



**KNOW ME
SUPPORT ME**

Living with epilepsy and a cognitive disability

A guide for families, carers and support workers

Purpose of this resource

No one with epilepsy should go it alone.

This booklet is part of a suite of epilepsy support resources that have been specifically designed for people who care for a person living with epilepsy and a cognitive disability, such as intellectual or learning ones. We have also developed resources for disability support workers so that they can provide high quality epilepsy support to clients.

Some people who live with epilepsy and a cognitive disability may find the 'easy English' *Learning about Epilepsy* booklet useful for learning about epilepsy and discussing its impacts

An 'Epilepsy: Know Me Support Me' approach means that people living with epilepsy and a cognitive disability are best understood and supported. It enables people to exercise choice and control over their life.

The information contained in this booklet is not intended to include everything about epilepsy and should not replace medical advice or training in epilepsy awareness and/or medication administration. Additional resources, such as tools and information sheets, have been developed to expand upon details and strategies outlined in this booklet.

Family members, carers and disability support workers may also want to visit our website www.epilepsyfoundation.org.au for further information.

The prevalence of intellectual disability and co-existing epilepsy is approximately 22%, and this rate grows with increasing levels of disability².

Studies indicate that the incidence of SUDEP (sudden unexpected death in epilepsy) is higher in people with an intellectual disability¹.

People who have cerebral palsy and an intellectual disability have a 48% chance of also having epilepsy³.

Epilepsy is believed to affect 5%–10% of children with Down syndrome, and an estimated 45% of adults with Down syndrome over the age of 50 will have some form of epilepsy^{4,5}.

Understanding epilepsy

Epilepsy is not biased and occurs regardless of gender, age, cultural or socio-economic status. Around 250,000 Australians live with epilepsy.

Epilepsy is one of the most common of all neurological conditions and can be diagnosed at any age. Anyone can have a seizure, but not all seizures lead to a diagnosis of epilepsy. Around 10% of Australians will have a seizure during their lifetime, with 3–4% of those then going on to be diagnosed with epilepsy. This means approximately 1% of the Australian population currently live with epilepsy.

Epilepsy and cognitive disability

Some people who have epilepsy also live with another disability. It is estimated that 1 in 4 people with a cognitive disability are likely to also live with epilepsy⁶.

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

The Australian Government recognises disabilities which can be broadly categorised as intellectual, learning, neurological, physical, sensory and psychiatric ones. Just as the types of disability are diverse so too are the disability classifications used in Australia. The severity of a disability is classified as profound, severe, moderate or mild according to the extent to which a person needs assistance with core activities, e.g. communication, mobility and self-care⁷.

- › For more information about disability types and classifications visit www.dss.gov.au/disability-and-carers

People living with epilepsy and a cognitive disability tend to have more severe, difficult to control seizures and an increased risk of preventable death⁸. The impact of epilepsy on a person with a cognitive disability and their family is often far greater than the seizure itself⁹.

Because of this it is important that people living with epilepsy and a cognitive disability have as much information as possible to understand the condition, feel safe and supported, and make informed decisions about the care provided to them.

Some people who live with epilepsy and a cognitive disability may find the 'easy English' *Learning about Epilepsy* booklet useful for learning about epilepsy and discussing its impacts.



- › Refer to the [Cognitive disability and epilepsy](#) information sheet

Certain conditions have a stronger correlation with epilepsy, such as Cerebral Palsy or autism¹⁰.

What is epilepsy?

Epilepsy is described as a neurological condition in which a person experiences seizures on a recurring basis. People living with a cognitive disability are more likely than the general population to also live with epilepsy.

What is a seizure?

A seizure is a temporary, sudden change in the electrical and chemical activity in the brain which causes a change in behaviour, thought, movement or sensation.

The brain transmits regular electrical impulses which carry messages between the brain and the body. When this pattern is disrupted by a sudden burst of activity a seizure can occur.

Every person's experience of a seizure is different. Some people have seizures every day, while others may only have a seizure occasionally. Some people are aware they are having a seizure, whereas others are not aware when they are having one.

Seizures can be provoked, known as 'reactive' or 'active symptomatic', whereby a particular external or internal factor brings the seizure on. Seizures can also be unprovoked, meaning there is no known cause of the seizure.

Most people think there is only one type of seizure – convulsive seizures. This is not true. In fact there are many different types of seizures experienced by people.

Seizure types

The ILAE (International League Against Epilepsy), the international scientific body devoted to the study of epilepsy, determines the official names of seizure types and epilepsy syndromes. Seizures fall into three categories: focal onset; generalised onset; and, unknown onset.

Focal onset seizures

Focal onset seizures start in one part of the brain (one hemisphere) and may or may not spread to other parts of the brain. Focal seizures are described based on their onset (motor or non-motor) and whether or not the person is aware during the seizure. Focal onset seizures include:

Focal aware seizures. The person is aware during these events and may experience feelings such as déjà vu, an unpleasant smell or taste, or sensations such as 'butterflies' or nausea. These seizures may also involve motor activity (such as involuntary and brief jerking of an arm or leg) or autonomic behaviours (such as fiddling with clothing or pointing). These seizures used to be called 'simple partial seizures'.

Focal impaired awareness seizures. During these seizures the person may appear confused and dazed and may do strange and repetitive actions (such as fiddling with their clothes, making chewing movements with their mouth or uttering unusual sounds). These seizures used to be called 'complex partial seizures'.



