Diagnosing epilepsy

Answering your questions

Epilepsy Smart Australia

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What is a seizure?

A seizure is a burst of uncontrolled electrical and chemical activity in the brain that can affect a person's movement, behaviour, sensation, and level of awareness. People with epilepsy can have a wide range of seizure types. Every person's seizure experience is different, and not all seizures are alike. However, the patterns of seizures tend to be consistent with an individual. Not everyone who has seizures has epilepsy.

How are seizures diagnosed?

Proper diagnosis is essential to help guide effective treatment. The doctor will take a thorough medical history, including eyewitness accounts about the seizures and suggest further medical tests. They may refer you to a neurologist or epileptologist who specialises in diagnosing and treating people with epilepsy.

A specialist diagnoses epilepsy based on several medical factors, including test results and whether a person has experienced two or more unprovoked seizures or is at risk for further seizures. An unprovoked seizure is a seizure that occurs without any apparent cause.

What medical tests might be suggested after a seizure?

- Electroencephalogram (EEG)
- Magnetic resonance imaging (MRI)
- Neurological assessment
- Blood test

What are the different types of seizures?

There are two main groups of seizures – focal and generalised. The difference between focal and generalised seizures is how they begin.

Focal seizures

Focal seizures (previously called partial seizures) start in one part of the brain and affect the body function controlled by that part of the brain. Focal seizures may be associated with reduced awareness. Such seizures are called 'focal impaired awareness seizures' (previously called complex partial seizures). Sometimes, however, people are aware that they are having a focal seizure. If they are fully aware during a seizure, the seizure is called a 'focal aware seizure' (previously called simple partial seizure). When a person is aware at the beginning of a focal impaired awareness seizure, they may experience auras or 'warning signs'. Common focal seizure auras include:

- An unpleasant taste or smell
- A sense of déjà vu
- A feeling of butterflies in the stomach or nausea

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Auras are often very brief but can happen in clusters. Some people may be aware that they are experiencing involuntary arm or leg jerking or odd behaviours such as fiddling with clothing. A focal seizure can spread to the other side of the brain and cause a bilateral convulsive seizure. This is called a 'focal to bilateral tonic-clonic seizure'.

Focal seizures often weaken or change a person's level of awareness and responsiveness. When this happens, these are called focal impaired awareness seizures, and the person may appear confused and dazed. They may also display strange and repetitive actions (automatisms), such as fiddling with their clothes, making chewing movements with their mouths or uttering unusual sounds. Focal impaired awareness seizures usually last for one to two minutes. The person may be confused or drowsy afterwards. They may have no memory of the seizure or the events just before or after it. This type of seizure can be mistaken for drug or alcohol-affected behaviour or psychiatric disturbance.

Generalised seizures

Generalised seizures involve the whole brain at the onset. There are many types of generalised seizures. Some are convulsive and others non-convulsive. Convulsive seizures involve stiffening and jerking arms and legs. Non-convulsive seizures are harder to notice and may involve staring or unusual activity.

Absence seizures (previously called petit mal seizures)

Absence seizures are short, non-convulsive seizures. They usually occur in children and younger people, with girls affected more frequently than boys. During absence seizures, the person's awareness and responsiveness change. The person may stare, their eyes roll back, or their eyelids flutter. It can be difficult to distinguish between absence seizures and daydreaming; however, absence seizures start suddenly and cannot be interrupted. They also last a few seconds and then suddenly stop. Once they stop, the person often goes back to doing whatever they were doing. Although these seizures usually last less than 20 seconds, they can occur many times daily and can be very disruptive to learning.

Myoclonic seizures

Myoclonic seizures are brief, shock-like jerks involving a muscle or a group of muscles. They usually involve the upper body, causing a person to drop things from their hands. Sometimes, they involve the whole body, which can result in a fall. These seizures only last a couple of seconds and can happen in isolation or a cluster. They often happen in the morning but can also happen at other times of the day. They should be distinguished from twitches during sleep, particularly when someone is falling asleep, which is usually a normal phenomenon.

