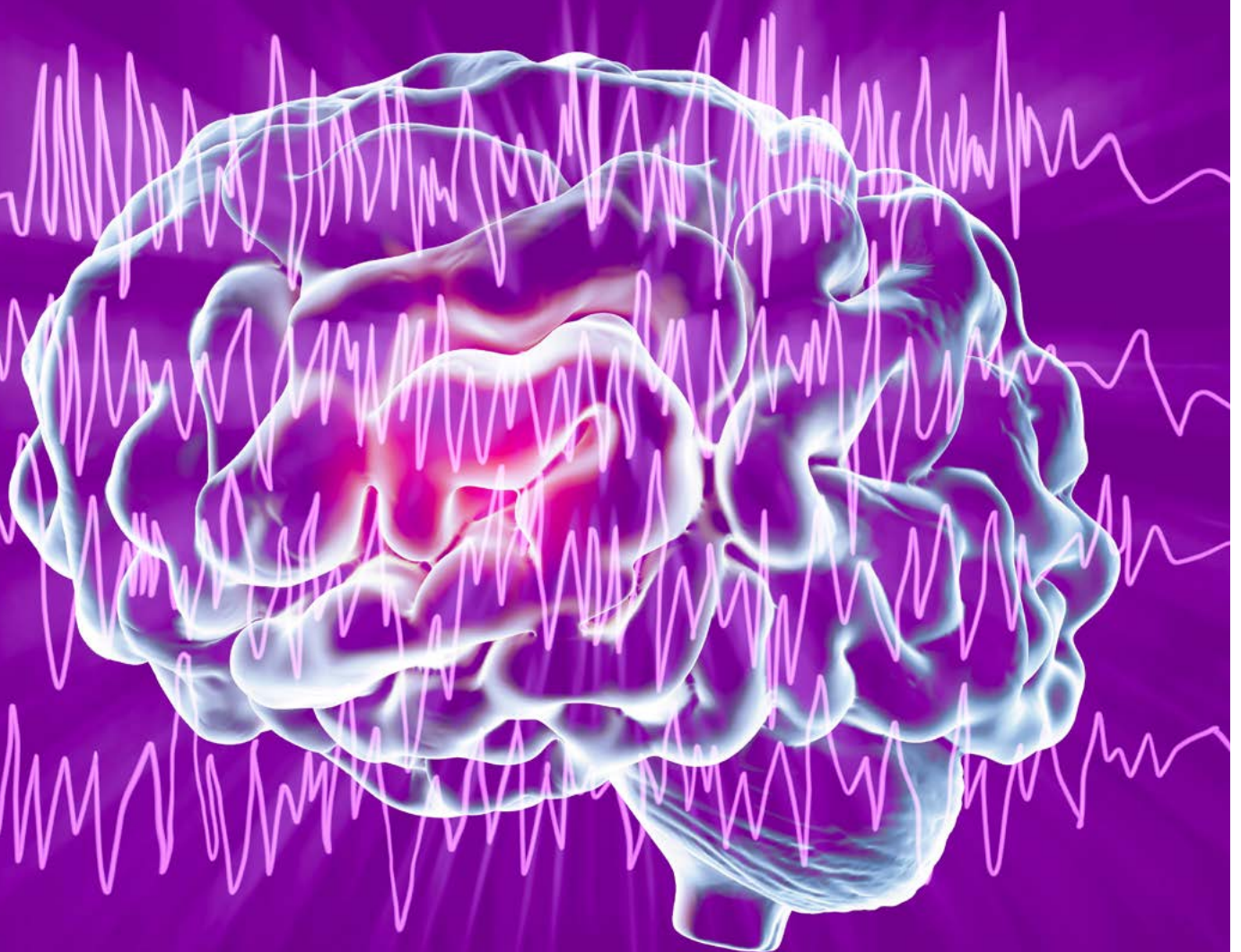


## Epilepsy Training for Support Workers





In the spirit of reconciliation Premium Health acknowledges the Traditional Custodians of country throughout Australia and their connections to land, sea and community. We pay our respects to their elders past, present and emerging and extend that respect to all Aboriginal and Torres Strait Islander peoples today.

# OUR PROMISE

“

**Premium Quality,  
without compromise.  
It's the Premium Health  
promise.**



**Phillipa Wilson**

Founder & Managing Director of Premium Health

**Our Trainers are  
Experienced Nurses  
and Paramedics**

Passionate about sharing  
their experience

**Premium Quality  
Programs**

We pride ourselves on the depth  
of our course content and the  
quality of our training materials

**Innovative Techniques,  
Empowering Outcomes**

Methods remembered for years  
to come

**Specialised Training,  
Contextualised to  
Your Workplace**

Relevant and customised to  
workplaces

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PUBLISHER: PHILLIPA WILSON

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## Welcome to your course and Premium Health.

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The aim of this resource is to provide the essential knowledge and skills required in your training.

We select our Premium Health trainers and assessors carefully. All are either nurses or paramedics with appropriate training qualifications, technical expertise and experience.

# EPILEPSY TRAINING FOR SUPPORT WORKERS

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# WHAT YOU NEED TO KNOW ABOUT YOUR COURSE

## Welcome

This resource provides support workers with the essential knowledge and skills to support a client living with epilepsy.

The essential knowledge to understand and recognise epilepsy, its trigger factors and the different types of seizures will be examined. The management of different types of seizures is explained. The different types of medications used to treat epilepsy, as well as strategies for minimising the risk for clients with epilepsy during everyday activities will be detailed.

## Evaluation of the program

Your feedback is important to us as we use this as part of our continuous improvement cycle. Please undertake our evaluation which will be discussed by your trainer during the course.

## Premium Health's customer service

We offer you an on-going service in relation to first aid, health care or mental health course information and invite you to call our office on **1300 721 292** or email us on [customerservice@premiumhealth.com.au](mailto:customerservice@premiumhealth.com.au).

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# EPILEPSY

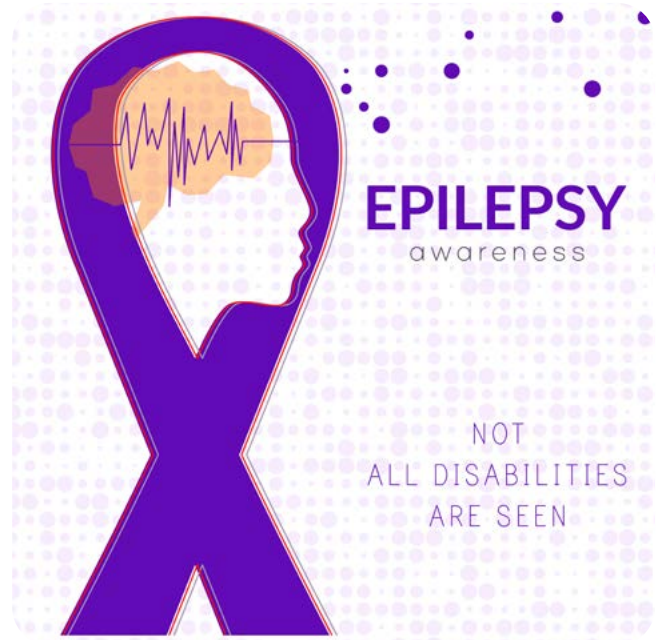
Epilepsy is a common condition that can develop at any age, regardless of gender or ethnic group. 12,000 people in Australia are diagnosed with epilepsy annually. Epilepsy is often diagnosed in infancy, childhood, adolescence and those over the age of 65yrs old. Up to 5% of the world's population may have a seizure at some time in their lives.

Epilepsy often first presents during childhood. But some people develop epilepsy later in life because of medical conditions such as cardiovascular disease including heart disease or stroke. Research has indicated that the incidence of epilepsy is increasing in the older population as a result of these conditions.

Epilepsy is not necessarily a life-long condition. It has been identified that some cases of childhood epilepsy can be outgrown or have long-term remission from seizures.

