of support document any changes and share that information with doctors.

Just as every person's epilepsy and seizure activity is different, so too is their medication and treatment plan.

Having a current Epilepsy Management Plan (EMP) and/or Emergency Medication Management Plan (EMMP) is therefore important for peace of mind and good health management.

What can you do to help?

- 1. Monitor behavioural changes.** People living with a cognitive disability may present with behaviours, mannerisms and characteristics particular to them. It is important that their circle of support (parents, siblings, extended family, friends, carers and support workers) keep a record of changes in behaviour that are new or unusual for the person and which may indicate seizure activity, as this will be useful to a doctor investigating the possibility of epilepsy.
- 2. Be aware of risks.** People living with cognitive disability and epilepsy tend to have more severe and difficult to control seizures, which can put them at a greater risk of injury and death. It is important that their circle of support understands the importance of managing risks while also making it possible for the person to do the things they want in order to live a fulfilling life.
- 3. Ensure the epilepsy diagnosis and treatment are understood.** As some people living with a cognitive disability may have communication and comprehension difficulties, it is important to take a person-centred approach.
- 4. Use risk management strategies.** Consider the use of safety devices and have a risk assessment conducted to increase the person's safety, regardless of whether they live with others, in supported accommodation or alone. Ensure that the person is aware of potential risks and understands that plans have been put in place to assist with self-care and safety management.
- 5. Record changes in seizure activity.** People with epilepsy can experience changes in the pattern, frequency and nature of their seizures. Observe and support the person to write down possible seizure activity changes and share this information with doctors, as this may indicate that changes to epilepsy treatment and/or anti-seizure medication (ASM) is required.
- 6. Monitor medication effects.** Some people living with a cognitive disability may also have other health conditions, making it important to watch for medication reactions in case of adverse side-effects.
- 7. Encourage a healthy lifestyle.** A positive lifestyle can greatly enhance people's physical and mental wellbeing. Support the person to join in social and leisure activities, get enough sleep, have a good diet, reduce stress, limit alcohol intake, and undertake suitable exercise.
- 8. Ensure regular medical reviews.** Regular reviews with an epilepsy specialist are important to assess current seizure activity and evaluate medication effects. To allow for the person and all caregivers to ask questions and understand treatments it may be necessary to book medical appointments that are longer than the standard time allocated.
- 9. Take a person-centred communication approach.** A person-centred approach is the key to achieving positive outcomes for people who live with cognitive disabilities, allowing the person to be actively involved in discussions and decisions. Sometimes it may be necessary to explain the person's communication needs to new specialists or healthcare workers, allowing for language or communication styles to be changed so that the person is always at the centre.

Other resources:

Epilepsy Smart

www.epilepsysmart.org.au

Epilepsy Australia

www.epilepsyaustralia.net

Lived experience

We recognise all people living with epilepsy and the impact it has on their lives. We take a moment to acknowledge the lived experience they have shared with us. In sharing their stories, we acknowledge the strength and resilience people living with epilepsy have shown in the face of not getting a fair go.

A medical note

The information contained in this publication provides general information about epilepsy. It does not provide specific advice. Specific health and medical advice should always be obtained from a qualified health professional.

Epilepsy support

The National Epilepsy Support Service is available Monday – Saturday, 9:00am – 7:00pm (AEST) to provide support and information across Australia.

Phone: 1300 761 487

Email: support@epilepsysmart.org.au

Epilepsy Smart Australia Program

National Epilepsy Support Service 1300 761 487

Website epilepsysmart.org.au



Australian Government
Department of Health

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