Atonic seizures

Atonic seizures cause a sudden loss of muscle strength, and the person often falls to the ground—these seizures usually last less than 15 seconds. Often called 'drop attacks', these seizures can cause head or facial injury. Wearing a helmet may minimise the risk of injury.

Tonic seizures

Tonic seizures increase normal muscle tone, causing the body, arms and legs to become stiff and rigid. These seizures often occur in clusters during sleep but can also occur when the person is awake. If the person is standing when a tonic seizure starts, they will fall quite heavily. Wearing a helmet may minimise the risk of injury—these seizures usually last less than 20 seconds.

Tonic-clonic seizures (previously called grand mal seizures)

During a tonic-clonic seizure, a person's body stiffens. Air is forced past the vocal cords, causing a cry or groan. If standing, the person falls to the ground (tonic phase). The person's limbs begin to jerk in strong, symmetrical, rhythmic movements (the clonic phase). The person may dribble from the mouth, go blue in the face, or lose control of their bladder or bowel as the body relaxes. As consciousness returns, the person may be confused, drowsy, agitated or depressed. They may have a headache and want to sleep. This drowsiness can last for several hours. Although this type of seizure can be frightening to watch, the seizure itself is unlikely to harm unless it lasts for a long time. The person experiencing the seizure might, however, vomit or bite their tongue. Sometimes, they can injure themselves if they hit nearby objects. Tonic-clonic seizures generally last from one to three minutes. If the active movements of the seizure last for 5 minutes, call an ambulance. Lengthy seizures, or a series of seizures without a normal break in between, suggest a dangerous condition called convulsive status epilepticus, which requires emergency treatment.

Why do seizures occur?

A seizure is a sign that there has been a disruption to the normal functioning of the brain. Seizures can be either provoked or unprovoked. A provoked seizure is caused by a known event such as a stroke, brain infection or low blood glucose. Events such as illness, flashing lights, stress, or sleep deprivation can trigger seizures in people who have epilepsy. Unprovoked seizures happen without a known cause. For almost 60% of people diagnosed with epilepsy, the cause of their seizures is not immediately known and further investigations are needed to determine the underlying cause. Modern investigations and technologies such as improved medical imaging and genetic testing are revealing causes in more and more patients.

Is there a treatment for seizures?

Deciding on the correct treatment for your epilepsy is important and requires specialist expertise. It is common for people with epilepsy to have other health conditions which require medications. Your specialist will consider these factors in developing your epilepsy treatment plan.

Anti-seizure medication

Anti-seizure medications (ASMs) are the most common treatment for people with epilepsy. Around 70% of people with epilepsy can have good seizure control if they take their medication correctly.

Emergency medication

If you have many seizures or seizures which last a long time, your specialist may also prescribe emergency medication. You will also receive a medically endorsed Emergency Medication Management Plan (EMMP) from your specialist.

Diet

Your specialist may suggest dietary therapy when anti-seizure medications alone do not work. There are several dietary therapies used for epilepsy management. These diets are all high in fat and low in carbohydrates. You will need a referral to a specialist dietary therapy clinic, which has doctors and dietitians who have expertise in providing dietary treatment for epilepsy. This will ensure the diet is safe and effective. The primary dietary therapies used in epilepsy management include:

Ketogenic diet

The ketogenic diet is a high fat, low protein and low carbohydrate, medically supervised diet. It is used as a treatment for epilepsy when a young child or infant is not responding well to ASM.

With the ketogenic diet, you consume up to 90% of your total energy from fats. It has a good amount of protein but is very low in carbohydrates. A dietitian must determine how many kilojoules are needed in your (or your child's) diet. Once this is determined, a meal plan is created. All meals in the diet must be weighed and measured. All food and fluids are provided in a specific ratio of fats to protein and carbohydrates combined, e.g. 4:1 or 3:1.

