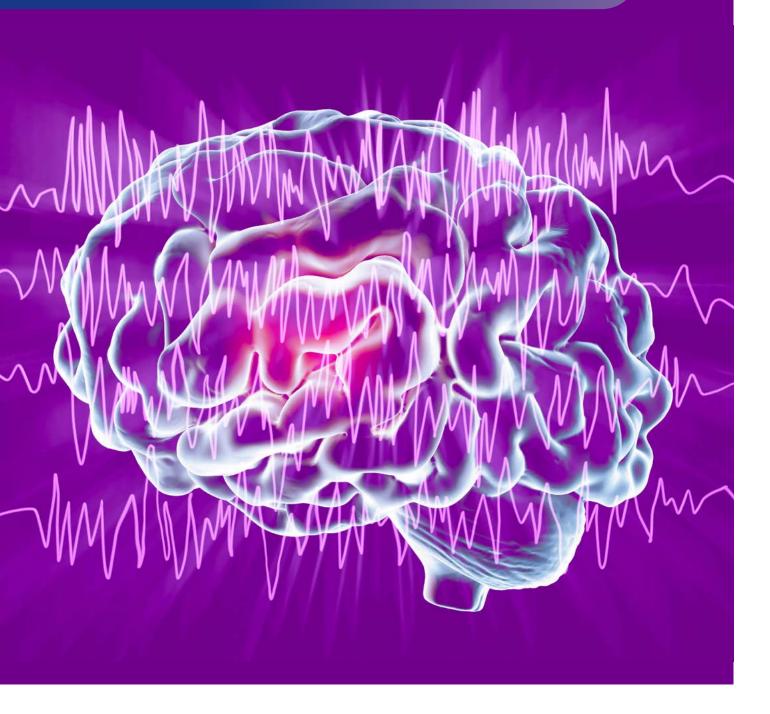


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Epilepsy Training and Midazolam Administration for Support Workers



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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.

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Phillipa Wilson Founder & Managing Director of Premium Health

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Welcome to your course and Premium Health.

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 AND MIDAZOLAM ADMINISTRATION 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.

This resource also introduces the safe principles and techniques of Midazolam administration in accordance with a client's epilepsy management plan and emergency medication plan.

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.

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EPILEPSY

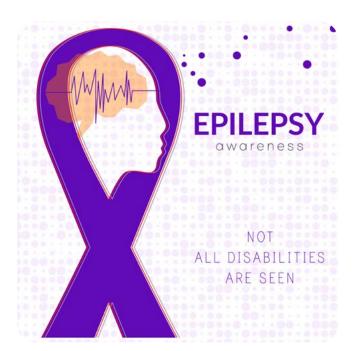
Epilepsy is a common condition that can develop at any age, regardless of gender or ethnic group. 12,000 people in Australia are diagnosed with epilepsy annually. Epilepsy is often diagnosed in infancy, childhood, adolescence and those over the age of 65yrs old. Up to 5% of the world's population may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

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.

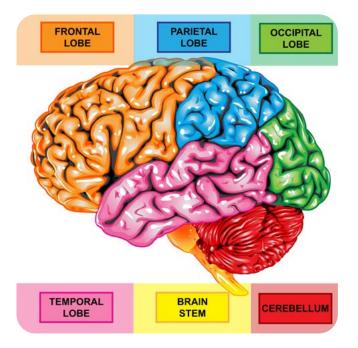
Cognitive impairment such as autism spectrum disorder, down syndrome and cerebral palsy are commonly occurring disabilities with epilepsy.

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.

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

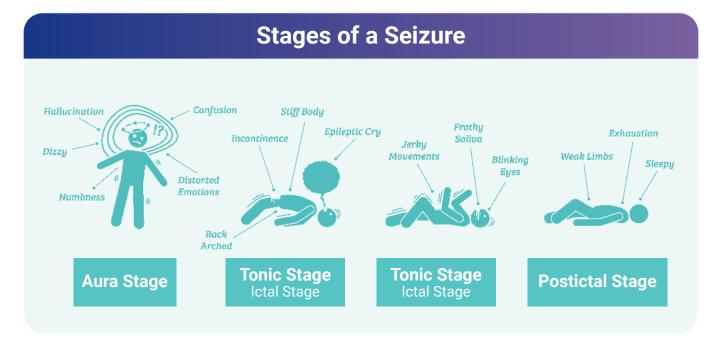
Seizures take many different forms. It can range from:

- 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.