If a person is diagnosed with epilepsy it simply means that they have started experiencing seizures on a recurring basis. The diagnostic point for an individual to be classed as having epilepsy is to experience at least two unprovoked seizures.

The seizures in epilepsy may be related to a brain injury or family history e.g. genetics, but more often than not, the cause is completely unknown. Seizures tend to be unpredictable and occur without provocation.



People with epilepsy often experience negative psychological reactions or social exclusion because of the community's perception of epilepsy. This response to epilepsy is a social stigma as people can be frightened of what they believe epilepsy to be.

It is important to understand that epilepsy is a condition of the brain, not a mental illness or a contagious disease. Some people find witnessing a seizure of any type frightening because they don't know what to do, they feel helpless or are afraid of the body's automatic movements. Others find the person's lack of awareness during a seizure frightening. Some find the confusion or disorientation which the person may experience after the seizure difficult to manage.

It is commonly thought that epilepsy always involves convulsions or "grand mal" seizures. In fact, there are approximately 40 different types of seizures. When a tendency to have recurrent seizures (more than one) occurs, it is then that a diagnosis of epilepsy is made, along with neurological testing by specialists.

It is estimated that up to 15% of referred individuals to an epilepsy specialist, do not actually have epilepsy and have been misdiagnosed.

**Epilepsy is also associated with an increased risk of death, up to 2-3 times the general population, which may be related to:**

- underlying brain disease e.g. brain tumour or infection
- seizures leading to drowning, burns or head injury
- prolonged or ongoing seizures known as Status Epilepticus
- sudden and unexplained causes
- a seizure that masks a respiratory or cardio-respiratory arrest event

### CAUSES OF EPILEPSY

**Epilepsy can be caused by a number of things such as:**

- injury
- brain trauma or injury
- infection
- neurosurgery
- drug and alcohol abuse
- cardiovascular disease
- stroke
- pre-natal injury or birth trauma
- brain tumours
- neurological malformations
- genetic predisposition

Epilepsy does occur as a single medical condition but it is also associated with several other conditions such as cerebral palsy, intellectual disability, autism, and dementia or as a result of traumatic brain injury. Over 50% of people with epilepsy have no known cause.



### DISABILITIES AND EPILEPSY

Epilepsy is highly prevalent in people with intellectual disabilities. 1 in 4 people with a cognitive disability also live with epilepsy versus 1 in 150 people having epilepsy in the general population. However, not all people with a disability will have epilepsy and not all people with epilepsy identify as having a disability.

Epilepsy in clients with intellectual disability are often misdiagnosed or undiagnosed as seizures can be misinterpreted due to poor communication, behaviours of concern or muscle control. Some seizures present similar to mannerisms of someone with an intellectual disability.

Cognitive impairment such as autism spectrum disorder, down syndrome and cerebral palsy are commonly occurring disabilities with epilepsy.

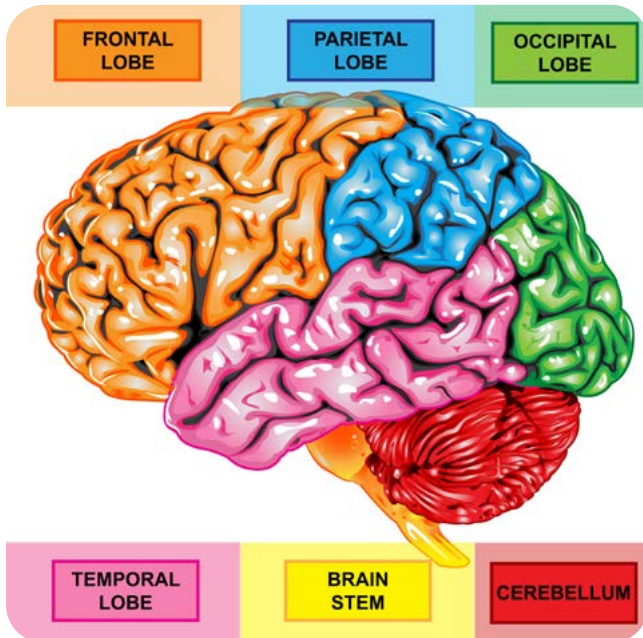
**Clients with an intellectual disability and a diagnosis of epilepsy are more likely to experience:**

- more than one category of seizure
  - uncommon or unusual categories of seizures
  - longer or more severe seizures
  - behavioural side effects of medications
  - seizures mistaken for other types of mannerisms related to their disabilities instead of epilepsy
-



# SEIZURES

Our brain is responsible for our feelings, thoughts, movement and control of body functions.



It is the most complex organ of the body. It is a delicate organ, made up almost entirely of nerve cells, sitting within the chamber of the skull and protected by the thickness of the skull. It is surrounded by cerebral spinal fluid which cushions the brain against sudden movement and provides nourishment to the brain along with the brain's blood supply. At any given moment there are millions of electrical impulses running through the brain. The brain is constantly receiving and responding to hundreds of messages from the environment and the internal organs of our body.

The brain is divided into two halves down the centre. Each half of the brain is divided into lobes called left and right hemispheres which control various functions of the body.

<b>Frontal</b>	Cognitive functions and voluntary movement. Concentration, memory, decision making, judgement, emotional response, impulse control, language and consciousness
<b>Temporal</b>	Sensory input, language and emotion. Hearing ability, memory, interpreting language, visual perceptions and behaviour
<b>Parietal</b>	Touch temperature and pain receptors. Controls or processes touch, temperature, pain perception, awareness of the body and sensation
<b>Occipital</b>	Visual processing centre

The brain has millions of nerve cells (neurons) that generate electrical impulses which travel around the brain to provide messages to the spinal cord, muscles and nerves. If neurons all start firing at once, or has a sudden burst of firings, the brain can be subject to misfiring. This overwhelms the rest of the brain and a seizure is likely to occur.

**Seizures take many different forms. It can range from:**

- a brief loss of consciousness
- sensory disturbance such as tingling or numbness
- changes in what a person may see, hear or smell
- odd sensations which the person may find difficult to describe
- confusion or disorientation
- abnormal or unusual behaviour such as automatic and repetitive behaviour like chewing, swallowing or picking at clothes
- a major convulsion (which is what most people think of as being epilepsy)

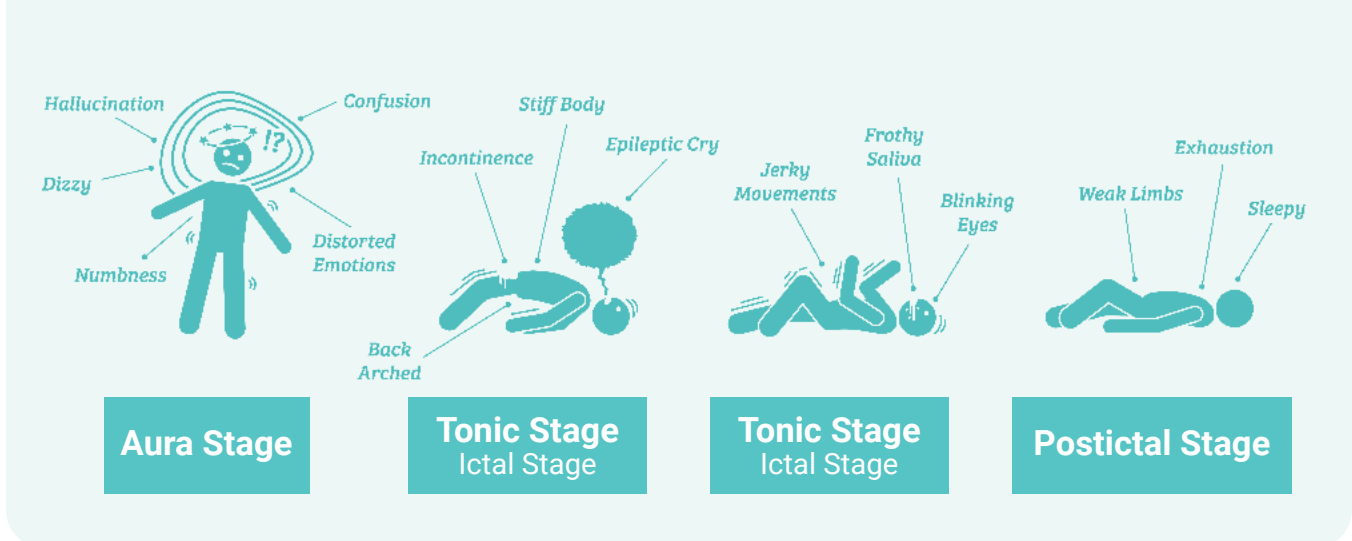
A seizure can occur for many different reasons. A seizure may result from a high temperature, a blow to the head, following a faint, or withdrawal from medicines or illicit substances and from diagnosed conditions such as epilepsy.