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Generalised onset seizures

Generalised seizures involve both hemispheres (sides) of the brain. Generalised seizures are presumed to affect a person's awareness or consciousness in some way, and consequently may pose safety risks for the person.

Motor onset seizures involve changes in muscle activity, which can include stiffening, jerking, loss of muscle control or convulsions. Non-motor onset are often called absence seizures and involve the person 'zoning out' for a brief period and are often misinterpreted as day dreaming.

Generalized onset seizures include: myoclonic seizures; tonic-clonic seizures; absence seizures; tonic seizures; atonic seizures; and, myoclonic absence seizures.

Unknown onset seizures

For some people, despite lots of tests and investigations, the type of seizure is unknown. In this case, because the onset is unknown, people who experience these seizures may have varied states of awareness.

Status epilepticus

Status epilepticus is said to occur when a seizure lasts too long, where seizures occur in close succession or the person doesn't recover between seizures. Status epilepticus can occur with any type of seizure and is categorised as convulsive or non-convulsive. It is considered a medical emergency and an ambulance must be called if:

- a convulsive tonic-clonic seizure lasts for 5 minutes or longer or the person has repeated seizures for 30 minutes or longer
- a non-convulsive seizure continues for 10 minutes. A non-convulsive seizure can be harder to recognise than convulsive status epilepticus. The person may be confused or not fully aware but not 'unconscious' (as experienced during a tonic-clonic seizure).



"I had an accident and my brain was damaged. After that I started having seizures. I sometimes fall over when I have a seizure or just stare into space. I live in a home with other people and our carer makes sure the house is safe for me. She also makes sure I take my medication every day."

What could a seizure look like?

Seizures are different for each person. It depends on which part of the brain the seizure occurs in and what functions that part of the brain controls. Some seizure features include:

- a person's body stiffening and falling to the ground, followed by strong, symmetrical, rhythmic movements (tonic-clonic)
- loss or disturbance of awareness ('absence', blackout spells), blank stare
- feelings of déjà vu or an unpleasant smell or taste
- confusion, disorientation
- a fall, sometimes with no memory of the fall
- involuntary movement — twitching or abnormal sensory disturbance of limb/s or face without a loss of consciousness

- automatisms — repetitive, automatic trance-like movements (e.g. fiddling with clothes, repeated use of strange words or repeated swallowing)
- sleep disturbances, restlessness, inability to maintain a regular REM sleeping pattern
- loss of bladder or bowel control.

A person may be alert during a seizure and remember what happens. Alternatively, the person may not remember the seizure at all or only remember certain aspects before or after the seizure. A person's level of awareness can vary greatly, and depends on the type of seizure being experienced and from which part of the brain it originates. Following a seizure, the person may feel tired and sleepy, confused, angry, sad or worried. Confusion following a seizure can last several hours, days or sometimes even weeks.

A person who has communication difficulties may struggle to explain how they feel before, during or after a seizure. The *Learning about Epilepsy* booklet, which uses easy English and descriptive images, can assist families, carers and support workers to better understand how a person feels prior to, during or after a seizure.



Epilepsy specialists

Epilepsy is usually managed by a person's primary care doctor (such as a GP) and neurologists who care for people with neurological disorders. A neurologist who specialises in epilepsy, called an epileptologist, may also be involved. These specialists can be found in hospital settings and private practice.

People living with epilepsy and a cognitive disability may find that the medical management team also includes doctors and healthcare professionals the person is already connected to. In addition, other epilepsy specialists may form part of a multi-disciplinary epilepsy care team and can include (but is not limited to): neurosurgeons; psychiatrists; psychologists; radiologists; nurses; social workers; speech and language therapists, occupational therapists; physiotherapists; and, pharmacists.

Causes

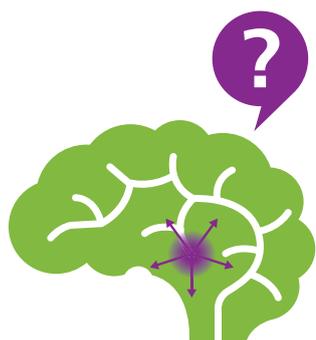
There are many causes of epilepsy and seizures. It is very important that the cause of seizures is investigated as this will help determine a person's appropriate epilepsy treatment management plan.

- Epilepsy can be something a person is born with or it can be acquired at another stage in life.
- One or more genetic mutations may lead epilepsy.
- Some people are born with epilepsy syndromes which lead to seizures and the development of other disabilities.

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- Some disabilities or conditions can be linked to the development of epilepsy (e.g. cerebral palsy).
- A brain injury or infection can result in scar tissue which leads to seizures.
- Having a stroke can lead to epilepsy.
- Epilepsy can also be caused by a brain tumour impacting on the brain's normal electrical and chemical functions.

Sometimes the cause of the epilepsy may contribute to a person developing another disability or health condition. For example, a person may have a head trauma accident which results in them becoming paralysed, as well as being diagnosed with epilepsy.



“My son often had bad seizures when travelling on the minibus to his day program. We discovered that he was getting highly excited and flapping his hands at passing vehicles, and this was what was increasing the likelihood of a seizure. The support worker introduced an iPad with his favourite songs, which he found relaxing. His seizures reduced a lot after introducing this approach.”

