SEIZURES & EPILEPSY

Answering your frequently asked questions

Seizure FIRST AID
Seizures are not uncommon and they can occur for the first time at any age. Up to 10% of the population will have a seizure at some time. Approximately 50% of people who have a seizure will not have another. For people at risk of recurring seizures, 60-70% can expect seizure control with medication.
A person who has an unexplained collapse, 'blackout' or 'turn' is usually anxious to know why this happened, but the reason is not always easy to find. Medical tests or a visit to a specialist may be recommended and time can pass before a diagnosis is made.

Many people feel that something serious must be wrong and may be surprised to learn that they are quite well. Others feel that too much fuss is being made and may be shocked to learn that they may have had an event such as a seizure. It is common for people to feel confused and uncertain about their health under these circumstances. This booklet answers some frequently asked questions.

What is a seizure?

The brain controls the body's actions, sensations and emotions through nerve cells that carry messages between the brain and the body. These messages are transmitted through regular electrical impulses. A seizure occurs when sudden bursts of electrical activity in the brain disrupt this pattern. The kind of seizure and the parts of the body affected by it relates to the part of the brain in which the irregular electrical activity occurred. Seizures can involve loss of consciousness, a range of unusual movements, odd feelings and sensations, or changed behaviour.

How are seizures diagnosed?

There are many medical reasons why people lose consciousness, experience periods of time when they are 'not quite with it' or have unusual sensations. These include panic attacks, migraine, fainted (sometimes called 'syncope'), seizures, stroke and heart disease. A definite diagnosis is important, but because the person often has little or no memory of the event it can take time to come to the right answer.

The doctor will begin by taking a thorough medical history and examining the patient. Eyewitness accounts can assist greatly with the diagnosis, so it is useful for a friend or family member who saw the event to accompany the patient to the first appointment.

If a stranger witnessed the event, a written description or a phone number for the doctor to call can be helpful.

Tests may be arranged, and these will vary depending upon the doctor's initial assessment. They may include blood tests, an EEG [electroencephalogram], a CT scan [computerized tomography] or an MRI [magnetic resonance imaging].

Sometimes it is very clear why a person has experienced a collapse or 'blackout'. But occasionally, even after all the appropriate tests and a thorough examination of the person's medical history, it is still not possible to make a definite diagnosis. This can be frustrating.

Often it is a matter of simply waiting for a definite answer. More events may allow a clear diagnosis, or a further test may provide an answer. It is better to be a little uncertain rather than to jump to conclusions and make a wrong diagnosis.

Can tests confirm that a seizure occurred?

People often assume that tests such as an EEG, a CT scan or an MRI will tell if they have had a seizure. However, information from tests alone cannot confirm that a seizure has occurred. The doctor relies heavily on information from the patient and witnesses to make a diagnosis.

The EEG test records the electrical activity of the brain. However, electrical changes can often be seen only during a seizure, so a normal EEG, taken when a seizure is not occurring, doesn't mean that a seizure has not occurred at some other time. An abnormal EEG can suggest that the person is more likely to have seizures, and this can be helpful to the doctor. However, an EEG can be abnormal for many reasons.

CT and MRI scans show how the brain is built and, occasionally, a possible cause for seizures can be seen on a scan. However, like an EEG, the scans can be normal in people who have seizures, and not everything unusual on a scan will be a cause of seizures. In some people, the EEG and CT or MRI scans are normal and yet, based on the history, the doctor is certain that the person has had a seizure.
Medical tests that might be suggested after a seizure or blackout include:

**Blood tests**

Blood tests check the general health of a person.

**Electroencephalogram (EEG)**

EEG records small electrical signals from the brain onto a computer or paper. Small discs, called electrodes, placed on the scalp with temporary glue, pick up the electrical signals and pass them along wires to the EEG machine.

Recordings take about 20 minutes, while patients rest or sleep. At times, patients are required to open and close eyes, breathe deeply or look at flashing lights. EEG tests are safe, painless and do not give electric shocks. For best results, hair must be clean and dry, with no hairspray, mousse, gel or oil.

Sometimes, the doctor will request a 'sleep-deprived' EEG and the patient is asked to restrict sleep the night before the test. In drowsy patients, the EEG can occasionally provide additional information.