Modified ketogenic diet

The modified ketogenic diet is often recommended for adults but can be considered for older children or teenagers (in consultation with your dietitian and epilepsy specialist).

On the modified ketogenic diet, you will consume up to 75% of your total energy from fats. It has a good amount of protein but is low in carbohydrates. A dietitian must determine your or your child's total energy (kilojoules or calories) needs. They will then create a meal plan with you and teach you how to calculate the correct portion sizes of fats, protein, and carbohydrates at each meal.

Low glycaemic index treatment

The low glycaemic index treatment (LGIT) is a low carbohydrate diet that allows small amounts of specific types of carbohydrates that are known to only have a minor effect on blood sugar levels. This diet is also high in fat and includes a good amount of protein.

Children or adults who have successfully reduced their seizures for a number of years by following either the classic ketogenic or modified ketogenic diets may be able to move on to the less restrictive LGIT.

Medium-chain triglycerides supplements

Medium-chain triglycerides (MCTs) specifically refer to fats with a chain length of between 6-12 carbons. The MCTs are absorbed

quickly and converted to ketones more readily than long-chain fats. The MCTs come as supplements in the form of oils, emulsifiers or powders. They are usually used as part of another dietary treatment, such as with the classic ketogenic diet, modified ketogenic diet or LGIT.

Surgery

Epilepsy is sometimes caused by an area of abnormal brain tissue. The size and position of the area, referred to as the epilepsy focus, varies between individuals. If surgery can remove the epilepsy focus, seizures can often be prevented. The chance of successful surgery and the risks of complications differ for each patient, and your doctor will discuss with you whether this is an appropriate treatment.

Can all doctors treat seizures?

People who may have had a seizure will usually be advised to attend a follow-up appointment. This might be a review with the original treating doctor or a referral to another doctor.

Often, the diagnosis is made by a neurologist or paediatrician who may then send the person back to their GP to continue treatment. If seizures are not well controlled, it may be necessary to return to the specialist for regular visits to develop a treatment plan. Neurologists who specialise in the diagnosis and treatment of epilepsy are called epileptologists.

If you have any doubts about whether you are getting the help you need, you may find it helpful to speak to a staff member from the National Epilepsy Support Service. They can often help you clarify what is happening and understand what your doctor has told you.

Is it common to feel tired and anxious after a seizure?

Some people only remember certain parts of their seizure. After a seizure, the person may feel tired and sleepy, confused, angry, sad or worried. Confusion following a seizure can last several hours, days or sometimes even weeks.

People who have seizures that cause them to lose consciousness can risk injuring themselves and others. This is especially the case if the person is driving or engaging in activities around water, fire, heights, or machinery. There are strict rules about the length of time you need to be seizure-free before you are allowed to drive. Contact the driver licensing authority in your state/territory for information and advice about driver eligibility and fitness to drive. Also, be sure to have a responsible person with you if you are swimming or participating in activities involving machinery, heights, water, or fire.

Are seizures dangerous?

Epilepsy differs from person to person. Taking the time to understand your epilepsy will help you (and your doctor) better manage your condition. Here is what to do:

- Ask your doctor to explain your diagnosis and write down the important information. If you are unsure about something, ask questions. It is in your best interest to fully understand your condition.
- Keep a seizure diary – keeping a record of the types of seizures you experience and how long they last is a good idea. You can use a notebook, access our Seizure Record Form, or use an app like Seizure Tracker. You may need to ask someone to write this down for you or take a video of your seizures, which you can show to your doctor during consultations.

Who can provide information about seizures?

The National Epilepsy Support Service provides support and information for people living with epilepsy across Australia.

It operates Monday to Friday, 9.00am to 5.00pm (AEST). **Phone**: 1300 761 487. **Email**: support@epilepsysmart.org.au. The National Epilepsy Support Service is not a medical emergency line.

How can the National Epilepsy Support Service help?

Support Service staff can help with information and resources to support the health and wellbeing of people living with epilepsy. Resources include epilepsy information sheets, Epilepsy Management Plans, Emergency Medication Management Plans, and education and training.

