



Ten things you should know

Ten things you should know about epilepsy in people who live with a cognitive disability

1. Epilepsy, while a common neurological condition, carries with it serious risks and consequences.
2. People living with cognitive disability have a 25% 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 are 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-epileptic drug (AED) 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 of 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 understand 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 is understood.** As some people living with a cognitive disability may have communication and comprehension difficulties, it is important to take a person-centred approach to ensuring that the person understands their epilepsy diagnosis and treatment. Consider using easy English tools to help the person explain how they are feeling and the impact that living with epilepsy is having on their life.
- 4. Use risk management strategies.** Consider 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-epileptic medications (AEDs) 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.

Where to go for further information:

Epilepsy Foundation www.epilepsyfoundation.org.au

Epilepsy Smart www.epilepsysmart.org.au

Epilepsy Learning www.learning.epilepsyfoundation.org.au

Epilepsy Foundation YouTube www.youtube.com/user/EpilepsyVictoria

Epilepsy Australia www.epilepsyaustralia.net



This information sheet is part of a suite of resources that are targeted to family members, carers and support workers, to assist with caring for people living with epilepsy and a cognitive disability.

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 an appropriately qualified health professional.

Epilepsy Foundation, 587 Canterbury Road, Surrey Hills, VIC 3127, Australia, Telephone: (03) 8809 0600.
www.epilepsyfoundation.org.au

Epilepsy Information Line 1300 761 487

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