### WHAT HAPPENS DURING A SEIZURE?

A seizure can take on many different forms and affect individuals in different ways. Not all parts or phases of the seizure are visible or easy to identify from each other.

Seizures do have a beginning, middle and end. As a support worker, it is important to understand these stages. This way you can recognise early what is happening to a client, to potentially avoid, keep safe and/or manage during a seizure.

## Stages of a Seizure



### Prodrome (beginning)

Some individuals may have 'warning' signs before a seizure occurs. For instance, they might experience feelings, sensations or changes in behaviours anywhere from a few seconds to a few days before a seizure. These signs are not generally part of the seizure.

An **aura** is however the first symptom of a seizure and considered part of the seizure. Often the feeling, sensation or smell is indescribable and the same or similar each time the seizure occurs. An aura can occur alone and be classified as a focal onset aware seizure.

As well as indescribable feelings an individual might also experience unpleasant sensations such as; dizziness, headache, nausea or numbness or tingling in part of the body.

### Ictal phase (middle)

The ictal (middle) phase of a seizure is the period from the first symptoms such as aura to the end of seizure activity in the brain. The seizure activity in the brain is detectable on an electroencephalogram (EEG). This is a non-invasive test which detects electrical activity through metal discs and wires pasted onto the scalp and these pick up activity of the brain cells. This is then amplified onto a computer screen as a recording which the doctor then can interpret.

**Symptoms in this phase of the seizure can affect; awareness, sensory input, emotions and thought changes. Signs and symptoms can range from mild to severe**

### ICTAL PHASE SYMPTOMS

• temporary confusion	• loss of consciousness	• numbness
• staring	• psychic symptoms; fear, anxiety, déjà vu	• strange smells or tastes and/or nausea
• muscle twitching	• loss of senses	• incontinence
• loss of movement	• muscle contractions or cramps	• sweating and/or change in colour e.g. pale or flushed
• uncontrollable jerking movements	• change in behaviour	• heart racing

## Postictal (end) phase

The postictal phase of the seizure is where an individual's seizure starts to end. Some individuals will recover immediately and others may take minutes to hours to recover to their usual state. The recovery phase can be influenced by what type of seizure the individual has experienced; what part of the brain has been impacted and any injury they may have sustained during a seizure.

**Individuals may experience some of the following during the postictal phase of seizure:**

POSTICTAL PHASE SYMPTOMS		
• sleepy	• difficulty communicating	• nausea
• confusion	• fuzziness or light headedness	• injuries; cuts, bruises, head injury
• memory loss	• frustrated	• pain
• scared	• embarrassed	• general weakness in limb side of body or whole body
• anxious	• ashamed	• urge to go to bathroom or incontinence of bowel or bladder

## CATEGORIES OF SEIZURES

**In the past, the most common terms to describe seizures included:**

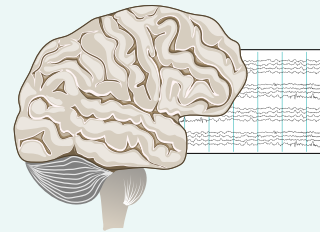
- grand mal and
- petit mal

These descriptions used were quite accurate, however were often used to describe a big seizure versus a little seizure.

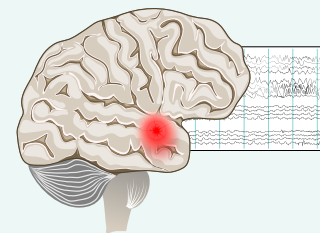
A new classification system developed by The International League Against Epilepsy (ILAE), the world's main scientific body for researching epilepsy, has recently revised the categories of seizures and updated the classification system. The old system did not capture many types of seizures, the new system hopefully not only being accurate but also more encompassing.

## Epilepsy

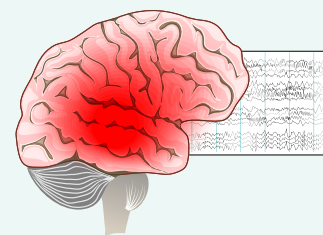
### Healthy



### Focal seizure



### Generalised epilepsy



**Seizures will be classified depending on three factors:**

1. The onset location (where in the brain the seizure starts from).
2. Whether the individual is aware or unaware during the seizure.
3. If the seizure produces movement.

**Seizures are now divided into three main categories:**

- focal onset
- generalised onset
- unknown onset

## FOCAL ONSET SEIZURES

Previously referred to as 'partial seizures', focal onset seizures arise in one small area of the brain. They are often very subtle or unusual, and may go unnoticed or be confused with other events. They produce symptoms relating to that part of the brain's function such as motor, sensory, autonomic or psychic.

Around 60% of people with Epilepsy have focal seizures. A focal seizure may progress to affect both sides of the brain causing muscle stiffening and jerking, known as bilateral tonic-clonic seizure.

FOCAL ONSET SEIZURES		
<b>Focal aware</b>	<ul style="list-style-type: none"> <li>individual fully aware</li> <li>may not be able to respond</li> <li>usually brief</li> </ul>	<ul style="list-style-type: none"> <li>can be further classified as motor or non-motor</li> </ul>
<b>Focal impaired awareness</b>	<ul style="list-style-type: none"> <li>awareness impacted either for whole or some of the seizure</li> <li>often mistaken for drug or alcohol intoxication</li> </ul>	<ul style="list-style-type: none"> <li>may appear confused, dazed or disoriented</li> <li>may make chewing movements</li> <li>fiddle with clothing</li> <li>scream</li> </ul>
<b>Focal motor seizure</b>	<ul style="list-style-type: none"> <li>some type of movement happens due to seizure</li> </ul>	<ul style="list-style-type: none"> <li>jerking</li> <li>twitching</li> <li>stiffening movements of body</li> <li>automatisms: licking lips, walking, rubbing hands, running</li> </ul>
<b>Focal non-motor seizure</b>	<ul style="list-style-type: none"> <li>other symptoms occur first</li> </ul>	<ul style="list-style-type: none"> <li>sensation, emotions, thinking</li> <li>nausea</li> <li>butterflies in stomach</li> <li>déjà vu</li> </ul>

### GENERALISED ONSET SEIZURES

Generalised seizures involve both sides of the brain from the onset and usually causes loss of consciousness. They can be classified further by the movement seen

during the seizure.

GENERALISED SEIZURES		
<b>Generalised motor seizure</b>	<ul style="list-style-type: none"> <li>tonic-clonic</li> </ul>	<ul style="list-style-type: none"> <li>stiffening (tonic) and rhythmic jerking (clonic) involved</li> <li>tonic seizures alone are usually brief lasting about 20 seconds</li> </ul>
	<ul style="list-style-type: none"> <li>clonic</li> </ul>	<ul style="list-style-type: none"> <li>uncommon, cause jerking in various parts of the body</li> </ul>
	<ul style="list-style-type: none"> <li>myoclonic</li> </ul>	<ul style="list-style-type: none"> <li>sudden single jerks of muscle groups or muscle for 1-2 seconds</li> </ul>
	<ul style="list-style-type: none"> <li>atonic</li> </ul>	<ul style="list-style-type: none"> <li>brief loss of muscle tone, person falls to ground or sudden head nod</li> </ul>
<b>Generalised non-motor seizure</b>	<ul style="list-style-type: none"> <li>absence</li> </ul>	<ul style="list-style-type: none"> <li>brief change in awareness</li> </ul>

### UNKNOWN ONSET SEIZURES

Unknown onset seizure is used when a diagnosis cannot be made as either generalised or focal. It may only be a temporary classification as more tests occur and more information becomes available.