Our staff can also help you access comprehensive support services, including support workers or epilepsy educators who can help the person with epilepsy meet their individual goals. Our staff can also help you to develop an Epilepsy Management Plan and an Emergency Medication Management Plan and train carers in administering emergency medication.

What can I talk to Support Service staff about?

The National Epilepsy Support Service is staffed by people who know how epilepsy affects health, wellbeing and daily life. They can provide information on a range of topics, including:

- epilepsy and seizure management
- seizure first aid
- maintaining health
- risk minimisation strategies
- medication management
- disclosure
- childhood and epilepsy
- pregnancy
- diet and epilepsy
- epilepsy and education
- work
- epilepsy in the later years
- disability and epilepsy.

Seizure classification and terminology

Old terminology	New Terminology
Absence	Generalised absence
Atonic	Focal/generalised atonic
Aura	Focal aware
Clonic	Focal/generalised clonic
Convulsion	Focal/generalised motor tonic-clonic, tonic, clonic, focal to bilateral tonic-clonic
Drop attack	Focal/generalised atonic, focal/generalised tonic
Grand mal	Generalised tonic-clonic, focal to bilateral tonic-clonic, unknown onset tonic-clonic
Infantile spasms	Focal/generalised/unknown onset epileptic spasms
Major motor	Generalised tonic-clonic, focal-onset bilateral tonic-clonic
Minor motor	Focal motor, generalised myoclonic
Myoclonic	Focal/generalised myoclonic
Petit mal	Absence
Psychomotor	Focal impaired awareness
Secondarily generalised tonic-clonic	Focal to bilateral tonic-clonic
Simple partial	Focal aware
Temporal lobe	Focal aware/impaired awareness
Tonic	Focal/generalised tonic
Tonic-clonic	Generalised/unknown onset tonic-clonic, focal to bilateral tonic-clonic

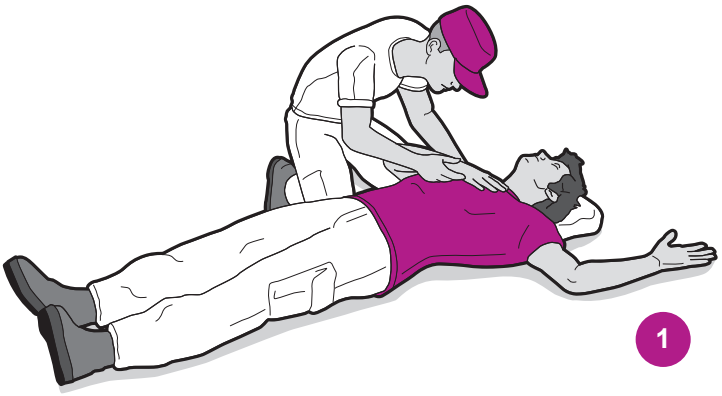
**Adapted from the Instructional Manual from the ILAE 2017 Operational Classification of Seizure Types.*

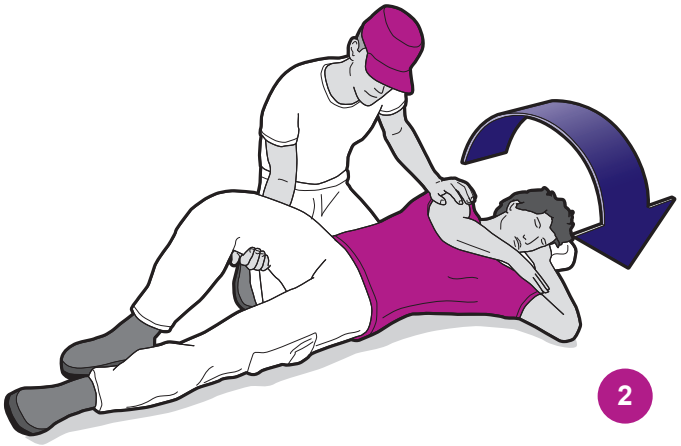
Seizure first aid

Tonic-clonic (convulsive) seizures

A tonic-clonic seizure involves loss of consciousness, muscle stiffening, falling, and jerking movements.