**EEG Ambulatory Monitoring**

When an EEG needs to be collected over hours or days, a compact recording machine can be worn by the patient during normal activities.

**EEG/Video Monitoring**

Sometimes, it is useful to perform an EEG over an extended period while the patient is monitored by a video camera. If an episode occurs and is recorded, the doctor can view a video of the event and a simultaneous EEG recording of the brain's activity. Video monitoring is performed in hospital as a day procedure or over several days.

**Computerized Tomography (CT)**

Computerized x-ray techniques reveal obvious structural abnormalities or damage to the brain. The patient lies on a table that allows the head to be scanned by the CT unit. A special dye is usually injected into a blood vessel in the arm to circulate in the blood stream and enhance image quality.

**Magnetic Resonance Imaging (MRI)**

MRI uses harmless magnetic field and radio waves to provide more detail than a CT scan. It produces very clear images of the brain without using x-rays.

The patient lies on a table inside a tunnel-shaped scanner and a mirror provides visual contact with staff. While operating, the machine makes a loud thumping noise. People with metal in their bodies or medical devices such as pacemakers are usually not able to have an MRI.

**Electrocardiogram (ECG)**

An electrocardiogram measures the electrical activity of the heart. Sensors called electrodes, which detect the electrical currents, are attached to the chest, arms and legs with suction cups or gel. The information is recorded on a screen or paper. The test is safe and non-invasive.

**Holter Monitor**

A holter monitor is used to carry out an ECG over an extended period. Electrodes are attached to the body with adhesive patches and connected to a small recording device which is worn over the shoulder or on a belt. Holter monitoring may uncover a cardiac rhythm problem which only occurs occasionally or at certain time of the day or night.

**Loop Monitor**

The Loop monitor is a small device about the size of a matchbox which can be inserted under the skin in the chest area to record heart rhythms over weeks or months. The insertion of the monitor is a short surgical procedure carried out under local anaesthetic.

**Tilt Table Test**

A tilt table test checks the body’s response to sudden changes in blood pressure and heart rate. The patient is strapped to a motorized table which tilts from the lying to standing position. An ECG machine and blood pressure monitor measure changes. A fine tube may be inserted into an arm vein to administer medication. The test aims to identify patients with a tendency to fainting and therefore during the test some patients may black out. This test can sometimes rule out epilepsy.
Isn’t a seizure and a convulsion the same?

Many people think the word seizure describes a convulsion, where someone generally becomes unconscious and falls with their limbs jerking. But a convulsion is just one type of seizure, called a tonic-clonic seizure or generalized seizure [grand mal seizure or fit].

There are many different types of seizures and in adults most seizures are not convulsions. While many people who experience recurring seizures will experience a convulsive seizure at some time, others experience seizures as episodes where they go blank for a few seconds or minutes, or behave in ways that are out of character, occurring without their conscious control.

What are the different types of seizures?

Generally, seizures fall into two categories: focal or partial seizures and primary generalized seizures. The difference between these types is how they begin.

Focal or Partial Seizures

Focal or partial seizures start in one part of the brain [that is at a focal point in the brain] and affect that part of the body controlled by that part of the brain.

- **Simple partial seizures**

  Simple partial seizures are localized seizures, affecting only one part of the brain. The symptoms the person experiences will depend on the function that part of the brain controls. The seizure may involve the involuntary movement or stiffening of a limb, feelings of *déjà vu*, an unpleasant smell or taste, or sensations in the stomach such as ‘butterflies’ or nausea. The person remains alert throughout the seizure and can remember what happens. The seizure usually lasts less than two minutes.

  A simple partial seizure can progress to a complex partial seizure and/or a secondarily generalized seizure.

- **Complex partial seizures**

  This type of seizure also affects only one part of the brain but the person’s conscious state is altered rather than lost. The person may often appear confused and dazed and may do strange and repetitive actions like fiddling with their clothes, making chewing movements or uttering unusual sounds. These behaviours may also be described as trance-like or robot-like and are called automatisms. The seizure usually lasts for one to two minutes but the person may be confused and drowsy for some minutes to several hours afterwards and have no memory of the seizure or the events just before or after it. This type of seizure can be mistaken for drug/ alcohol-affected behaviour or psychiatric disturbance.