Triggers

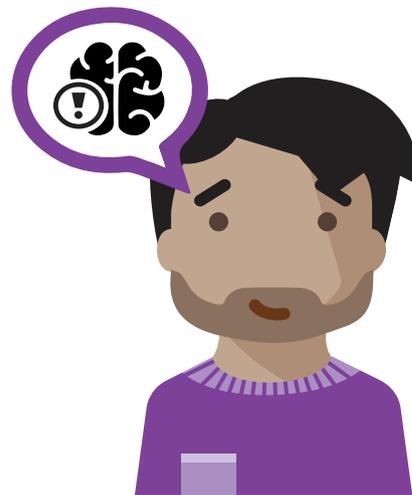
Triggers are situations or events that can bring on a seizure. Triggers differ from person to person and not all people experience triggers. Some common seizure triggers include:

- missed medication
- feeling unwell, overheated or running a temperature
- dehydration
- low blood sugar from missed meals
- drugs and alcohol, including prescribed medication
- sleep deprivation as a result of not getting enough rest/sleep



- significant emotional and/or physical stress
- bright, flashing or flickering lights.

These triggers alone do not explain why a seizure has occurred because not everyone who is exposed to one of these triggers will have a seizure. Observations made by the person, family, carers or support workers are important in identifying trends in possible seizure activity and triggers.



Not all seizures lead to a diagnosis of epilepsy.

Getting a confirmed diagnosis of epilepsy can sometimes be a lengthy process and involve various tests.

Investigation and diagnosis

People of any age may develop epilepsy. Some people may have been diagnosed with epilepsy early in life, whereas others are not diagnosed until they are teenagers or adults.

Some people who live with a cognitive disability may experience seizures which are not always recognised as epileptic in nature. Misdiagnosis can happen when physical or behavioural changes are assumed to be related to another disability, rather than an actual seizure.

An acute symptomatic seizure refers to a seizure provoked by an acute illness or injury to the brain and does not necessarily lead to a diagnosis of epilepsy. An unprovoked seizure is a seizure which occurs without any obvious immediate cause. Only further investigations by a specialist, such as a neurologist or epileptologist, can assist in identifying the cause of the seizure and whether there is a diagnosis of epilepsy.

The specialist will examine a person's medical history, any eyewitness accounts and conduct medical tests before a diagnosis of epilepsy is made. Medical tests may include blood tests, an EEG (electroencephalogram), a CT scan (computerized tomography) or an MRI (magnetic resonance imaging).

Sometimes the diagnosis of epilepsy in a person living with a cognitive disability may be complicated due to a range of issues. These may include the person experiencing difficulty in providing a history or describing behaviours that could indicate seizure activity. Stereotyped mannerisms or behaviours may be mistaken for seizure related movements. Or, the person may experience difficulty tolerating certain investigations, such as EEGs and MRIs.

Research suggests that in people with a cognitive disability there are significant rates of misdiagnosis of epilepsy; either diagnosing non-epileptic seizures as epilepsy or failing to treat episodes that are in fact epileptic in nature¹¹. This reinforces the importance of providing specialists with observation information during the diagnostic period.

For people who live with a cognitive disability, the investigation and treatment may involve input from other doctors involved in the care of that person. For example, if a person is already supported by a GP or psychologist, the neurologist investigating the possibility of epilepsy may call on those other specialists for input and information. However, the person or their carer will always be asked if it is OK to speak with other specialists involved in the care of the person.

Other conditions:

Existing disabilities and health conditions can make the diagnosis of epilepsy more complex. There are many other medical conditions and disability features which may resemble seizures or epilepsy. These can include temporary loss of consciousness, weakness in limbs, migraines, dizziness, panic attacks, confusion, psychiatric behaviours, and sleep disturbances.



Cognitive disability:

People with a cognitive disability may show symptoms similar to those sometimes associated with seizure activity. Symptoms may include memory, confusion or behavioural issues. Sometimes this can make it difficult to obtain a clear diagnosis, or lead to diagnosis taking some time.

A diagnosis of epilepsy is more likely if: these symptoms differ from the person's usual behaviours, seizure activity occurs during sleep, and/or new behaviours or activity are noticed.

Non-epileptic seizures:

Seizures provoked by an acute illness or injury to the brain do not necessarily lead to a diagnosis of epilepsy. Similarly, unprovoked seizures which occur without any obvious immediate cause may or may not be epilepsy.

A number of tools may be of use if you think a person has been experiencing seizures and needs referral for diagnosis:

- Refer to the [Observation Statement](#) or [Witness Statement](#) resources to record seizure activity
- Refer to the [Epilepsy: Referral pathways](#) resource

Treatment

Deciding on the correct treatment for epilepsy is important and requires specialist expertise. A specialist will take into account a person's co-existing disability and any health conditions when developing their epilepsy treatment plan.

Anti-epileptic drugs (AEDs)

For most people diagnosed with epilepsy, anti-epileptic drugs (AEDs) are prescribed. AEDs do not cure epilepsy, but they can control or reduce seizure activity. The best outcome from taking AEDs is that a person becomes seizure free. But in some cases the medication alone can't control a person's epilepsy. Finding the right medication, or combination of medications, can take some time.

Some medications, either over the counter ones or ones prescribed for other conditions, can lower a person's seizure threshold. These can include mental health and psychiatric medications (e.g. antidepressant and antipsychotic ones). Any concerns about how other medications may interfere with AEDs should be discussed with the doctor.

Under no circumstances should an AED dosage be altered without specialist advice.

Any identified side effects, or difficulties with medication compliance, should be documented for discussion with the person's doctor.