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:

POSTICAL 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

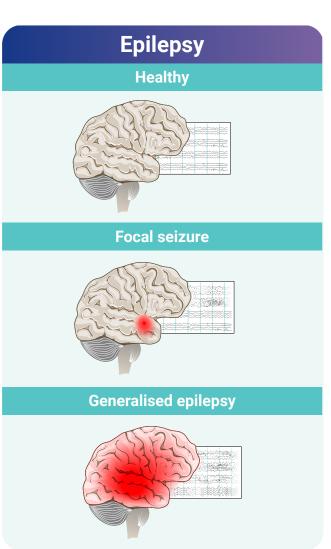
CATEGORIES OF SEIZURES

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.



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		
Focal aware	 individual fully aware may not be able to respond usually brief 	 can be further classified as motor or non- motor
Focal impaired awareness	 awareness impacted either for whole or some of the seizure often mistaken for drug or alcohol intoxication 	 may appear confused, dazed or disoriented may make chewing movements fiddle with clothing scream
Focal motor seizure	 some type of movement happens due to seizure 	 jerking twitching stiffening movements of body automatisms: licking lips, walking, rubbing hands, running
Focal non- motor seizure	 other symptoms occur first 	 sensation, emotions, thinking nausea butterflies in stomach déjà vu

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		
Generalised motor seizure	• tonic-clonic	 stiffening (tonic) and rhythmic jerking (clonic) involved tonic seizures alone are usually brief lasting about 20 seconds
	• clonic	 uncommon, cause jerking in various parts of the body
	• myoclonic	 sudden single jerks of muscle groups or muscle for 1-2 seconds
	• atonic	 brief loss of muscle tone, person falls to ground or sudden head nod
Generalised non-motor seizure	• absence	 brief change in awareness

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

Convulsive status epilepticus	 single tonic- clonic seizure lasting up to 5 minutes or more person goes into a second seizure without recovering from the prior seizure repeated seizures for 30 minutes or more 	 emergency treatment such as medication or oxygen may be required call ambulance
Non- convulsive status epilepticus	 continuous absence seizures continuous focal non-awareness seizures 	 if non-convulsive seizure lasts longer than 10 minutes call an ambulance

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 wellmanaged 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



14 SEIZURES

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 or 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

nausea

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

• Epilim, Valpro (sodium

Lamictal (lamotrigine)

Neurontin (gabapentin)

Rivotril (clonazepam)

(carbamazepine)

Trileptal (oxcarbazepine

Gabitril (tiagabine)

Commonly prescribed epilepsy medications include:

valproate)

Tegretol

- Dilantin (phenytoin)
- Frisium (clobazam)
- Keppra (levetiracetam)
- Mysoline (primidone)
- Phenobarbitone (phenobarbitone)
- Sabril (vigabatrin)
- Topamax (topiramate)
- · Zarontin (ethosuximide)

F

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 antiepileptic 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) and 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

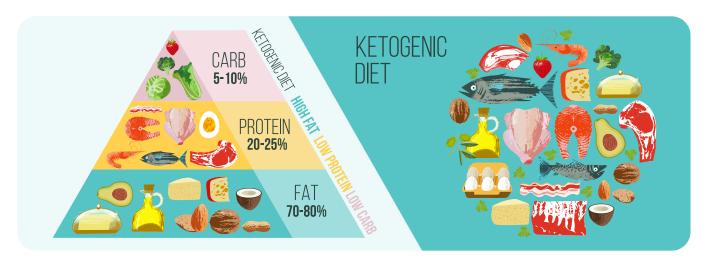
A small percentage of people may be eligible for surgery. It is only considered for those with focal seizures. Surgery may involve removing a certain part of the person's brain that causes the seizures or cutting the nerve pathways which transmit the seizure activity. The kind of seizures a person has 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

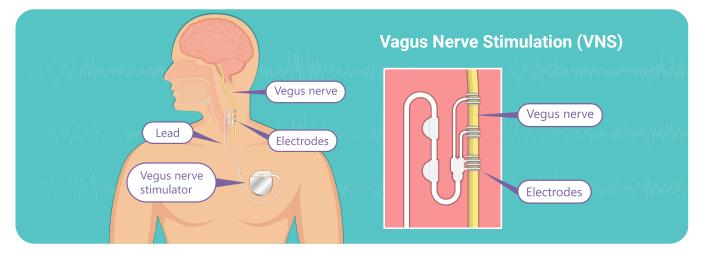


DIET

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 is 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:

 medications used to manage epilepsy 	 client's seizure types including: what they look like, how long they typically last for, how often they typically occur (per month)
 if there is emergency seizure medication prescribed 	 client's known seizure triggers
 emergency procedures to be following in the event of a seizure including when to call 000 	 how the client would like to be supported during a seizure
 emergency contact details 	 seizure first aid and post seizure monitoring
 supervision requirements for bathing and swimming 	