### STATUS EPILEPTICUS

Status epilepticus is a medical emergency. This is where a seizure is prolonged, where seizures occur one after another within a very short period of time with no signs of recovery from the last seizure. Status Epilepticus can occur with any seizure type e.g. convulsive or non-convulsive.

#### The longer a seizure occurs;

- the less likely the person will come out of it on their own
- the higher the chance of long-term damage
- the high the chance of death

#### Status epilepticus can be classified as either:

- convulsive status epilepticus
- non-convulsive status epilepticus

<b>Convulsive status epilepticus</b>	<ul style="list-style-type: none"> <li>• single tonic-clonic seizure lasting up to 5 minutes or more</li> <li>• person goes into a second seizure without recovering from the prior seizure</li> <li>• repeated seizures for 30 minutes or more</li> </ul>	<ul style="list-style-type: none"> <li>• emergency treatment such as medication or oxygen may be required</li> <li>• call ambulance</li> </ul>
<b>Non-convulsive status epilepticus</b>	<ul style="list-style-type: none"> <li>• continuous absence seizures</li> <li>• continuous focal non-awareness seizures</li> </ul>	<ul style="list-style-type: none"> <li>• if non-convulsive seizure lasts longer than 10 minutes call an ambulance</li> </ul>

### SEIZURE TRIGGERS

There are many factors that can trigger an epileptic seizure. For some people a combination of trigger factors may result in a seizure or epileptic episode, while for others it may be only a single trigger factor.

#### Examples of seizure triggers include:

- alcohol, illegal and prescribed drugs
- poor nutrition, low blood sugar levels
- caffeine
- lack of sleep
- missed medication
- emotional stress
- dehydration or over-hydration
- infections, illness and/or pain
- menstruation

- sensitivity to physical stimuli i.e. heat, lights, sound
- extreme fatigue or physical exhaustion
- under stimulation and/or over stimulation
- strong smells
- constipation

### SEIZURE CONTROL



Most people have their epilepsy and seizures well-managed by a combination of medication, good diet, adequate sleep and exercise.

Some people may have poor seizure control for various reasons. Frequent or regular seizures can have a number of detrimental effects on the person’s wellbeing.

Intractable or medically refractory epilepsy is a term used for those people who have poor seizure control. This poor seizure control often occurs despite trying many different types and combinations of medication. Keeping a seizure diary can be helpful.

#### The people most likely to have poor seizure control include:

- people with disabilities, mental health issues, multiple seizure types, English as a second language, children, all of which makes communication difficult
- people who have focal seizures
- people who may not take their anti-epileptic medication as regularly as prescribed
- people who have other medical conditions or are in poor health, which requires several medications to manage these conditions
- people who have been prescribed the wrong medication for their seizure type



Frequent seizures can have the effect of causing poor concentration and tiredness which can also impact on:

- work
- financial issues because of increased sick leave;
- increased risk of accidental injury
- becoming socially isolated
- causing relationship problems

There also is an increased risk of sudden, unexplained death (SUDEP).

### SUDEP

Sudden unexpected death in epilepsy is when a person with epilepsy dies suddenly and prematurely and no reason for death is found. This classification excludes people dying in status epilepticus and those who drown.

**Risk factors for a client experiencing SUDEP include:**

- uncontrolled or frequent seizures
- tonic-clonic seizures, especially at night whilst asleep
- many years living with uncontrolled epilepsy
- missed doses of medication
- increased alcohol consumption

### SAFETY

Some people with epilepsy will wear special pieces of jewellery or identification (for example MedicAlert) that show that they will need special medical care in an emergency.

Smartwatches and monitors are also available that can detect seizures and send alerts to family members or carers. Whilst these don't guarantee safety or detection of all seizures, they can provide people with peace of mind.

Some examples include:

**Smartwatches** – these can monitor heart rate, oxygen levels, detecting unusual events such as heart rate going out of range. These can be connected via Bluetooth to mobile phones and alert family or emergency services of the persons location.

**Sleep activity monitors** – these monitor motions and movements and can make time-stamp recordings, making an alert sound if anything unusual is detected.

**Under mattress sensors** – these monitors detect convulsive seizures, as well as detecting if someone has left the bed and not returned in a short period.

**Wireless smart socks** – these monitors are similar to smartwatches and monitor heart rate and oxygen levels.

### EPILEPSY TREATMENT

There is currently no known cure for epilepsy. The role of therapeutic substances and treatments in managing epilepsy is primarily focused on reducing seizure frequency, with the ultimate goal of achieving complete seizure freedom. It is also important to improve the quality of life for the individual with epilepsy and to consider adverse events and likelihood of treatment withdrawal.

70% of individuals achieve good seizure control and become seizure free with antiepileptic medication management within 5 years of diagnosis .

Antiepileptic medications (knowns as AEDs) cannot be stopped suddenly due to the high risk of withdrawal symptoms. They need to be given at the same time each day. As a support worker looking after a client on antiepileptic medications, you need to ensure that the client's medications are under regular review to assess for benefits and adverse side effects.

### EPILIM

Epilim is the most common antiepileptic medication used for epilepsy.



**Some common side effects of antiepileptic medications include:**

- dizziness
- anti-social behaviour
- nausea
- depression
- fatigue
- blurred/double vision

**Commonly prescribed epilepsy medications include:**

• Dilantin (phenytoin)	• Epilim, Valpro (sodium valproate)
• Frisium (clobazam)	• Gabitril (tiagabine)
• Keppra (levetiracetam)	• Lamictal (lamotrigine)
• Mysoline (primidone)	• Neurontin (gabapentin)
• Phenobarbitone (phenobarbitone)	• Rivotril (clonazepam)
• Sabril (vigabatrin)	• Tegretol (carbamazepine)
• Topamax (topiramate)	• Trileptal (oxcarbazepine)
• Zarontin (ethosuximide)	

## CLONAZEPAM



Clonazepam was one of the first benzodiazepine to be used for the treatment of epilepsy.

Today, Clonazepam is mainly used as an add-on anti-epileptic drug, for those clients still having seizure activity whilst on other AEDs. Even though it is an effective medication, it has some neurotoxic side effects as well as issues with tolerance (the longer a person is on the medication, the less effective it becomes).

Clonazepam is mostly given in the treatment of absent and myoclonic seizures.

As with most AEDs, clonazepam usage needs to be closely monitored, because if it is stopped too quickly a person may experience withdrawal symptoms. Clonazepam withdrawal can include status epilepticus or worsening of seizures.

Clonazepam given as a daily medication, can be taken in tablet or wafer formation.

Clonazepam may be prescribed for the treatment of emergency seizures (status epilepticus) can be given intravenously or rectally.

Like other benzodiazepines, one of Clonazepam's main side effects is sedation with respiratory depression. Therefore, it is crucial to monitor the effect of the medication when first being given to a client, or in any dose increases and report back to the client's doctor.

Children, generally tolerate Clonazepam better, in terms of less side effects, than adults. As such, it is more commonly prescribed in children.

## ALTERNATIVE TREATMENT OPTIONS

There are other treatment options available for people who have difficulty managing their seizures. These include surgery, ketogenic diet and vagus nerve stimulation. Because of the complicated nature of these treatment options, they must be discussed with, trialled and supervised, usually by a team of medical specialists or surgeons.