› Refer to the [Medication and epilepsy](#) information sheet

Emergency medication

If a person has many seizures, seizures which last a long time and/or lives a long distance from medical assistance, the specialist may also prescribe emergency medication.

If emergency medication is prescribed the specialist will advise when it is to be administered, how it is to be stored and how it is to be administered. The specialist will also provide a medically endorsed Emergency Medication Management Plan (see the 'Managing your Epilepsy' section).

Any identified side effects of emergency medication should be discussed with the person's doctor.

› Refer to the [Medication and epilepsy](#) information sheet

Diet

Another treatment which the specialist may suggest is diet treatment options such as the Ketogenic diet or a Modified Atkins Diet. It is important to understand that these dietary therapies should only be used under the supervision of a doctor. As these diets require strict observation, family, carers and support workers may need to be closely involved in assisting a person to follow the dietary requirements.

Ketogenic diet

The Ketogenic diet is a high fat, low protein and low carbohydrate medically supervised diet. It is sometimes used as a treatment for epilepsy that does not respond to AEDs (sometimes called 'drug resistant epilepsy' or 'refractory epilepsy').

Modified Atkins Diet

A Modified Atkins Diet is a special high fat, medically supervised diet that is also used for difficult to treat seizures. Heavy cream, butter and vegetable oils provide the necessary fat. This diet differs from the Ketogenic diet as it allows consumption of protein rich foods such as meat, chicken, eggs and fish.

Sometimes medications and other treatments don't work and a person will continue to have seizures which impact on their quality of life. In this case, and after comprehensive investigations and testing, a doctor may recommend surgery or an implant.

Surgery

Epilepsy is sometimes caused by an area of abnormal brain tissue which is causing seizures to occur. The size and position of the area that is causing seizures, referred to as the epilepsy focus, varies between individuals. If surgery can remove the epilepsy focus, seizures can often be prevented or reduced. The chance of successful surgery and the risks of complications differ for each patient.

Vagus Nerve Stimulation (VNS)

VNS helps to prevent seizures by sending regular, mild pulses of energy to the brain via the vagus nerve. VNS is sometimes referred to as a 'pacemaker for the brain'. The VNS is implanted under the skin, near the chest, and a wire from the device is wound around the vagus nerve in the neck.

Informed consent and capacity

A person over the age of 18 and living with epilepsy and a cognitive disability is presumed to be able to give informed consent to medical treatment, such as epilepsy investigations and the provision of medication. Informed consent can also include the option to refuse treatment.

If a person living with epilepsy and a cognitive disability is refusing treatment, it is important for doctors, family and carers to explain the treatment to them so they can make an informed decision. Discussion should include use of plain language and any technical concerns should be explained in lay terms¹².

If a person refuses treatment and you are concerned about their welfare, discuss the impact that not taking medication may mean. If, after doing this, the person still does not consent to treatment you may want to consider a capacity assessment and/or make an application for guardianship.



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Living with epilepsy

Living with epilepsy and a cognitive disability can have a significant impact on the life of a person, as well as all those who care for them. This section provides information about how to best support a person who lives with epilepsy and a cognitive disability.

Impacts of epilepsy

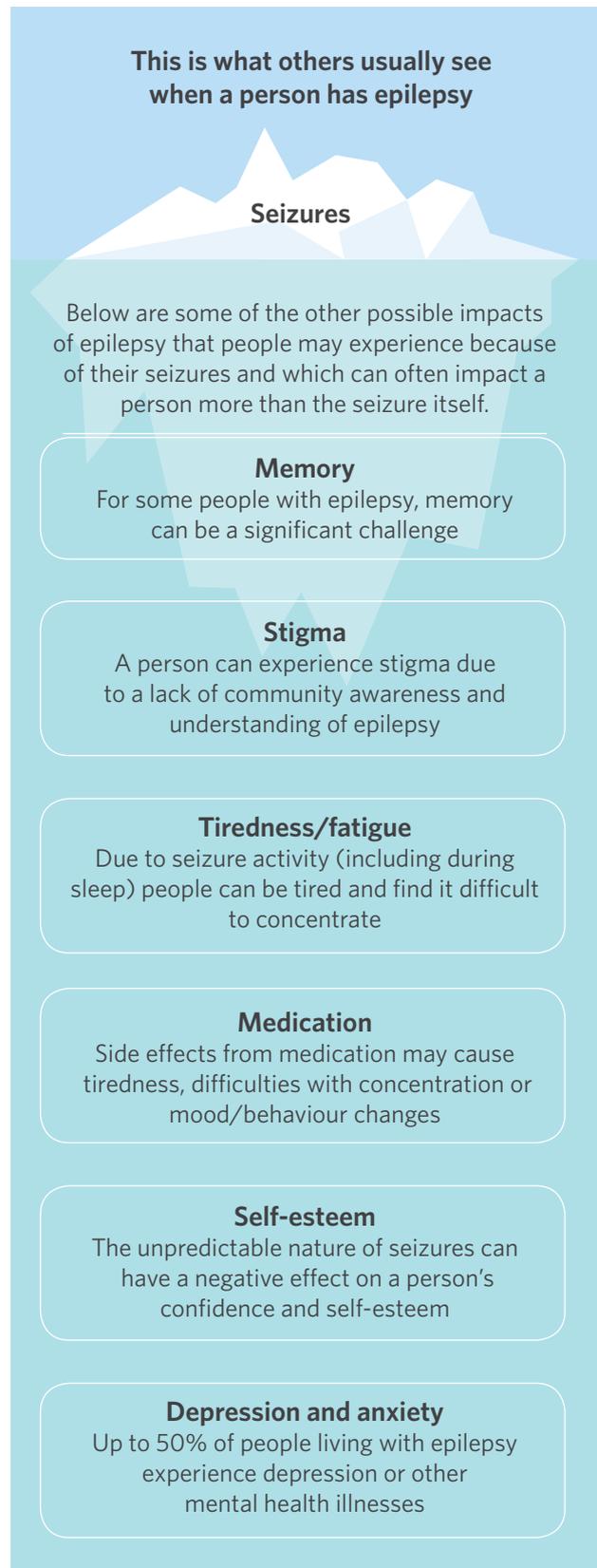
Living with epilepsy and a cognitive disability doesn't only impact on the person, but also on their circle of support. The circle of support may include parents, siblings, extended family, friends, carers and support workers. This network often play a role in assisting the person to safely manage their epilepsy.