- Record the time and duration of the seizure.
- Remove any objects that could cause injury.
- Do not try to stop the jerking or put anything in their mouth.
- Protect their head with a pillow or jacket.
- As soon as possible, roll the person onto their side. You may need to wait until the seizure movements have ceased.
- If there is food, fluid or vomit in the mouth, roll the person onto their side immediately.
- Talk to the person, assessing their return to full consciousness.
- Stay with and reassure the person until they have recovered.

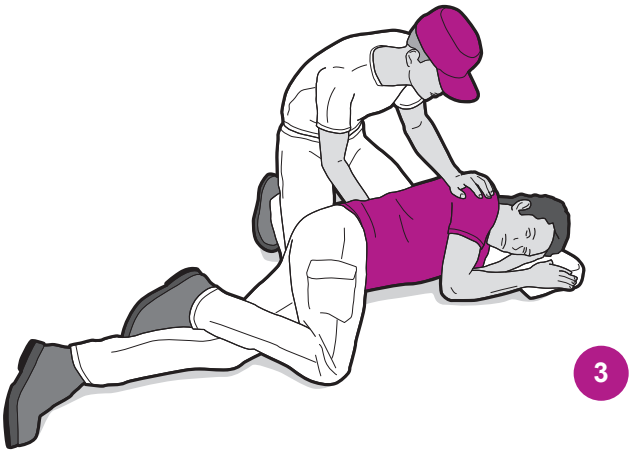




Seizure with impaired awareness

This is a non-convulsive seizure.
The person may show signs of confusion, unresponsiveness or unusual movements or behaviour.

- Record the time and duration of the seizure.
- Avoid restraining the person and guide safely around objects.
- Talk to and reassure the person while monitoring their response.
- Stay with the person until they have recovered.



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First aid for seizures occurring in water

Many people with epilepsy find that by putting in place the right safety measures, they can enjoy the positive health benefits of swimming. Swimming safely not only reduces your risk of harm, but it can also increase your confidence.

What to do before you swim

1. Understand where you will be swimming. Understanding the swimming conditions will allow you to appreciate and avoid any special risks. Be sure to understand the details around where you will be swimming ahead of time. Will you be indoors or outdoors? In a pool or open water?

2. Talk to your doctor. Before you agree to participate in a water-based activity, talk to your doctor about reducing risk.

3. Find someone to supervise. Swimming without supervision is risky, especially if you have epilepsy. Before you enjoy your swim or water activity, make sure that someone with appropriate water safety and lifesaving skills is available to supervise.

4. Take your medication. Make sure that you have taken your ASMs before you swim. If you have not been taking them regularly, or have recently missed a dose, do not swim.

Water safety tips

If you or someone in your care has epilepsy, it is a good idea to follow these water safety tips:

- Never swim or participate in water activities alone.
- Tell the lifeguard on duty about your epilepsy and any relevant health conditions before entering the water.
- Never swim if you have not taken your ASMs or are intoxicated or sleep-deprived.
- Always swim and participate in water sports that are within your limits.
- Ensure you have someone actively supervising your swimming who keeps an eye on your wellbeing at all times. This person should:
  - Understand your epilepsy and any other relevant health conditions, and have a copy of your Epilepsy Management Plan.
  - Be a strong swimmer and know how to intervene if necessary.
  - Know how to respond in the event of a seizure and can call 000 if needed.
- If you have experienced uncontrolled seizures in the past:
  - Always have a minimum of 1:1 active supervision in and around the water.
  - Ensure the active supervisor is in the water and stays within arm's reach. In some instances, additional supervision may be needed.
  - Consider the use of a flotation device or life jacket.