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:

 an order for the	 the equipment required
emergency medication	to administer the
signed by a doctor	medication
 the circumstances that	 emergency procedures
medication is to be	to be followed including
given	when to call 000
 the route of	 the positive effects and
administration e.g.	possible side effects of
buccal or intranasal	the medication
 how many doses in a 24hr period can be given 	 post monitoring and recording requirements including who is notified of the event

For guidelines on EMMPs please visit the Epilepsy Foundation website:

https://epilepsyfoundation.org.au/understandingepilepsy/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 clients 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.



SEIZURES

SEIZURE TYPE	ΤΟ DO	WHEN TO CALL 000
Tonic-Clonic seizures	 Remain calm. Time the seizure. If there is something present in their mouth e.g. food, water, roll them onto their side in the recovery position. Protect them from injury, move objects away from them. Place something soft under their head. Loosen any tight clothing. 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. 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. Stay with the person, until they have fully recovered and/or until a paramedic arrives if ambulance has been called. Reassure the client. Keep by standers away, maintain the dignity and privacy of the client. 	 The seizure lasts 5 minutes or more or a second seizure begins before the client full recovers. If the client remains non-responsive or 5 minutes or more after the seizure has stopped. The client has sustained an injury. The client has swallowed water. The client is pregnant. It's the client's first seizure. The support worker is uncomfortable managing the situation. The client asks for medical assistance. It is otherwise stated on the client's EMP.
DO NOT:	 > Do not restrain the person, do not move them (unless they are in danger). > Do not put anything in the client's mouth. > Do not give the client water, food, or solid medications (unless they are fully alert). 	
Stimulant agents	 > Gently guide the client past obstacles, away from danger. > Remove any harmful objects nearby e.g. hot liquids etc. > Calmly talk to the client, explain they are safe and ask if they are ok. > Reassure the client and stay with them until they recover or until an ambulance arrives if needed. 	 > If the seizure lasts for 5 minutes or more, the client may be having non-convulsive status epilepticus. > The client has sustained an injury. > The client has swallowed water. > The client is pregnant. > It's the client's first seizure. > The support worker is uncomfortable managing the situation. > The client asks for medical assistance. > It is otherwise stated on the client's EMP.

SEIZURE TYPE	ΤΟ DO	WHEN TO CALL 000
Focal aware seizures	 Gently assist the client to cease any activity they are participating in. Assist the client to sit down. Reassure the client that they are safe. Stay with the client until they recover or until the ambulance arrives if needed. 	 > If further medical assistance was needed for another reason. > 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. > It is otherwise stated on the client's EMP.
Tonic and Atonic seizures	 Assess the client for injuries. Calmy talk to the client and ask if they are ok. Reassure the client that they are safe. Stay with the client until they recover or until the ambulance arrives if needed. 	 > The client has sustained an injury. > The client has swallowed water. > The client is pregnant. > It's the client's first seizure. > The support worker is uncomfortable managing the situation. > The client asks for medical assistance. > It is otherwise stated on the client's EMP.
Absence seizures	 > Remove any objects that could pose a danger to the client e.g. hot liquids etc. > Calmy talk to the client and ask if they are ok. > Reassure the client. > Assist the client to resume the activity they were involved in before the seizure commenced if they have recovered. > Stay with the client until they have recovered or until an ambulance arrives if needed. 	 > If the seizure lasts for 5 minutes or more, the client may be having non-convulsive status epilepticus. > The client has sustained an injury. > The client has swallowed water. > The client is pregnant. > It's the client's first seizure. > The support worker is uncomfortable managing the situation. > It is otherwise stated on the client's EMP.

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

Unconscious client



MANAGEMENT

Follow DRSABCD first aid action plan:

- Check for dangers to yourself, bystanders and client.
- Make the area safe by removing the danger from the client or the client from the danger. Only continue when safe to do so.
- > Check client's response with simple verbal commands e.g "open your eyes, squeeze my hand".
- > If the client only displays minor response such as groaning but no eye opening, treat as unconscious.
- > Call for an ambulance 000 if needed (client's EMP should state when an ambulance needs to be called).
- > Position the client on their back, open their mouth and check for foreign material or obstructions.
- > If airway needs clearing, roll client into recovery position, open mouth and drain matter downwards, roll back onto client's back.
- > Lift chin upwards using a pistol grip to open airway.
- > Assess for normal breathing: adult approximately 15 breaths per minute.
- Look for the even movement of the rising and falling of the lower chest for 10 seconds.
- Listen for the sound of regular breathing.
- > Feel air escaping from the mouth/nose with your hand or cheek.
- > A client who is breathing normally is then to be turned onto their side in the recovery position.
- > If the client is not breathing or not breathing normally begin resuscitation.
- > 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.

