

When you have Epilepsy

For people who have been
recently diagnosed



EPILEPSY ACTION
AUSTRALIA

Newly Diagnosed Epilepsy



“Showing people you can make the **most of life** with epilepsy has been wonderful.”
Jeff Lawrance

A removable seizure first aid poster is located in the centre of this booklet.



Epilepsy Action Australia provides education and support services to children and adults with epilepsy across Australia

Experiencing a seizure or series of seizures is a confronting situation. Not knowing what is happening and the fear of the unknown can leave you feeling anxious, upset or frightened. This is a common reaction and it is often a relief to be given a diagnosis. When you hear the word *epilepsy* a multitude of feelings and emotions may be evoked.

Many people have little knowledge or experience of epilepsy. You may wonder what this diagnosis means to you and your family and how it will affect your life. Accurate information can bring a greater sense of confidence and control and provide strategies to manage life with epilepsy.

Generally, people with epilepsy cope very well after the initial period of adjustment. The majority of people achieve good seizure control with medication and can live a full and active life. Epilepsy need not necessarily limit expectations or achievement.

What is epilepsy?

Epilepsy is common, affecting about 2% of Australians during their lifetime and can affect anyone regardless of age, gender, level of intelligence, culture or background. Epilepsy is a disorder that causes a disruption of the electrochemical activity of the brain resulting in recurrent, unprovoked seizures.

There are several types of epilepsy depending upon the area of the brain involved during the seizure. For example some people will experience changes in sensation, movement and behaviour during seizures. Other seizures begin with sudden loss of consciousness and muscle stiffening. Seizures can last from a few seconds to minutes.

Your doctor will speak with you about the type of seizures you are experiencing.

The three most common are:

- ◆ Generalised tonic clonic
- ◆ Focal dyscognitive
- ◆ Absence

Generalised tonic clonic seizures

These particular seizures begin with a sudden loss of consciousness. If standing the person may fall to the ground. The body stiffens (tonic) followed by rhythmic jerking of the muscles (clonic). Breathing becomes shallow or temporarily suspended causing the lips or complexion to change colour. Some people have an excess of saliva which may be slightly bloodstained if the tongue is bitten. Others may experience urinary

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“I hid my epilepsy for years without telling anyone – I didn’t want to lose my job on TV or playing soccer. I thought everyone would **discriminate** against me. Now I know people can deal with it.”

Paul Wade

incontinence. The seizure usually lasts less than two minutes followed by a period of confusion, agitation or sleep. Headaches or muscle soreness are also common afterwards.

Focal dyscognitive seizures

These seizures vary widely. The person may feel the seizure starting with a particular sensation or emotion called an aura. As the seizure goes on, awareness and responsiveness is altered producing a vague, confused or dreamlike appearance. The person may not respond to you or may respond inappropriately. They may also display behaviour such as chewing, repetitive movements, fiddling with clothes and wandering aimlessly.

The person does not usually collapse to the ground like a tonic clonic seizure. After the seizure there may be a short period of confusion and the person may need to sleep.

Absence seizures

Usually these seizures start in childhood but they can be experienced by adults and consist of a brief loss of awareness lasting 10-20 seconds. They may occur many times a day. The person appears to stare vacantly and their eyes may flutter or turn upward. While the person is unaware of

their surroundings during the seizure, they recover immediately afterwards. Absence seizures are often mistaken for daydreaming or lack of concentration and can disrupt learning by creating gaps in the information a person receives.

Seizure triggers

Certain circumstances can trigger (or set off) seizures, which vary between individuals. The level at which this occurs will depend on a person’s seizure threshold or sensitivity. Everyone has a seizure threshold, however this is lower in some people and they are more susceptible to seizures.

Avoiding identified triggers can help to reduce seizure frequency. Common triggers include:

- ♦ Lack of sleep.
- ♦ Missed medication/s.
- ♦ Extreme fatigue or physical exhaustion or stress.
- ♦ Consumption of too much alcohol or illicit drug use such as amphetamines or ecstasy.
- ♦ Fever associated with colds and infections or gastric upsets.