## SURGERY

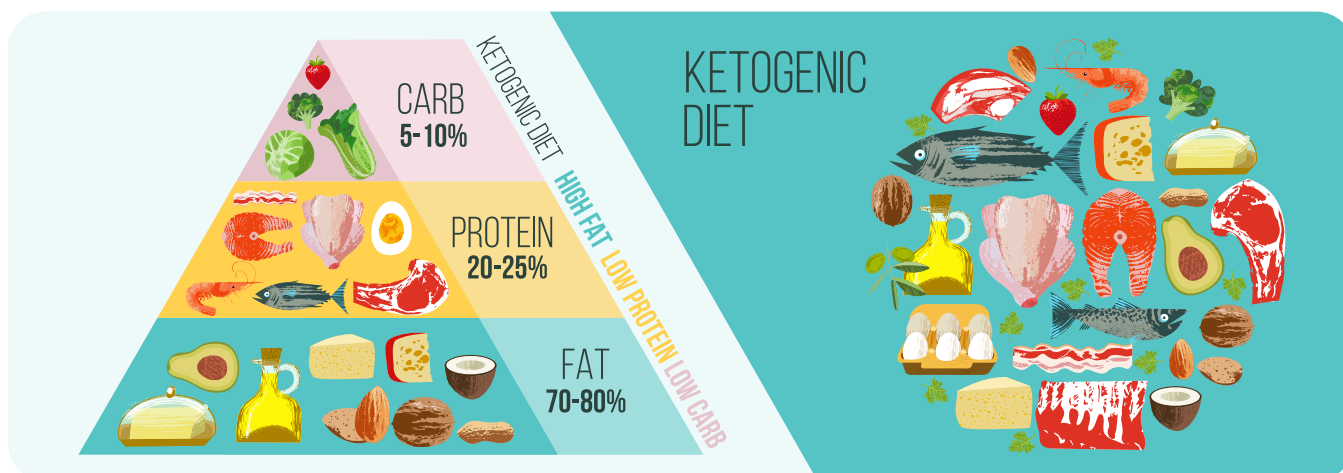
A small percentage of people may be eligible for surgery. It is only considered for those with focal seizures. Surgery may involve removing a certain part of the person's brain that causes the seizures or cutting the nerve pathways which transmit the seizure activity. The kind of seizures a person has and the part of the brain where they begin determines whether surgery is likely to help or not and which specific type of operation may be effective. Epilepsy Action Australia reports that approximately 70% of people who have epilepsy surgery become seizure free.

There are two main types of brain surgery for epilepsy. The most common is called focal resection. The surgeon removes the area of the brain that causes the seizures. The most common example of this type of surgery is the temporal lobectomy (removal of part of the temporal lobe of the brain). The aim of resection surgery for epilepsy is to reduce or even eliminate the seizure disorder.

Another rare type of surgery known as a hemispherectomy, is only suitable for a very small number of individuals, commonly children. It involves removing an entire side of the brain. It is only considered when one side of the brain is functioning very poorly, meaning that post removal the individual has not lost function.



The second, less common type of epilepsy surgery is called corpus callostomy. This is a surgical disconnection or cutting of the nerve pathways called the corpus callosum. These nerve fibres connect the two halves of the brain, meaning when disconnected prevents a seizure spreading from one side of the brain to the other. This procedure may be helpful when seizures begin in areas that are too important to remove. Disconnection procedures generally provide relief from frequent seizures but are not a cure for epilepsy.



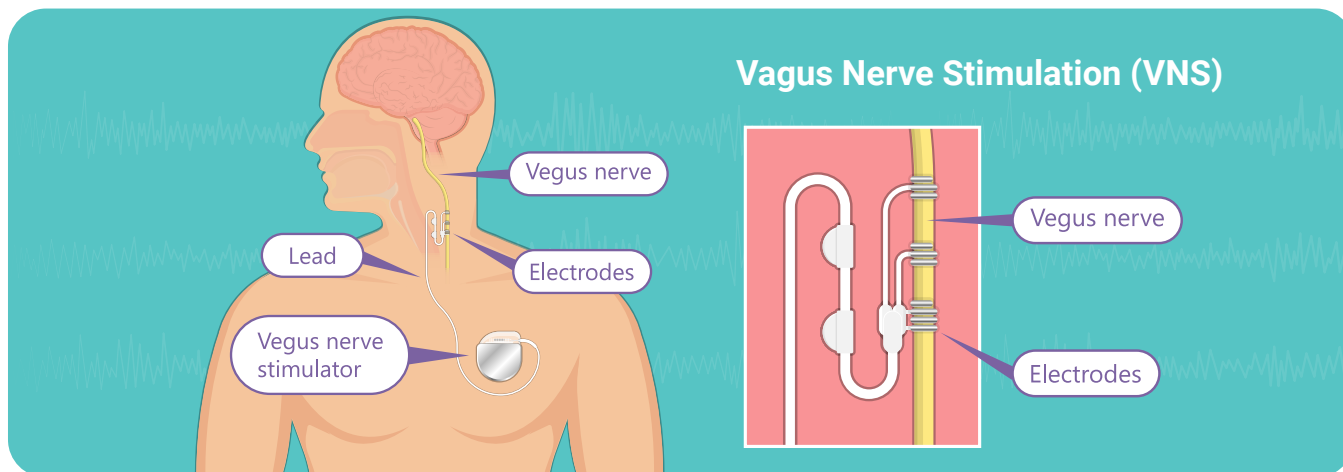
### DIET

Change in diet, does not replace anti-epileptic medications. Change in a client's diet, to support the reduction of seizure activity, should be closely supervised by a dietician.

Ketogenic diet is a medically prescribed and monitored diet that may be a suitable treatment option for children, adolescences and some adults. The diet is 80% high fat, 5% low carbohydrate with 15% controlled protein, ensuring the body burns fat rather than carbohydrate and protein for energy. This will produce ketones, and the diet will maintain that level of ketones.

The Ketogenic diet is generally considered as only a short-term treatment. It has been mostly effective for certain childhood epilepsy syndromes. It has been used as a treatment since the 1920s, but little is known about how it works.

The Modified Atkins diet (MAD) is high fat where protein is encouraged however carbohydrate intake is limited. It is a mix between the classic Ketogenic diet and Atkins diet. The individual is encouraged to consume lots of dairy and oils, proteins such as meat, eggs and fish and carbohydrate counts are monitored. The individuals' ketosis level is checked daily, usually through a urine strip checking.



### VAGUS NERVE STIMULATION (VNS)

The vagus nerves are a pair of nerves that start in the brain and run through the body.

There is a vagus nerve on both sides of the body, that runs from the brain stem to the large bowel or colon. It supplies nerve fibres to the pharynx (throat), larynx (voice box), trachea (windpipe), lungs, heart, oesophagus and the intestinal tract as far as the transverse portion of the colon. The vagus nerve also brings sensory information back to the brain from the ear, tongue, pharynx, and larynx.

Vagus nerve stimulation (VNS) is where a stimulator device is implanted under the skin on the upper chest, under the left collar bone. A wire connecting the device is threaded up to the left vagus nerve. It acts

like a 'pacemaker' for the brain. It provides regular, mild electrical messages through the vagus nerve, to reduce the irregular electrical brain activity that results in seizures. The device stimulation intervals will be adjusted to the individuals need, generally set to deliver a stimulation for 30 seconds every 5 minutes.

People that may know a seizure is coming can use a special made magnet to activate the VNS in order to stop or reduce the length of the seizure. The magnet is small enough that it can be worn by the individual on a belt or wrist strap.

The battery can last up to ten years and when the battery requires replacement it needs surgical intervention.



### MEDICINAL CANNABIS (CBD)

In 2016, Australian State and Federal government introduced legislation to facilitate the trial introduction of medicinal cannabis as a treatment for epilepsy and other conditions.

The Epilepsy Foundation supports the current interest in these trials and the leadership at the political government to progress research through clinical trials.

Currently in Australia, medicinal cannabis is imported and regulated by the Therapeutic Goods Administration (TGA). Those individuals needing to access medicinal cannabis require a script from their treating doctor, and be granted under the Special Access Scheme (SAS). Most forms of medicinal cannabis will contain less than 2% THC (the psychotropic component of cannabis) and therefore will only be classed as a Schedule 4 drug not requiring more than the SAS permit.