If the client is in wheelchair, stroller, seat or car seat, bus seat:

- > Leave the client seated.
- > Protect the client from falling if there is no seat belt.
- > Ensure wheelchair or stroller brakes are on.
- > Support the client's head, place something soft under the head if no headrest.

Once seizure has stopped:

- > Lean the client slightly to one side, tilt the head forward and assess if the airway is clear.
- > To clear airway open mouth, tilt head to side and forward, allow liquid to drain out.
- > 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.
- > Stay with the client until they fully recover or an ambulance arrives if needed.
- > Calmly talk to the client and reassure them.
- > Keep bystanders away to protect the client's privacy and dignity.

Seizures from a seated position



SITUATION

Seizures in water



MANAGEMENT

A seizure in water includes pool, bath or ocean:

- Support the client's head so that their face and airway remain above the surface.
- > Tilt the client's head back to ensure a clear airway.
- > Remove the client from water as soon as the seizure has stopped.
- Gain assistance from others, consider the use of a flotation device, when removing the client from water.
- > Roll the client onto their back as soon as possible, check airway.
- > If clients airway requires clearing turn onto side.
- > If clients airway is clear check breathing.
- If client is breathing and breathing normally place them on their side recovery position.
- > If not breathing or not breathing normally commence resuscitation.
- > Call 000 and follow operator's instructions.
- Even if the client fully recovers, they need urgent medical review, as inhaling water can cause heart and/or lung damage.

A client with epilepsy should be supervised at all times when a client is having a shower or bathing.

Supervision must start from the time the client begins a bath until all water in the bath is completely emptied.

- > Do not lock the bathroom door whilst client in in bathroom.
- > Ensure there is a nonslip mat or soft material on the floor.
- > It is safer for a client with epilepsy to have a shower rather than a bath.
- > Use a shower seat where possible.
- > Use protective or padded covers on bathroom handles and taps in case of seizure.
- Shower facilitates should be separate cubicle versus dual bath shower combination.
- 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.

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.



MIDAZOLAM



Midazolam belongs to a group of drugs called benzodiazepines. It is mainly used as a sedative or hypnotic for medical and surgical procedures. It is a short acting sedative which is also used in the emergency treatment of seizures. In epilepsy, it is prescribed for people who have severe, cluster or prolonged seizures as it can quickly stop the seizure. Midazolam is a clear, colourless liquid.

Midazolam is given by the intranasal (into the nose) or buccal (cheek) method, and is directly absorbed through the lining nose and cheek into the blood stream. Once absorbed into the bloodstream, Midazolam travels to the brain and attaches to receptors which control the electrical impulses which are causing the seizure. Midazolam also works by relaxing the muscles and usually takes effect quickly.

Although the plastic ampoules are labelled 'For slow IV or IM injection', it can be given by trained support workers by the buccal or intranasal method.

Midazolam is also available in glass ampoules in the hospital setting, and is not recommended to use to give via the intranasal or buccal route. Midazolam can be given by trained professionals as per doctors orders e.g. registered nurses via injection, but in most community settings it is given by support workers via the nose (intranasal), or to the space between the cheek and teeth (buccal). Swallowing Midazolam is not recommended as it is not absorbed well into the stomach.

Midazolam can be given either by drops squeezed directly from the plastic Midazolam ampoule (ampoule method) or from drops from a syringe where Midazolam is drawn up from the ampoule (syringe method).

Side effects of midazolam

Some possible side effects and adverse reactions that may be experienced by a client who is given midazolam include:

• drowsiness or tiredness	coughing or hiccups
• headache	 irritation and stinging in the nostrils (if given intranasally)
• weakness	 altered mood e.g. giggly, hyperactive, aggressive (rare cases hostile)
• nausea or vomiting	 altered balance, unsteady on feet
 slow breathing 	 confusion or disorientation

PREPARING MIDAZOLAM

As when administering any medications follow the directions of the prescribing doctor, know and follow your organisation's policies and procedures.

- > Wash your hands (or use alcohol-based hand rub).
- > Wear gloves where appropriate.
- Check the 6 rights of safe medication practice.



