Cognitive disability and epilepsy



Epilepsy is more prevalent in people who live with a co-existing cognitive disability.

It is important for those who care for someone who lives with epilepsy and a cognitive disability to understand how best to assist the person live a safe and supported life.





Cognitive disability and epilepsy

The term 'cognitive disability' refers to a range of intellectual or cognitive (thinking skills) differences or deficits, including intellectual disability, developmental delay, developmental disability and learning disability. Cognitive disability may be associated with a range of brain impairments, including acquired brain injuries (ABIs) or neurodegenerative conditions, such as dementia.

People who live with a cognitive disability are more likely, than the general population, to also live with epilepsy. It is estimated that 1 in 4 people with a cognitive disability also live with epilepsy.

The cognitive disability may be one that a person was born with or developed early in life. In other cases, a person may have developed a cognitive disability later in life, for example as a result of a traumatic brain injury.

Certain conditions have a stronger correlation with epilepsy and cognitive disability than others, such as Cerebral Palsy, Down syndrome, and Autism Spectrum Disorders.

Evidence suggests that in people with a cognitive disability there are high rates both of misdiagnosis of non-epileptic seizures as epilepsy, and failure to diagnose or to treat episodes that are epileptic in nature. Because of this, diagnosing epilepsy can often be a complex and lengthy process.

People living with epilepsy and a cognitive disability tend to have seizures that are more severe and difficult to control, an increased risk of mental health issues and an increased risk of preventable death.

What does this mean for the person?

- The person may experience difficulty in providing a history or describing behaviours that could indicate seizure activity.
- The person may present with mannerisms, movements or behaviours which are mistaken for being part of their cognitive disability rather than seizure activity.
- The person may require assistance in order to manage their prescribed anti-epileptic medication (AED) and epilepsy management strategies.
- The person may have difficulty tolerating certain medical investigations necessary to diagnose epilepsy.

What can you do to help?

- The person's cognitive disability and epilepsy needs to be taken into account.
- As diagnosing epilepsy in a person living with a cognitive disability can sometimes be challenging and complex, the support network should look out for behaviours and activity that are atypical.
- It is important that family and support workers keep a record of changes in signs or symptoms (new or uncommon) to the person, which may indicate seizure activity. Records will be useful to a doctor investigating the possibility of epilepsy.
- Ensure the person's Seizure Management Plan (SMP) is reviewed and endorsed by their specialist every year.
- If the person has an Emergency Medication Management Plan (EMMP), ensure it is reviewed every year and that their support network has been trained appropriately.

- Implement risk strategies, consider use of safety devices and have a risk assessment conducted to enhance the safety of the person.
- Support the person to engage in social and leisure activities, as participation in these can greatly enhance physical and mental health and wellbeing.
- Support the person to have adequate sleep, maintain a healthy diet, reduce stress, limit alcohol consumption, and undertake appropriate exercise/activities.
- As some people living with a cognitive disability may have communication and comprehension difficulties, it is important that the person understands their epilepsy diagnosis, treatment plan and are engaged in discussions and decisions regarding their care. Consider using easy English tools to assist the person to be actively involved.

Where to go for further information:

Epilepsy New Zealand http://epilepsy.org.nz/



National Support Centre

Epilepsy House, 6 Vialou Street, Hamilton Central, Hamilton 3204 PO Box 1074, Hamilton 3240 Phone: 07 834 3556

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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.