What to do if a generalised tonic-clonic seizure occurs in the water

The person supervising your swimming or water activity needs to know what to do if a generalised tonic-clonic seizure happens in the water. The current recommendations for this are:

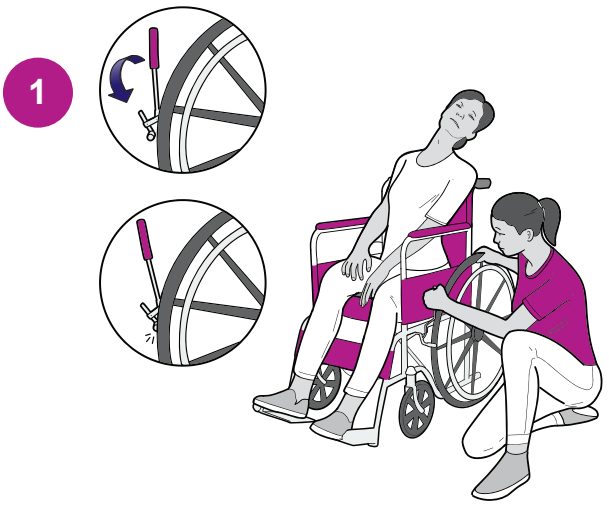
- Support the person with epilepsy by keeping their head out of the water.
- Check that their airway is kept clear.
- Remove the person from the water once their active seizure movements have ceased.
- If one seizure quickly follows another or their active movements do not cease, remove the person from the water as safely and as quickly as possible. This may require the assistance of others. In some instances, it is beneficial to remove the person from the water at the shallowest part of the pool.

- In open water environments where it is difficult to keep the person's airway clear, remove the person from the water as soon as it is safely possible to do so.
- If a convulsive seizure occurs in water, check if they are breathing, and dial 000 immediately.
- Commence CPR if they are not breathing.
- If breathing, move into the recovery position once active movements have ceased.
- Do not restrain and do not put anything in the mouth of someone having a convulsive seizure.

Wheelchair first aid

A person with epilepsy will have an Epilepsy Management Plan. The plan will advise you on how to assist and support them if they have a seizure in a wheelchair. These steps could include:

- Record the time and duration of the seizure.
- Leave the person seated in the wheelchair and secure the chest harness and/or seat belt where available.
- Do not try to move the person unless the Epilepsy Management Plan says so. Moving the person could cause you or the person to be injured.
- Remove any nearby objects that could cause harm, where practical.
- Make sure the wheelchair brakes are on and secure.
- Remove wheelchair tray table, if applicable, to avoid injury.
- If the person is in a wheelchair where footplates and foot anchoring buckles/ velcro straps are in use, undo the straps to allow free movement of limbs during a tonic-clonic convulsive seizure.
- Support the head with something soft if there is no moulded headrest.



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- Tilt the person's head into a position that keeps the airways clear. This may include turning the head to the side to allow excessive secretions to drain.
- Recline the wheelchair using the tilt/recline function, if available. Avoid tilting the wheelchair from the wheels.
- Do not try to restrain the person or put anything in the mouth.
- Do not give the person anything to eat or drink until you are sure that they have completely recovered.
- Reassure and let the person know you will stay until they recover, or until the paramedics arrive if an ambulance has been called.

CALL 000 FOR AN AMBULANCE:

- **If it is their first seizure.**
- **If you do not know the person or if there is no Epilepsy Management Plan.**
- **If the seizure lasts for 5 minutes or more.**
- **If the seizure stops, but the person does not regain consciousness within 5 minutes.**
- **If another seizure begins.**
- **When a serious injury has occurred.**
- **If the person was eating or drinking, or there is food, fluid or vomit in their mouth.**
- **If the seizure occured in water.**
- **If you believe the person is pregnant or has diabetes.**

Epilepsy Smart Australia Program **National Epilepsy Support Service** 1300 761 487 **Website** epilepsysmart.org.au

The Epilepsy Smart Australia Program received funding from the Australian Government.

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