ACTION	STEPS
	 Mucosal Atomiser Device (MAD) Free one ampoule by gently tearing away from the pack by twisting the ampoule away from the pack.
	Flip down to clear solution from the neck of ampoule. Avoid touching the neck area.
	Twist the top off the ampoule and pull away to remove lid, without squeezing the solution.
	 Place syringe without needle on end of ampoule. Invert (syringe on bottom and ampoule on top of syringe). Draw midazolam into syringe, by pulling on plunger of syringe.
	Once all midazolam liquid is drawn into syringe, remove ampoule off tip of syringe.

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INTRANASAL ADMINISTRATION

ACTION	STEPS
	 Place the Mucosal Atomiser Device (MAD), onto the end of the syringe. This will turn the midazolam into a fine spray.
	 > Place the client on their back. > Tilt their head backward. > Place the MAD into a nostril, plugging the nostril with the MAD. > Push the plunger in rapid bursts into the nasal (so as to be spraying a fine mist). > Place two short bursts in each nostril, until required amount of midazolam is given, swapping nostrils after the bursts – this helps the midazolam be absorbed by the mucous membrane and not roll down the nasal cavity and the back of the client's throat.
	 Syringe Method Place client onto their side (recovery position). Open their mouth. Insert the syringe between the inside of the lower cheek and teeth. Gently squeeze the plunger of the syringe until the required amount of midazolam has been given. Do not give too fast or midazolam will trickle down the throat of the client (not being absorbed by the mucous membranes). You may need the assistance of another support worker to help position the client.
	 Ampoule Method Place client on their side (recovery position). Open their mouth. Insert the top of the ampoule, aiming for the inside of their lower cheek. Gently squeeze the ampoule every 1-2 seconds until the prescribed amount of midazolam is given. Do not squeeze too fast on the ampoule or midazolam will trickle down the throat of the client (not being absorbed by the mucous membranes). You may need the assistance of another support worker to help position the client.



IMPORTANT INFORMATION

- > Ensure there are adequate supplies of Midazolam.
- > Check the expiry date of Midazolam regularly.
- > Return expired ampoules to
- > Once it is expired it may not be effective or safe to use.
- > A seizure management plan and emergency medication procedure need to be prepared and followed.
- > Midazolam has been associated with severe respiratory depression.
- > Therefore, staff should observe breathing carefully and check for evidence of cyanosis (i.e. blueness around lips and fingertips).
- > Under no circumstances can staff administer Midazolam using an intravenous injection.

RECORDING



Support workers must:

- document the time and duration of the client's seizure
- · document all seizure medication on the client's medication administration chart
- complete all records including the name, dose, date, time, site of administration and support worker's name that administered

MONITORING AND RECOVERY

Following the administration of medication, support workers must observe the client to determine:

- · effectiveness of the medication
- · if the seizure is recurring
- · side effects of the medication
- monitor the clients breathing

Sometimes, a client's breathing may become shallower and slower (respiratory depression). If this happens a support worker must call triple zero (000) for emergency medical assistance.

As recovery from seizures varies greatly between individuals, the length of time a client is monitored and how they should be supported after a seizure and medication administration, should be identified on their care plan.



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.

APPENDIX 1 GLOSSARY OF TERMS

Aura	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
AEDs	Anti-epileptic drugs
Buccal	Topical route of medication administration to the oral mucosa between the teeth and cheek
Corpus Callostomy	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
Convulsive	Medical condition where body muscles contract and relax rapidly and repeatedly
Déjà vu	A feeing of having already experienced the present situation
EMP	Epilepsy management plan
ЕММР	Emergency Medication Management Plan
Ictal phase	The middle phase of a seizure. The period from first symptom to end of seizure activity
Intranasal	Nasal administration of medication
Ketogenic diet	Very low carbohydrate, high fat diet resulting in a state called ketosis
MAD Modified Atkins Diet	Less restrictive variation of the ketogenic diet. Unlimited protein and fat
MAD Mucosal Atomiser Device	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
Neurons	Basic unit of the brain. A specialised cell within the nervous system designed to transmit information to other nerve cells, muscle or gland cells
Postictal phase	Phase immediately after a seizure has stopped. Can last for second, minutes or hours
Prodrome	Period during which an individual experiences some symptoms or sings of change in functioning, signalling and impending onset of disease state
SUDEP	Sudden, unexpected death of someone with epilepsy that was otherwise healthy
VNS	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 www.epilepsy.org.au/

Epilepsy Foundation

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/

www.epilepsyfoundation.org.au/understandingepilepsy/epilepsy-and-seizure-management-tools/ epilepsy-plans/_

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- · Diabetes training for support workers
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And many others...

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