Understanding the person’s individual situation is an important step towards providing appropriate support. This section provides information about people living with epilepsy and cognitive disabilities.

Whether you are a person living with epilepsy, care for someone who does, or are an interested community member, we hope that you find this information useful.

The term ‘cognitive disability’ refers to a range of intellectual or cognitive (thinking skills) differences or impairments, 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.

Among people with a cognitive disability, there are higher rates of misdiagnosis of non-epileptic seizures as epilepsy. In other cases, there can be a 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 are at a greater risk of having seizures that are
more severe and difficult to control, an increased risk of mental health issues and an increased risk of Sudden Unexpected Death in Epilepsy (SUDEP).

While each person is different, challenges that a person with epilepsy and a cognitive disability may face include:

- Difficulty in providing a history or describing behaviours that could indicate seizure activity
- Presenting with mannerisms, movements or behaviours which are mistaken for being a feature of their cognitive disability, rather than seizure activity
- Requiring assistance in order to manage their prescribed anti-epileptic medication (AED) and epilepsy management strategies
- Potential difficulty tolerating certain medical investigations necessary to diagnose epilepsy.