**The current recommendations around the use of medicinal cannabis in Australia are as follows:**

- medicinal cannabis for the treatment of epilepsy is only recommended as an additional treatment to existing AEDs (anti-epileptic medications)
- for individuals over 25 years old, there is insufficient evidence to support the use of medical cannabis for treatment of epilepsy
- likely adverse events that the prescribing doctor and individual must be aware of include; diarrhoea, drowsiness and appetite changes, worsening seizures, convulsions and severe diarrhoea and behavioural difficulties may affect the goals of the epilepsy treatment and increase the likelihood of treatment withdrawal
- where there is no strong evidence to support dosing and preparations of medicinal cannabis for epilepsy treatment, CBD use should be re-evaluated after 1 week of therapeutic use, to determine any benefits

### SEIZURE MANAGEMENT

It is very important when looking after a client with epilepsy to have an epilepsy management plan (EMP) in place. The EMP should be accessible to all those involved in looking after the client including; client's family, friends and support workers. This will allow for easy identification of the safety requirements of the client as well as how to manage before, during and after the client's seizure.

### EPILEPSY MANAGEMENT PLAN (EMP)

A client's EMP is developed in conjunction with the client, relevant next of kin or family, client's neurologist, general practitioner and relevant support staff.

It needs to include:

<ul style="list-style-type: none"> <li>• medications used to manage epilepsy</li> </ul>	<ul style="list-style-type: none"> <li>• client's seizure types including: what they look like, how long they typically last for, how often they typically occur (per month)</li> </ul>
<ul style="list-style-type: none"> <li>• if there is emergency seizure medication prescribed</li> </ul>	<ul style="list-style-type: none"> <li>• client's known seizure triggers</li> </ul>
<ul style="list-style-type: none"> <li>• emergency procedures to be following in the event of a seizure including when to call 000</li> </ul>	<ul style="list-style-type: none"> <li>• how the client would like to be supported during a seizure</li> </ul>
<ul style="list-style-type: none"> <li>• emergency contact details</li> </ul>	<ul style="list-style-type: none"> <li>• seizure first aid and post seizure monitoring</li> </ul>
<ul style="list-style-type: none"> <li>• supervision requirements for bathing and swimming</li> </ul>	

Staff must ensure that they maintain accurate record keeping of seizures and administration of medication. They must also ensure that first aid procedures are well documented and readily accessible. Staff caring for people with epilepsy should receive regular training on issues regarding the management of epilepsy. The instructions in a person's epilepsy or seizure management care plan must be followed when the person has a seizure.

The following guideline on an epilepsy management plan, can be found at the Epilepsy Foundation website.

<https://epilepsyfoundation.org.au/wp-content/uploads/2019/09/EMP-Seizure-x-1-unrestricted.pdf>

### EMERGENCY MEDICATION MANAGEMENT PLAN (EMMP)

If a client has been prescribed emergency seizure medication, it is to be indicated on the EMP as well as when it would be given. However, a separate emergency medication management plan (EMMP) is also required.

#### The EMMP must include:

<ul style="list-style-type: none"> <li>• an order for the emergency medication signed by a doctor</li> </ul>	<ul style="list-style-type: none"> <li>• the equipment required to administer the medication</li> </ul>
<ul style="list-style-type: none"> <li>• the circumstances that medication is to be given</li> </ul>	<ul style="list-style-type: none"> <li>• emergency procedures to be followed including when to call 000</li> </ul>
<ul style="list-style-type: none"> <li>• the route of administration e.g. buccal or intranasal</li> </ul>	<ul style="list-style-type: none"> <li>• the positive effects and possible side effects of the medication</li> </ul>
<ul style="list-style-type: none"> <li>• how many doses in a 24hr period can be given</li> </ul>	<ul style="list-style-type: none"> <li>• post monitoring and recording requirements including who is notified of the event</li> </ul>

For guidelines on EMMPs please visit the Epilepsy Foundation website:

<https://epilepsyfoundation.org.au/understanding-epilepsy/epilepsy-and-seizure-management-tools/epilepsy-plans/>

### SEIZURE RECORDING AND SEIZURE DIARY



Although the person may experience a warning aura, obviously they will not be aware of what happens to them during the seizure. It's best to have someone who witnessed their seizure to write down what they saw before, during and after the seizure. Remember to include the date and time of the seizures and any possible triggers for the seizure. This will help in establishing the seizure pattern and any changes in response to any new treatments.

There are many epilepsy seizure diaries, from electronic computer diaries and smartphone apps to paper-based recording charts. There is also the consideration, with the client's and family's permission, to try to record seizures to provide more visual information to the client's doctor.

#### Some information that would be helpful for a support worker to record:

- the date and time of the seizure/s
- length of time the seizure was observed
- where the seizure occurred
- what the client was doing just before the seizure occurred
- did anyone witness the seizure?
- how the client felt before the seizure/s
- did the client experience any unusual feelings before the seizure?
- had there been any alcohol or drug (prescription or recreational) before the seizure?
- were any parts of the body affected during the seizure?
- did the client lose consciousness, sustain an injury or experience changes to their breathing pattern?
- did the client do anything unusual or out of the ordinary during the seizure?
- was the client able to respond to others during the seizure?
- did the client bite their tongue or the inside of their cheek during the seizure?
- did the client lose bowel and bladder control?
- does the client remember anything about the seizure?
- how long did it take the client to fully return to normal after their seizure?

### MANAGING TRIGGERS

It is important to note on a client's epilepsy management health care plan, any known or suspected seizure triggers. This assists in the support workers, making adjustments in the client's lifestyle to maintain a healthy balanced lifestyle, e.g. balanced diet, sleep schedule, socialisation and exercise. This will greatly assist in reducing exposure to known common seizure triggers.

### SEIZURE FIRST AID

Understanding how and when to provide a first aid response for a client having a seizure can assist in reducing the impact and potential adverse effects on that client.

When a trained support worker is available to assist a client during a seizure, they must follow any written instructions from the client's doctor documented in the client's EMP and EMMP.

# EPILEPSY First Aid



## Stay Safe Side

### Do



1 Remain calm



2 Keep the person safe from harmful objects



3 Look at a watch and time the seizure



4 Make the person as comfortable as possible



5 When seizure end Turn the person onto their side



6 If seizure more than 5 minutes call 000



7 Stay with them until they awake

### Do Not



1 Do not panic



2 Do not restrain



3 Do not put anything in their mouth

SEIZURE TYPE	TO DO	WHEN TO CALL 000
<b>Tonic-Clonic seizures</b>	<ul style="list-style-type: none"> <li>➤ Remain calm.</li> <li>➤ Time the seizure.</li> <li>➤ If there is something present in their mouth e.g. food, water, roll them onto their side in the recovery position.</li> <li>➤ Protect them from injury, move objects away from them.</li> <li>➤ Place something soft under their head.</li> <li>➤ Loosen any tight clothing.</li> <li>➤ As soon as the seizure stops, roll the person onto their side (recovery position) and tilt their chin upwards to open airway and assist in breathing.</li> <li>➤ Monitor the client's breathing; every 2 minutes roll the client onto their back and look, listen and feel for breathing for at least 10 seconds, if breathing normally, roll back into recovery position.</li> <li>➤ Stay with the person, until they have fully recovered and/or until a paramedic arrives if ambulance has been called.</li> <li>➤ Reassure the client.</li> <li>➤ Keep bystanders away, maintain the dignity and privacy of the client.</li> </ul>	<ul style="list-style-type: none"> <li>➤ The seizure lasts 5 minutes or more or a second seizure begins before the client fully recovers.</li> <li>➤ If the client remains non-responsive or 5 minutes or more after the seizure has stopped.</li> <li>➤ The client has sustained an injury.</li> <li>➤ The client has swallowed water.</li> <li>➤ The client is pregnant.</li> <li>➤ It's the client's first seizure.</li> <li>➤ The support worker is uncomfortable managing the situation.</li> <li>➤ The client asks for medical assistance.</li> <li>➤ It is otherwise stated on the client's EMP.</li> </ul>
<b>DO NOT:</b>	<ul style="list-style-type: none"> <li>➤ Do not restrain the person, do not move them (unless they are in danger).</li> <li>➤ Do not put anything in the client's mouth.</li> <li>➤ Do not give the client water, food, or solid medications (unless they are fully alert).</li> </ul>	
<b>Stimulant agents</b>	<ul style="list-style-type: none"> <li>➤ Gently guide the client past obstacles, away from danger.</li> <li>➤ Remove any harmful objects nearby e.g. hot liquids etc.</li> <li>➤ Calmly talk to the client, explain they are safe and ask if they are ok.</li> <li>➤ Reassure the client and stay with them until they recover or until an ambulance arrives if needed.</li> </ul>	<ul style="list-style-type: none"> <li>➤ If the seizure lasts for 5 minutes or more, the client may be having non-convulsive status epilepticus.</li> <li>➤ The client has sustained an injury.</li> <li>➤ The client has swallowed water.</li> <li>➤ The client is pregnant.</li> <li>➤ It's the client's first seizure.</li> <li>➤ The support worker is uncomfortable managing the situation.</li> <li>➤ The client asks for medical assistance.</li> <li>➤ It is otherwise stated on the client's EMP.</li> </ul>