  At times complex partial seizures can spread to become secondarily generalized seizures.

Primary Generalized Seizures

Primary generalized seizures involve the whole brain and therefore involve the whole body. There are many types of generalized seizures – some convulsive, others non-convulsive.

- **Absence seizures** *previously called petit mal seizures*

  This is a brief, non-convulsive event, usually occurring in the young, and involves the whole brain. With this type of seizure, the person’s awareness and responsiveness are impaired. They simply stare and their eyes might roll back or their eyelids flutter.

  It can be difficult to tell the difference between absence seizures and daydreaming. However, absence seizures start suddenly, cannot be interrupted, last a few seconds, and then stop suddenly and the person resumes what they were doing. Although these seizures last less than 10 seconds, they can occur many times daily, and thus be very disruptive to learning.

- **Myoclonic seizures**

  Myoclonic seizures are brief, shock-like jerks of a muscle or a group of muscles, usually lasting no more than a second or two, which at times can result in a fall. There can be just one, but sometimes many will occur within a short time.

- **Atonic seizures**

  Atonic seizures cause a sudden loss or decrease of normal muscle tone and the person often falls to the ground. Seizures usually last less than 15 seconds. Often called ‘drop attacks’, these seizures can cause head or facial injury. Wearing protective headwear may avoid injury.
- **Tonic seizures**
  Tonic seizures greatly increase normal muscle tone and the body, arms, or legs make sudden stiffening movements. These seizures most often occur in clusters during sleep, although they can occur when the person is awake. If the person is standing they will fall quite heavily, often injuring their head. Protective headwear may avoid injury. 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 being forced past the vocal cords causes a cry or groan, and they fall to the ground [the tonic phase]. Their limbs then begin to jerk in strong, symmetrical, rhythmic movements [the clonic phase]. The person may dribble from the mouth, go blue or red in the face, or lose control of their bladder and/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 a number of hours.

  Although this type of seizure can be frightening to watch, the seizure itself is unlikely to seriously harm the person having the seizure. They may, however, vomit or bite their tongue and can sometimes injure themselves if they hit nearby objects as they fall or convulse.

  Tonic-clonic seizures generally last 1 to 3 minutes. If the active movements of the seizure last more than 5 minutes it is advisable to call an ambulance. Prolonged seizures, or a series of seizures without a normal break in between, indicate a dangerous condition called *convulsive status epilepticus* and demands emergency treatment.

**Why do seizures occur?**

Seizures are most common in young children and the elderly, but they can occur for the first time at any age.

Sometimes it is easy to see the cause of a seizure. For example, a seizure may occur at the time of a bad head injury or brain infection. Seizures are occasionally caused by high fevers (especially in children), the use of certain drugs or excessive intake of alcohol. In other cases an injury or infection of the brain that happened a long time ago can cause a seizure.

Seizures may also be brought on by significant stress or lack of sleep. These ‘triggers’ alone, however, do not explain why a seizure has occurred. After all, not everyone who is stressed or sleep-deprived will have a seizure. Tests are still needed to ensure that no other cause can be found. It appears that certain people are simply more prone to having seizures than others. This is, at times, described as having a ‘low-seizure threshold’ and may be due to an individual's genetic makeup.

In many cases, despite thorough medical investigation, the cause of a seizure cannot be determined.

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Mark

’I had my first seizure at 32 … in a restaurant. Having seizures made me feel like my world was *falling apart*. I had no idea what it would mean for my life. But there was treatment for me … and now I’m OK.’

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**Will there be more seizures?**

Experiencing a seizure does not necessarily mean that a person will continue to have seizures. Many people have only one seizure. It is not possible to know for certain who will have more than one.

The circumstances of the seizure, the family history or the test results might suggest that the risk of another seizure is higher in some people.

**What is the difference between seizures, epilepsy and seizure disorder?**

A seizure is the physical sign that there has been a disruption to the normal functioning of the brain. As discussed, there can be quite a few explanations for why seizures occur.