Often the person's circle of support are providing assistance to ensure that the person is taking medication as prescribed, attending specialist appointments and observing seizure activity. Family, carers and support workers may also be assisting the person to manage any impacts which are compounded by their co-existing cognitive disability.

It is important that family, carers and support workers ensure that they are looking after themselves and seek support if they find that caring for the person is affecting their own wellbeing. If that is the case consider speaking to a doctor, healthcare professional or support service for personal support.

The iceberg analogy highlights the impacts that anyone living with epilepsy may experience. However some people living with a cognitive disability may experience these impacts to a greater extent. If impacts or other concerns are identified these can be discussed with specialists or other healthcare workers involved in caring for the person.

The iceberg analogy



Behaviours of concern

As discussed earlier sometimes misdiagnosis of epilepsy can occur when physical or behavioural changes are assumed to be related to another disability or condition, rather than an actual seizure.

The Victorian Government's *Positive practice framework: A guide for behaviour support practitioners* recognises severe and complex epilepsy coupled with arrested cognitive, emotional and/or social development as factors that may lead to behaviours of concern in some people. This online resource is for behaviour support practitioners, and brings together current research, knowledge and practice strategies. It operationalises positive behaviour support and promotes a person-centred approach to responding to people presenting with behaviours of concern. It promotes a whole-of-life approach; empowering a person with disability to exercise their human rights and to live in, be included in and participate in the community.

Whilst this framework reflects some Victorian legislation and policy, it provides information, and strategies that can guide ethical and effective practice in any part of Australia.

› Refer to <https://providers.dhhs.vic.gov.au/positive-practice-framework-word>

The Australian Department of Social Services (DSS) also provides information about government payments, programs and best practice approaches. DSS also provides links to agencies and departments across Australia and in all states and territories.

› Refer to www.dss.gov.au/disability-and-carers

Communicating with the person

As many people who live with epilepsy and a cognitive disability receive support from family, carers or support workers it is important that everyone understands the epilepsy diagnosis and treatment plan. It is also important that a person-centred approach is taken, allowing the person to be actively involved in discussions and decisions. A person-centred approach places the person at the centre of all discussions, plans and choices taking into account their life experience, values, culture, interests, beliefs and goals.



It is recommended that communication strategies take account of the person's receptive and expressive communications skills (including any augmentative or alternative communication techniques, aids or devices)¹³.

A person-centred approach also means that specialists take the same approach and speak directly to the person. Sometimes it may be necessary to explain the person's preferred way of communicating with their treating doctor. This will help the doctor, particularly if new to the person, modify the language and approach they take when discussing seizures, epilepsy and treatment.

It is also important that the specialist responds to questions directed by the person's family members and caregivers, as this helps to ensure that everyone understands diagnostic and treatment matters. This is particularly important when family and caregivers are involved in administering medication and maintaining seizure activity records.

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. So be sure to book longer appointment times with specialists if required.

It is valuable to use person-centred approaches and tools that will assist the person to understand their epilepsy diagnosis and treatment. This can assist them to understand what epilepsy means, what is going to happen and reduce any fears or concerns they may have. Family, carers and support workers may find that the easy English *Learning about Epilepsy* booklet can help with this.



“My mum helped me to make a seizure diary. Now everyone in my family helps me to fill it out because sometimes I forget.”

Recording seizures

It is valuable to document seizure activity in order to provide up-to-date information to any specialists involved in the care of the person. Recording how often seizures are taking place, how long symptoms last and how seizures are affecting behaviours is a useful diagnostic and epilepsy treatment tool.

It can be helpful to record seizure events with a video camera or phone as this can assist the treating doctor to best understand and observe what happens when seizures occur.

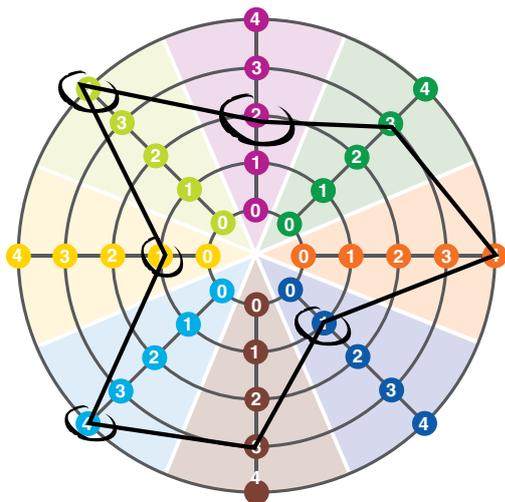
Wellbeing mapping

A person may benefit from taking part in a ‘wellbeing mapping’ exercise which allows for a person to review most aspects of living with epilepsy and how it impacts on their life. The Wellbeing Map™ is a tool in which this information can be recorded and help a person to prepare for specialist consultations, so that nothing is forgotten and overlooked during the meeting.