SEIZURE TYPE	TO DO	WHEN TO CALL 000
<b>Focal aware seizures</b>	<ul style="list-style-type: none"> <li>› Gently assist the client to cease any activity they are participating in.</li> <li>› Assist the client to sit down.</li> <li>› Reassure the client that they are safe.</li> <li>› Stay with the client until they recover or until the ambulance arrives if needed.</li> </ul>	<ul style="list-style-type: none"> <li>› If further medical assistance was needed for another reason.</li> <li>› If the client experiences focal aware seizures in clusters or progresses to a focal impaired awareness seizure or a convulsive one, more assistance is required.</li> <li>› It is otherwise stated on the client's EMP.</li> </ul>
<b>Tonic and Atonic seizures</b>	<ul style="list-style-type: none"> <li>› Assess the client for injuries.</li> <li>› Calmy talk to the client and ask if they are ok.</li> <li>› Reassure the client that they are safe.</li> <li>› Stay with the client until they recover or until the ambulance arrives if needed.</li> </ul>	<ul style="list-style-type: none"> <li>› The client has sustained an injury.</li> <li>› The client has swallowed water.</li> <li>› The client is pregnant.</li> <li>› It's the client's first seizure.</li> <li>› The support worker is uncomfortable managing the situation.</li> <li>› The client asks for medical assistance.</li> <li>› It is otherwise stated on the client's EMP.</li> </ul>
<b>Absence seizures</b>	<ul style="list-style-type: none"> <li>› Remove any objects that could pose a danger to the client e.g. hot liquids etc.</li> <li>› Calmy talk to the client and ask if they are ok.</li> <li>› Reassure the client.</li> <li>› Assist the client to resume the activity they were involved in before the seizure commenced if they have recovered.</li> <li>› Stay with the client until they have recovered or until an ambulance arrives if needed.</li> </ul>	<ul style="list-style-type: none"> <li>› If the seizure lasts for 5 minutes or more, the client may be having non-convulsive status epilepticus.</li> <li>› The client has sustained an injury.</li> <li>› The client has swallowed water.</li> <li>› The client is pregnant.</li> <li>› It's the client's first seizure.</li> <li>› The support worker is uncomfortable managing the situation.</li> <li>› It is otherwise stated on the client's EMP.</li> </ul>

## RISKS ASSOCIATED WITH EPILEPSY

- **Falls:** Particular care and supervision of participants in the bathroom, kitchen and any room with hard surfaces is required.
  - **Burn-related injuries:** Scalding can occur in the kitchen or bathroom during seizures. Minimise the risk of burns, such as by reducing hot water temperature or supervising as appropriate.
  - **Sudden unexpected death in epilepsy:** There is an estimated 20-fold increased risk of unexpected death among people with epilepsy, compared to the general population. Seizure detection tools such as smart watches or pressure mattresses can be used for people who are at risk.
  - **Risk of drowning:** Ensure particular care and supervision is given to a person at risk of seizures when showering or bathing, or when swimming. Seizure detection such as smart watches or baby monitors may be useful to alert to or detect seizure activity.
  - **Aggression:** May occur as a seizure is ending when the person is confused.
- Factors that may have contributed to deaths include inadequate epilepsy medication, poor recording of epilepsy management, inadequate seizure monitoring, support staff not being aware or confident of best practice in responding to seizures, and lack of access to medical reviews or specialist consultations.

## MANAGING A CLIENT IN DIFFERENT SITUATIONS

SITUATION	MANAGEMENT
<p data-bbox="140 349 368 376"><b>Unconscious client</b></p> 	<p data-bbox="547 349 979 376"><b>Follow DRSABCD first aid action plan:</b></p> <ul style="list-style-type: none"> <li data-bbox="547 398 1171 425">➤ Check for dangers to yourself, bystanders and client.</li> <li data-bbox="547 448 1437 506">➤ Make the area safe by removing the danger from the client or the client from the danger. Only continue when safe to do so.</li> <li data-bbox="547 528 1422 586">➤ Check client's response with simple verbal commands e.g "open your eyes, squeeze my hand".</li> <li data-bbox="547 609 1362 667">➤ If the client only displays minor response such as groaning but no eye opening, treat as unconscious.</li> <li data-bbox="547 689 1386 748">➤ Call for an ambulance 000 if needed (client's EMP should state when an ambulance needs to be called).</li> <li data-bbox="547 770 1386 828">➤ Position the client on their back, open their mouth and check for foreign material or obstructions.</li> <li data-bbox="547 851 1406 909">➤ If airway needs clearing, roll client into recovery position, open mouth and drain matter downwards, roll back onto client's back.</li> <li data-bbox="547 931 1155 958">➤ Lift chin upwards using a pistol grip to open airway.</li> <li data-bbox="547 981 1394 1008">➤ Assess for normal breathing: adult approximately 15 breaths per minute.</li> <li data-bbox="547 1030 1437 1088">➤ Look for the even movement of the rising and falling of the lower chest for 10 seconds.</li> <li data-bbox="547 1111 1038 1137">➤ Listen for the sound of regular breathing.</li> <li data-bbox="547 1160 1299 1187">➤ Feel air escaping from the mouth/nose with your hand or cheek.</li> <li data-bbox="547 1209 1422 1267">➤ A client who is breathing normally is then to be turned onto their side in the recovery position.</li> <li data-bbox="547 1290 1406 1317">➤ If the client is not breathing or not breathing normally begin resuscitation.</li> <li data-bbox="547 1339 1437 1397">➤ Stay with client and monitor signs of client's circulation e.g. colour should be normal, they client should be warm around the neck and re assess breathing every 2 minutes and re-assess breathing for 10 seconds.</li> </ul>
<p data-bbox="140 1458 416 1516"><b>Seizures from a seated position</b></p> 	<p data-bbox="547 1458 1262 1485"><b>If the client is in wheelchair, stroller, seat or car seat, bus seat:</b></p> <ul style="list-style-type: none"> <li data-bbox="547 1507 847 1534">➤ Leave the client seated.</li> <li data-bbox="547 1556 1166 1583">➤ Protect the client from falling if there is no seat belt.</li> <li data-bbox="547 1606 1066 1632">➤ Ensure wheelchair or stroller brakes are on.</li> <li data-bbox="547 1655 1453 1682">➤ Support the client's head, place something soft under the head if no headrest.</li> </ul> <p data-bbox="547 1704 852 1731"><b>Once seizure has stopped:</b></p> <ul style="list-style-type: none"> <li data-bbox="547 1753 1401 1812">➤ Lean the client slightly to one side, tilt the head forward and assess if the airway is clear.</li> <li data-bbox="547 1834 1437 1861">➤ To clear airway open mouth, tilt head to side and forward, allow liquid to drain out.</li> <li data-bbox="547 1883 1437 1942">➤ Once clear, tilt the client's chin (with mouth closed) upwards to move tongue off airway, creating an open airway and assist in client's breathing.</li> <li data-bbox="547 1964 1437 1991">➤ Stay with the client until they fully recover or an ambulance arrives if needed.</li> <li data-bbox="547 2013 1066 2040">➤ Calmly talk to the client and reassure them.</li> <li data-bbox="547 2063 1299 2089">➤ Keep bystanders away to protect the client's privacy and dignity.</li> </ul>