However, if a person is told they have epilepsy it simply means that they have started experiencing seizures on a recurring basis. The seizures in epilepsy may be related to a brain injury or a family tendency, but often the cause is completely unknown. They tend to be unpredictable and occur without provocation.

While epilepsy is also known as a seizure disorder, it is not just one disorder. As there are different types of seizures, so too are there different types of epilepsy disorders, called the epilepsies, each with its own particular set of features. When a disorder is defined by a characteristic group of features that usually occur together, it is called a syndrome.

Epilepsy syndromes are defined by a cluster of features. These features include:
seizure type/types and their severity and frequency,
- the age of onset,
- the causes of the seizures and whether there is a familial link,
- the part of the brain involved,
- electroencephalograph (EEG) activity,
- seizure provoking factors, and
- the presence of other disorders in addition to seizures.

By understanding the nature and presentation of a particular syndrome the treating doctor can implement the most appropriate form of treatment and may be able to predict whether seizures will lessen or disappear over time.

Is there treatment for seizures?

Medication does not cure epilepsy but it can prevent seizures occurring. Whether or not to prescribe medication will depend on how highly the doctor rates the risk of another seizure and how seriously this would impact on the person's wellbeing.

Optimally, decisions about treatment are made jointly by the doctor and the patient after consideration of the patient's circumstances. The type of seizure will, in part, determine the medication used. Of people at risk of recurring seizures, more than 60% are likely to achieve complete seizure control with medication within a year.

Is treatment usually prescribed after one seizure?

Medication is not given to everyone who has a single seizure. But if a doctor feels the risk of another seizure is high, early treatment with medication may prevent further seizures.

Commencing medication does not always mean that it must be taken for life. Regular medical reviews are recommended and many people need medication for a limited time, usually a few years. Withdrawing from medication should always be carried out under medical supervision. Do not suddenly stop taking medication as this can provoke seizures and, possibly, a medical emergency. All changes in the dose should be guided by the treating doctor.

Generic formulations of many antiepileptic medications are now available and it is government policy for pharmacists to ask if a cheaper brand would be preferred. Switching between preparations is not recommended, whether switching from designer drug to generics or vice versa, or switching from generic to generic, due to the risk of breakthrough seizures.

Seizure medication can interact with other medications including the contraceptive pill and some common over-the-counter treatments. It's important for people to check for this when a doctor, pharmacist or other medical practitioner, suggests new medications.

‘I was cutting a client’s hair when I had my first seizure. Having one in public was embarrassing and it really affected my self-confidence. What was very helpful was finding health care workers who actually understood not just the seizures but also the personal emotions that a seizure can trigger.’

Candi
Seizures often happen without any pattern, so it can be frustrating for people to take tablets when they do not have frequent seizures. Where there is uncertainty and medication is recommended, people can be unsure about whether they really need to keep taking tablets.

But epilepsy is a “silent” disorder. You may feel perfectly well for months between seizures, unless they occur in clusters, but this does not mean the epilepsy is cured or is gone. Some people find it helpful to think of their medication as an ‘insurance policy’ as even one seizure carries risks, especially while driving, or in water, or handling machinery.

Taking medication is a personal choice, and patients are encouraged to discuss any concerns with their doctors to ensure that they have a good understanding of why treatment is recommended for them.

Any side effects that are thought to be a result of the medication should be discussed with your doctor or epilepsy counsellor. Sometimes the medication can be carefully switched to avoid unwanted side effects.

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 the GP to continue treatment. If seizures are not well controlled, it may be necessary to return to the specialist for regular visits until the treatment is sorted out. Sometimes, neurologists who specialize in epilepsy are called in to help.

If you are in any doubt about whether you are getting the help you need you may find it useful to speak to an epilepsy counsellor at the Epilepsy Australia affiliate in your state or territory. They can often help you clarify what is happening and help you understand what you have been told by your physician.

Is it common to feel exhausted or anxious after a seizure?

People usually recover quickly from a seizure.

It is possible, however, for a person to feel drained for a day or two, especially after a generalized convulsion [tonic-clonic seizure]. After a first seizure there are often feelings of shock and anxiety, which can add to any strain. There may be concern that it will happen again. If a seizure occurs at work, there can be embarrassment. Friends or family also worry, especially if they witness a seizure. This can make them very protective of the person, causing relationship tensions.