Family, carers and support workers may want to assist the person to complete the Wellbeing Map and, in doing so, use it to guide a discussion about how living with epilepsy is affecting their life.

➤ Refer to www.epilepsywellbeing.com.au

Epilepsy Wellbeing Map™



Risk and safety

Research indicates that people who live with epilepsy and a cognitive disability tend to have a worse prognosis with lower rates of seizure freedom and higher rates of multiple anti-epileptic drug (AED) use. Evidence also shows that adults with epilepsy and a cognitive disability have higher rates of morbidity and mortality, including sudden unexpected death in epilepsy (SUDEP)¹⁴.



Life for people who live with epilepsy and a cognitive disability is about balancing risk with what they want to do in order to live a fulfilling life. As epilepsy is very individualised, the risks to people vary considerably and can often depend upon:

- age – infants, children and older people tend to be more susceptible to falls and accidents
- types of seizures – people who have more severe seizures, seizure clusters, frequent seizures or seizures which include falls are at a higher risk
- medication – people on multiple AEDs and/or on high doses can experience more side effects which may increase risks
- disability impacts – people who live with other disabilities may have mobility, assistance aids and/or comprehension issues which may increase risks
- engaging in high risk activities – consuming alcohol or illicit drugs, or taking part in high-risk sports can increase risks.

Risk management strategies can be found on page 21 and in the associated information sheet.

➤ Refer to the [Risk and epilepsy](#) information sheet

Social and physical activity

Encouraging people living with epilepsy and a cognitive disability to engage in social and leisure activity is a great way of enhancing physical and mental health and wellbeing.

Depending on the person's capacity, interests and needs, they should be supported to engage in activities that appeal to them. This may be socialising with friends and family, participating in community events and groups, or taking part in leisure or sporting activities. Some activities can be hazardous for a person living with epilepsy, so choosing

activities that provide a reasonable degree of safety and are consistent with the person's abilities are important considerations.

Many community and sports groups offer disability inclusive activities, but not all groups will have necessarily had experience with epilepsy. Because of this the person, family or support workers may need to meet with staff to discuss the epilepsy diagnosis and risks in order to develop individualised safety strategies. It is important that the person's Epilepsy Management Plan (EMP) is shared with staff so that anyone with a duty of care understands how to provide support should a seizure occur.

If a person has an Emergency Medication Management Plan (EMMP) then staff will need to be trained to administer the emergency medication as prescribed.

A healthy lifestyle can also assist with the management of epilepsy. It is important for a person who lives with epilepsy to get adequate sleep, have a balanced diet, reduce stress, limit alcohol consumption, and participate in appropriate exercise and stimulating activities.



Mental health and wellbeing

The co-existence of psychiatric or psychological disorders (such as anxiety, depression) in people living with a cognitive disability is not uncommon¹⁵. It is also estimated that around 50% of people living with epilepsy experience depression and around 20% experience anxiety¹⁶. So, people who live with epilepsy and a cognitive disability are at a greater risk of developing mental health conditions.

Sometimes, mental health issues are overlooked in people living with epilepsy and a cognitive disability because the person may have difficulty communicating their feelings, concerns, experiences and fears. In addition, their symptoms of depression and anxiety may not present in the same way as they would in the general population. Family, carers and support workers can play an important role in assisting to identify behaviours and symptoms which may indicate that the person is experiencing mental health issues.

Some possible anxiety symptoms include:

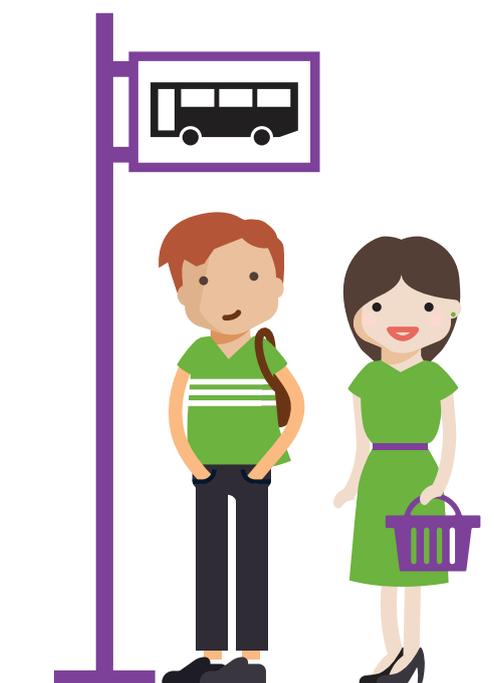
- hot and cold flushes
- racing heart
- obsessive thinking
- compulsive behaviour.



Some possible depression symptoms include:

- withdrawal from close family and friends
- lack of motivation
- unwillingness to participate in activities which are usually of interest
- risk taking behaviour
- attention seeking behaviour, which can sometimes present as frustration or anger
- difficulty forming and maintaining friendships
- lack of self-care and/or risk of self-harm
- fear of rejection or judgement by others. Living with mental health issues may impact on a person's willingness and motivation to take medication and manage their epilepsy effectively. As a result, family, carers and support workers may need to monitor the person to ensure they are taking their anti-epileptic drugs (AEDs).