SITUATION	MANAGEMENT
<p><b>Seizures in water</b></p> 	<p><b>A seizure in water includes pool, bath or ocean:</b></p> <ul style="list-style-type: none"> <li>➤ Support the client's head so that their face and airway remain above the surface.</li> <li>➤ Tilt the client's head back to ensure a clear airway.</li> <li>➤ Remove the client from water as soon as the seizure has stopped.</li> <li>➤ Gain assistance from others, consider the use of a flotation device, when removing the client from water.</li> <li>➤ Roll the client onto their back as soon as possible, check airway.</li> <li>➤ If clients airway requires clearing turn onto side.</li> <li>➤ If clients airway is clear check breathing.</li> <li>➤ If client is breathing and breathing normally place them on their side recovery position.</li> <li>➤ If not breathing or not breathing normally commence resuscitation.</li> <li>➤ Call 000 and follow operator's instructions.</li> <li>➤ Even if the client fully recovers, they need urgent medical review, as inhaling water can cause heart and/or lung damage.</li> </ul>
<p><b>Seizures in bathroom</b></p> 	<p>A client with epilepsy should be supervised at all times when a client is having a shower or bathing.</p> <p>Supervision must start from the time the client begins a bath until all water in the bath is completely emptied.</p> <ul style="list-style-type: none"> <li>➤ Do not lock the bathroom door whilst client in in bathroom.</li> <li>➤ Ensure there is a nonslip mat or soft material on the floor.</li> <li>➤ It is safer for a client with epilepsy to have a shower rather than a bath.</li> <li>➤ Use a shower seat where possible.</li> <li>➤ Use protective or padded covers on bathroom handles and taps in case of seizure.</li> <li>➤ Shower facilitates should be separate cubicle versus dual bath shower combination.</li> <li>➤ If client is having a bath, use a plug on a chain, so that is bath needs emptying quickly it can be pulled no matter where the client is positioned.</li> </ul>

## EMERGENCY SEIZURE MEDICATION



### WARNING

Only support workers trained in the administration of emergency medication to stop seizures may administer seizure medication.

When there is no support worker trained to administer emergency seizure medication on site, the support worker present must call triple zero (000) immediately.



## SUMMARY

When looking after a client with a diagnosis of epilepsy, it is important support workers follow their organisation's policies and procedures and follow a client's epilepsy management plan (EMP) and emergency medication management plan (EEMP). The client should have regular reviews with their treating doctor and their EMP and EEMPs updated.

If a client does experience a seizure, a support worker needs to remain calm, stay with the client, reassure the client and manage appropriately for their seizure presentation. If the client is unconscious, the support worker should place them in the recovery position, once the seizure has stopped, and if emergency medication such as Midazolam was given, stay with the client to monitor their breathing, until otherwise fully recovered or as specified on their EEMP.

As a support worker supporting a client with epilepsy, know when an ambulance needs to be called, and ensure doctors reviews are organised when a change in the client's regular seizure status is identified.

Epilepsy is a chronic non-communicable disease of the brain that can affect all people. When managed with a combination of medication and lifestyle modifications a client can live experiencing very few to no seizures all.

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## APPENDIX 1

### GLOSSARY OF TERMS

<b>Aura</b>	Used to describe the warning an individual feels before they have a tonic-clonic seizure. Is in fact a focal aware seizure, as this type of seizure can turn into another type of seizure
<b>AEDs</b>	Anti-epileptic drugs
<b>Buccal</b>	Topical route of medication administration to the oral mucosa between the teeth and cheek
<b>Corpus Callostomy</b>	Surgery for refractory epilepsy. The corpus callosum is cut through to stop the spread of epileptic seizure activity between the two sides of the brain
<b>Convulsive</b>	Medical condition where body muscles contract and relax rapidly and repeatedly
<b>Déjà vu</b>	A feeling of having already experienced the present situation
<b>EMP</b>	Epilepsy management plan
<b>EMMP</b>	Emergency Medication Management Plan
<b>Ictal phase</b>	The middle phase of a seizure. The period from first symptom to end of seizure activity
<b>Intranasal</b>	Nasal administration of medication
<b>Ketogenic diet</b>	Very low carbohydrate, high fat diet resulting in a state called ketosis
<b>MAD Modified Atkins Diet</b>	Less restrictive variation of the ketogenic diet. Unlimited protein and fat
<b>MAD Mucosal Atomiser Device</b>	Soft, conical plug on the tip forms a seal with the nostril, preventing medication escape. The spray atomizes drugs into a fine mist of particles 30-100 microns in size
<b>Neurons</b>	Basic unit of the brain. A specialised cell within the nervous system designed to transmit information to other nerve cells, muscle or gland cells
<b>Postictal phase</b>	Phase immediately after a seizure has stopped. Can last for second, minutes or hours
<b>Prodrome</b>	Period during which an individual experiences some symptoms or signs of change in functioning, signalling and impending onset of disease state
<b>SUDEP</b>	Sudden, unexpected death of someone with epilepsy that was otherwise healthy
<b>VNS</b>	Vagus nerve stimulation

## APPENDIX 2: RESOURCES

### Epilepsy Australia

<http://www.epilepsyaustralia.net/>

### Epilepsy Action (Australia)

1300 EPILEPSY (1300 37 45 37)  
Australia-wide Priority Call

EMAIL: [epilepsy@epilepsy.org.au](mailto:epilepsy@epilepsy.org.au)  
[www.epilepsy.org.au/](http://www.epilepsy.org.au/)

### Epilepsy Foundation

[www.epilepsyfoundation.org.au](http://www.epilepsyfoundation.org.au)

### Royal Children's Hospital, Melbourne

<http://www.rch.org.au>

### Better Health Channel, Victoria

#### Home Page: Epilepsy

[www.betterhealthchannel.vic.gov.au/](http://www.betterhealthchannel.vic.gov.au/)

[www.epilepsyfoundation.org.au/understanding-epilepsy/epilepsy-and-seizure-management-tools/epilepsy-plans/](http://www.epilepsyfoundation.org.au/understanding-epilepsy/epilepsy-and-seizure-management-tools/epilepsy-plans/)

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Premium Health has a range of health care, first aid and mental health training programs conducted by our nurses, paramedics or mental health practitioners.



Call us to discuss our onsite face-to-face and live virtual classroom options, delivered anywhere in Australia.

#### HEALTH CARE

- Assisting clients with medication
- Assisting clients with medication (part 2)
- Advanced medication - eye and ear drops, topical creams, oral liquids and patches
- Autism spectrum disorder
- Blood pressure – using a digital blood pressure machine
- Bowel management – elimination
- Coronavirus and infection control
- Dementia training for support workers
- Diabetes training for support workers
- Dysphagia for support workers
- End of life care
- Epilepsy training for support workers
- Epilepsy training and midazolam administration via intranasal and buccal routes
- Food safety awareness for support workers
- Infection control
- Managing behaviours with positive support
- Manual handling
- Nebuliser training for asthma
- Ostomy and stoma care for support workers
- Positive behaviour support
- Pressure injury – prevention and care for support workers
- Providing personal care with dignity and respect
- Shallow suctioning
- Tube feeding management
- Urinary catheter care
- Wound care awareness for support workers

#### FIRST AID TRAINING

- Cardiopulmonary resuscitation (CPR)
- Provide first aid
- Asthma and anaphylaxis
- Advanced first aid

#### MENTAL HEALTH

- Mental health first aid
- Leadership and resilience training
- Mental health awareness

And many others...

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