Because a witness to a seizure can describe what happened, it can be advantageous for the patient to take that person along when they visit the doctor. Having a companion can also be helpful to the patient if the doctor is giving a lot of information that might be hard to remember, or if the person is feeling anxious about the experience. If a patient prefers privacy or independence, the companion can leave the room once the doctor has heard the description of the event.

Having to stop driving for a period of time after a seizure can create pressure on employment, family, social and educational arrangements. People often feel frustrated and angry, and they may become depressed. Seizures can, in themselves, cause varying degrees of depression. Antiepileptic medication can sometimes help with the depression, but not always. Speaking with an epilepsy counsellor can help identify issues and explore ways these concerns might be managed.

Many people wonder if they really had a seizure and think the diagnosis may have been wrong. These reactions are common. Everybody wants to find answers quickly and get back to a normal life.

Are seizures dangerous?

Anything that affects a person's awareness or judgement can increase the risk of accidents. If someone has a seizure it is sensible to take particular care in the weeks or months that follow. Safety issues will vary according to an individual’s diagnosis, but the highest risk of another seizure is during the three months following the first seizure. The doctor will recommend guidelines for driving, the operation of dangerous machinery, working at heights and other high-risk activities.
There are laws about driving after seizures. Generally, people who have had a seizure are required to notify the local licensing body and stop driving until a medical report has been supplied. Most people who have had seizures do get back to driving, but the length of time that a person must stop driving varies among individuals.

Swimming alone is not advised and showers are recommended instead of baths. Special care also needs to be taken when using hot water or items that can cause burns. Turning on the cold tap first in the shower, bath or basin, and lowering the temperature of the hot water service are good safety hints for any home. Showers and baths and running water in any context, appear to be conducive to seizures in some people. A precautionary measure is to take medication first thing in the morning, 20 – 30 minutes before taking a shower.

Although many people who witness a seizure fear that the person may be harmed, especially by a generalized convulsion, the risk of brain damage or death from a seizure is low. A person is at most risk of harm if they are doing something dangerous, such as driving, when a seizure occurs. Ensuring that seizures are correctly diagnosed, that treatment plans are followed and that first aid information is available, minimizes risks.

You may hear about a phenomenon called SUDEP [Sudden Unexpected Death in Epilepsy] which is the name given to deaths that unexpectedly follow some seizures. You need to remember that deaths occur with many illnesses, from influenza to asthma. While we do not want to side step the truth that recurring seizures or epilepsy can cause death, we need to emphasize that it is uncommon and that working to control any illness is the best way to minimize risk.

Who can provide information about seizures?

Although the diagnosis and treatment of seizures has improved dramatically in recent years, many in the community are unaware of the latest developments. Resources, including library books and web pages, often contain out-of-date or biased information. Incorrect information can cause unnecessary worry and prolong poor and even ineffective seizure management.

For reliable information on any aspect of seizure diagnosis and management, or support for people affected by seizures in all Australian states, contact:

**EPILEPSY AUSTRALIA**

1300 852 853

www.epilepsyaustralia.net

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**SEIZURE FIRST AID**

**Tonic-clonic seizures**

A convulsive or tonic-clonic seizure starts when someone loses consciousness, stiffens unexpectedly, falls to the ground and starts jerking.

- ✔ **Time the seizure.**
- ✔ **Protect from injury** – remove any hard objects from the area.
- ✔ **Protect the head** – place something soft under their head and loosen any tight clothing.
- ✔ **Gently roll the person on their side** as soon as it is possible to do so and firmly push the angle of the jaw forward to assist with breathing. A person cannot ‘swallow their tongue’ but the tongue can move back to cause a serious block to breathing.
- ✔ **Stay with the person** until the seizure ends naturally and calmly talk to the person until they regain consciousness, usually within a few minutes.
- ✔ **Reassure the person** that they are safe and that you will stay with them while they recover.

- ✗ **Do not restrain the person’s movements.**
- ✗ **Do not force anything into the mouth.**
- ✗ **Do not give the person water, pills or food until they are fully alert.**

After the seizure, the person should be placed on their side. Keep in mind there is a small risk of post-seizure vomiting before the person is fully alert. Therefore the person’s head should be turned so that any vomit will drain out of the mouth without being inhaled. Stay with the person until he/she recovers (5 to 20 minutes).