Many mental health issues are treatable through psychotherapy, medication and education. It is important to identify any potential mental health symptoms and discuss these with specialists as soon as possible, as prompt diagnosis and early intervention can assist in positive health and social outcomes.



Transport and travel

Being able to get around is important for everyone; whether that is to visit friends, attend a medical appointment or travel to another part of Australia or the world. A person might get around by driving a vehicle or using public transport. Travel away from home might see a person use other types of transport such as planes or boats.

Some people living with epilepsy may not be able to drive or have their licence temporarily suspended due to seizure activity, and may also need to participate in a 'Fitness to Drive' assessment. If unable to drive and reliant on public transport or taxis, then the person should be aware of any risks and implement appropriate safety and planning strategies. If traveling away from home there are also a number of matters to consider, from ensuring that enough medication/prescriptions are packed through to minimising the risk of seizure triggers.

To ensure enjoyable transport and travel it is important for all people living with epilepsy to consider risks and implement appropriate safety strategies.

- Refer to the [Transport, travel and epilepsy information sheet](#)



Education and employment

Living with epilepsy and a cognitive disability does not mean education, training or employment pathways are out of the question. It is up to the individual to decide whether they feel able to study or work. But some reasonable adjustments may need to be made in education or workplace settings to assist the person to fulfill their potential.

When planning for education, training or employment it is important to focus on the person's goals and aspirations. There are a wide range of options including further education and training, apprenticeships, traineeships and employment.

- Refer to the [Education, employment and epilepsy](#) information sheet



Every person living with epilepsy must determine whether they need to or are required to disclose their diagnosis to their employer and co-workers. To learn more about whether disclosure about epilepsy is required, how to go about it and the discrimination laws that protect someone who does disclose view the Epilepsy Foundation *Disclosing your epilepsy - to get the job done* booklet.

Government support

Some people living with epilepsy and a cognitive disability may be eligible for Australian Government support and assistance. In addition, the person may also be eligible for National Disability Insurance Scheme (NDIS) support.

Australian Government

Most disability payments (Disability Support Pension, Mobility Allowance and Carer Payment) are managed by the Department of Human Services.

- To learn more about these payments and eligibility visit www.humanservices.gov.au

All states and territories also have a range of disability and related Acts which must be followed in their jurisdiction.

National Disability Insurance Scheme (NDIS)

The National Disability Insurance Scheme (NDIS) provides support to Australians with a disability. The NDIS supports people with a disability to build skills and capability so they can participate in the community and/or employment. It also helps people with a disability to: access mainstream services and supports; maintain informal support arrangements; and, receive reasonable and necessary funded supports.

› To learn more about the NDIS visit www.ndis.gov.au

The *Your epilepsy support and NDIS* booklet can assist in planning for NDIS meetings.



Other

Assistance may also be available through your state health or human services department, as well as local councils.

Disability rights

All people who live with a disability have the right to be an active member of society and to have a say in decisions that affect their lives.

A range of international, Australian and state-based Acts and Conventions protect the rights of people with a disability:

- United Nations – *Convention on the Rights of Persons with a Disability*
- Commonwealth of Australia – *Disability Discrimination Act 1992*
- Commonwealth of Australia – *Disability Standards for Education 2005*

› To learn more about disability rights visit www.humanrights.gov.au

Epilepsy management

The management of epilepsy is about understanding what is happening and putting in place the supports that a person needs and wants. It's all about being safe and having a good quality of life.

Taking a person-centred approach is the key to achieving positive outcomes for people who live with epilepsy and a cognitive disability.

People living with a disability may have other conditions requiring medications or specific support. Or a person may have additional physical or psychosocial issues which must be factored into their epilepsy management plan also. All cognitive, medical and health matters must be considered when developing an Epilepsy Management Plan (EMP), ensuring that a whole-of-person approach is being applied. To achieve this the involvement of other specialists and support workers who care for the person may also be required.

Epilepsy Management Plans

The Epilepsy Management Plan (EMP) and the Emergency Medication Management Plan (EMMP) are valuable tools which can assist in managing a person's care. The plans provide vital information about the type of seizures a person experiences, individual support needs, and any first aid or emergency medication procedure requirements. The person, their specialist, and circle of support should be involved in developing the plans so that epilepsy management needs and requirements are documented.



- › Plan templates are available online at <http://epilepsysmart.org.au>

Epilepsy Management Plan (EMP)

An Epilepsy Management Plan (EMP) documents the person's seizure description, triggers, behavioural changes and impacts, what to do in the event of a seizure, and post seizure support needs. Importantly the EMP documents the person's needs before, during and after a seizure. The EMP also identifies whether emergency medication has been prescribed and when to call for an ambulance (000).

It is recommended that an EMP is developed in conjunction with the person, their treating doctor, and their support people (family, carers or support workers). The EMP should be endorsed by the person's doctor and reviewed every year.

Only people who have received person specific training for the administration of emergency medication should administer it.

The Epilepsy Foundation offers this type of training.

Emergency Medication Management Plan (EMMP)

Sometimes a person living with epilepsy is prescribed emergency medications. These medications are only used in specific situations and are not used in place of daily epilepsy medications. Not all people diagnosed with epilepsy are prescribed emergency medications.

When emergency medication is prescribed by the person's specialist this information is recorded in an Emergency Medication Management Plan (EMMP). The EMMP is completed and reviewed annually by the doctor who manages the person's epilepsy and prescribes the emergency medication. The EMMP should be attached to the person's EMP.