In the event of a seizure follow instructions in the individual’s seizure care plan. However if you do not know the person, or there is no seizure care plan:

**Call an ambulance – 000 – if:**

- ✔ the seizure activity lasts 5 or more minutes or a second seizure quickly follows.
- ✔ the person remains non-responsive for more than 5 minutes after the seizure stops.
- ✔ If the person is having a greater number of seizures than is usual for them.
- ✔ the person is injured, goes blue in the face or has swallowed water.
- ✔ the person is pregnant.
- ✔ you know, or believe it to be, the person’s first seizure.
- ✔ you feel uncomfortable dealing with the seizure.
Complex Partial Seizures

With this type of seizure the person may appear unresponsive and confused. Automatic movements such lip smacking, wandering, or fumbling hand movements may be present. A complex partial seizure can be mistaken for drug/alcohol-affected behaviour or psychiatric disturbance.

✔ During a complex partial seizure you may need to gently guide the person past obstacles and away from dangerous places.

✔ As the seizure finishes, establish supportive communication.

✔ Call an ambulance if the person doesn’t start to recover after 5 minutes.

Absence Seizures

An absence seizure causes loss of awareness and responsiveness for a brief period. The person stares vacantly, the eyes may drift upwards and flicker. It may be mistaken for daydreaming. Recognize that a seizure has occurred, reassure the person and repeat any information that may have been missed.

Atonic / Tonic Seizures

✔ Seek medical attention if the person is injured.

First Aid for seizures occurring in water

In certain situations, a loss of consciousness is especially dangerous and emergency care must go beyond the routine procedures. A seizure in water is a life-threatening situation.

If someone is having a seizure in water e.g. bath, swimming pool:

✔ Support the person in the water with the head tilted so the face and head stay above the surface.

✔ Remove the person from the water as soon as the active movements of the seizure have ceased.

✔ Check to see whether the person is breathing. If not, begin CPR immediately.

✔ Call an ambulance – 000

✔ Even if the person appears to be fully recovered, call an ambulance. The person should have a full medical checkup as inhaling water can cause lung or heart damage.

Precaution: If a seizure happens out of the water during swimming activity, the person should not continue with swimming or water sports that day, even if the person appears to be fully recovered.

Wheel Chair First Aid

If someone has a seizure while confined in a wheelchair, seated on a bus, train or tram or strapped in a pram or stroller:

✔ Time the seizure.

✔ Protect the person by preventing them from falling if there is no seat belt.

✔ Make sure the wheelchair or the stroller is secure.

✔ Protect the head – place something soft under their head will help if there is no moulded head-rest. Loosen any tight clothing.

✔ Check whether you need to move any hard objects that might hurt arms and legs in particular.

✔ Sometimes they may need to be taken out of the chair at the end of the seizure e.g. if the airway is blocked or if they want to sleep.

✔ Stay with the person until the seizure ends naturally and calmly talk to the person until they regain consciousness, usually within a few minutes.

✔ Reassure the person that they are safe and that you will stay with them while they recover.

✖ Do not try to stop the seizure.

✖ Do not put anything in the person’s mouth.

✖ Do not try to remove them from their position – in most cases the seat provides some support.

Caution: If there is food, water or vomit in their mouth remove the person from their seat and roll them onto their side immediately. If it is not physically possible to move them, continue to support the person’s head to ensure that it does not tilt backward and remove the contents of the mouth when the seizure is over.

Call an ambulance – 000 – if:

✔ the seizure activity lasts 5 or more minutes or a second seizure quickly follows.

✔ the person remains non-responsive for more than 5 minutes after the seizure stops.

✔ If the person is having a greater number of seizures than is usual for them.

✔ the person is injured, goes blue in the face or has swallowed water, ingested food or vomit.

✔ you know, or believe it to be, the person’s first seizure.

✔ you feel uncomfortable dealing with the seizure.
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Disclaimer
This brochure provides general information about seizures. It does not provide specific advice. A diagnosis of your medical condition and treatment advice should be obtained from an appropriate health professional.

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