The EMMP is the authority for a trained person to administer the emergency medication in the event of a seizure requiring an emergency response. The EMMP also provides information on when to call for an ambulance (000).

- › Training in how to develop an Epilepsy Management Plans and deliver emergency medication is available at <http://epilepsysmart.org.au>

Risk management

Understanding epilepsy-related risks and putting risk management strategies in place is a good way of assisting the person to be supported in a safe and appropriate manner. It is important that the person and all those who care for them understand the potential risks and safety considerations that accompany an epilepsy diagnosis.

For services and organisations that care for a person with epilepsy, whether that is a supported accommodation or a community service, putting in place risk management strategies is an integral aspect of good operational management and governance practice.

A person living with epilepsy and a cognitive disability may live with family, friends or independently as well. When supporting a person living with epilepsy and a cognitive disability it is important to consider safety implications and risks, taking into account their living situation.

Safety

There are a number of devices, assistive technology and strategies available to assist with maintaining the safety of a person living with epilepsy.

- **Medical ID.** Medical information can be recorded on a Medical Bracelet or ID Card to advise medical personnel, emergency services and people in the community about an epilepsy diagnosis and appropriate support should a seizure occur.
- **Medical alert.** Medical alerts can assist by recognising if the person has a fall (these pendants can automatically raise an alert if a loss of balance is detected), regardless of whether the person is standing or in a wheelchair. Medical alerts can also be triggered manually when the person recognises a seizure is going to occur or

has just occurred. These alerts notify that assistance is required, i.e. the alert service can call for an ambulance or call a registered support person.

- **Assistive devices.** Depending on the person's seizure type safety helmets, anti-suffocation pillows, shower chair, outward opening doors, seizure dogs, and other assistive devices may be recommended.
- **Bathing strategies.** A shower is safer than a bath and a shower chair reduces the risks of falls. Attaching a hand held shower head to the tap in an unplugged bath could be a safer shower option also.
- **Falls and tripping strategies.** Floor surfaces can present trip, slip or fall hazards, so minimise surface clutter and consider soft wool carpeting or cushioned linoleum instead of hard flooring. If seizures that result in falls occur regularly, use of a protective helmet may be recommended.
- **Night seizure strategies.** Consider night time carer support and/or personal alerts to trigger alarms should nocturnal seizures occur. Consider the choice of bed linen and pillows when developing safety strategies. Bed pillows can present a suffocation risk in the event of a night-time seizure, and firm pillows or anti-suffocation pillows are considered safer to use.
- **Swimming strategies.** Swimming alone carries a risk of drowning should a seizure event occur in water. An observer or swimming companion trained in seizure first aid should always be present.

A home or support service organisation safety assessment can be performed by an occupational therapist. These healthcare professionals can make recommendations and develop strategies which can reduce risk and enhance safety.

➤ Refer to the [Risk and epilepsy](#) information sheet

Not all seizures are the same. It is important that all people who care for and support a person living with epilepsy know what to do before, during and after a seizure. This can greatly enhance the person's safety and wellbeing.

Seizure First Aid

Seizure first aid involves assisting the person, providing an immediate emergency response and seeking medical attention as required.

If the person has an Epilepsy Management Plan (EMP) and/or Emergency Medication Management Plan (EMMP) then members of the person's support network should:

- know where these plans are kept
- be trained in providing a seizure response in accordance with these plans and the person's wishes.

➤ A comprehensive seizure first aid poster and short video is available online <http://epilepsyfoundation.org.au/seizure-first-aid/>

Training

Family, carers and support workers play a key role in supporting people who live epilepsy and a cognitive disability. Providing appropriate person-centred support enables the person to live a fulfilling life. Epilepsy education and training ensures that the person's circle of support have the necessary skills and knowledge to meet the specific needs of the person.

It is recommended that family, carers and workers supporting a person living with epilepsy receive training in:

- understanding and managing epilepsy
- seizure first aid
- administration of emergency medication, where prescribed.

Only people who have received person-specific training for the administration of emergency medication should administer it. Where emergency medication is prescribed and a trained person is not available call **000** immediately. Tell the person who answers **000** that emergency medication has been prescribed and follow instructions until paramedics arrive.



An EMP and/or EMMP provide details on the emergency response required in the event of a seizure.

- › Refer to available training options online <http://epilepsyfoundation.org.au/epilepsy-education/>

Glossary

AEDs (anti-epileptic drugs). AEDs are the main form of treatment for people with epilepsy. There are many different AEDs used to treat seizures, and different AEDs work for different seizures.

EEG (electroencephalogram). An electroencephalogram is a test which shows electrical activity in the brain using small, flat discs attached to the scalp.

Cognitive disability. The term cognitive disability encompasses various intellectual or cognitive deficits, including intellectual disability, developmental delay, developmental disability, learning disabilities, and conditions causing cognitive impairment such as acquired brain injuries.

CT scan (computerized tomography). A computerised tomography scan uses X-rays to obtain cross-sectional images of the brain. CT scans allow the doctor to see inside the brain without surgery, and may assist in detecting abnormalities that could be causing seizures.

MRI (magnetic resonance imaging). Magnetic resonance imaging is a medical imaging test which uses strong magnetic fields, radio waves, and field gradients to generate images of the brain.

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

Epilepsy Australia is the peak association of epilepsy organisations in Australia. Contact details for epilepsy organisations in each state and territory can be found on this website.

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This resource 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