Recording seizures

Few doctors see their patients’ seizures. An accurate eyewitness description or video of seizures will help the specialist make decisions about investigations, diagnosis and treatment. If you are observing someone’s seizures, write a description of what you saw happen before, during and after the seizure. When the person has recovered, ask them to describe what they felt and remembered.

Medication

Medication is the first treatment of choice once a diagnosis of epilepsy has been established. Medication cannot cure epilepsy however in the majority of people it can prevent seizures with minimal side effects. The doctor will choose which medication to use based upon the type of seizures or epilepsy syndrome, the person’s age, gender, lifestyle, other health conditions and individual factors.

Medication is introduced slowly with the dose built up over days or weeks. During this time, its effectiveness in controlling seizures will be closely monitored as well as any unwanted effects. These may occur in some people while their body becomes accustomed to the drug. A few weeks after starting medication, most people find the unwanted effects tend to lessen or

disappear. If the drug is unsuccessful, a second may be trialled, and the first slowly withdrawn during a stabilising period.

It is important to take the medication as prescribed at regular times. Altering dosage or daily routine may provoke unexpected seizures or unwanted effects. Missing tablets may sometimes trigger a seizure. The goal is to keep a constant level of the medication in the bloodstream.

Tips for taking medication:

- ♦ Establish a regular routine to help you avoid forgetting medication.
- ♦ Take medication with meals or use a tablet dispenser.
- ♦ Maintain supplies to avoid running out of medication at the last minute, particularly if away from home.
- ♦ If a dose is missed it can generally be taken as soon as you remember.
- ♦ Do not double up on doses. It is important not to take the missed dose if it is close to the next one.
- ♦ Keep a record of doses that have been missed.

It is important to *never* stop or alter the dose of a drug without medical advice. Any withdrawal from antiepileptic medication should be done slowly and

FIRST AID FOR SEIZURES

TONIC CLONIC SEIZURE

Convulsive seizures where the body stiffens (tonic phase) followed by general muscle jerking (clonic phase).



DO

- ✓ Stay with the person
- ✓ Time seizure
- ✓ Protect from injury especially the head
- ✓ Roll onto side after jerking stops OR immediately if food/fluid/vomit in mouth
- ✓ Observe and monitor breathing
- ✓ Gently reassure until recovered

DO NOT

- ✗ Put anything in the person's mouth
- ✗ Restrain the person
- ✗ Move person unless in danger

FOCAL DYSCOGNITIVE SEIZURE (complex partial)

Non-convulsive seizures with outward signs of confusion, inappropriate responses or behaviour.

- Stay with the person
- Time seizure
- Gently guide away from harm
- Reassure until recovered
- DO NOT restrain the person unless in danger

CALL 000 FOR AN AMBULANCE IF:

- You are in any doubt
- Injury has occurred
- There is food/fluid/vomit in mouth
- Seizure occurs in water
- Person has breathing difficulties after jerking stops
- Another seizure quickly follows
- Seizure lasts longer than 5 mins
- The person is non-responsive for more than 5 mins after the seizure ends



This is not medical advice nor an exhaustive list of responses to seizures. This is a guide to help you consider your response to seizures. If you are in any doubt about what to do, do not hesitate to call an ambulance.

For more information or advice about epilepsy, contact Epilepsy Action Australia on **1300 37 45 37** or visit www.epilepsy.org.au



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“Epilepsy Action Australia’s information gave me a clear **understanding** of the types of seizures, knowing what were seizures and what were not.”
Maria Pasquarelli

under medical supervision. Suddenly stopping these drugs can provoke seizures, often more severe than usual.

Driving

Driver licensing authorities around Australia require people to be seizure-free for specific periods of time with clear evidence of seizure control before driving.

Generally people with recently diagnosed epilepsy are required to have a seizure-free period of at least six months from the start of therapy. However if a person has a history of uncontrolled seizures this can be extended for longer periods. This period may be decreased only on the advice of a consultant experienced in treating epilepsy.

A person with epilepsy who is granted a license is personally responsible for managing their condition. This includes reporting any seizure activity to their medical practitioner and continuing to take antiepileptic medication as prescribed, not driving if you have not had enough sleep and avoiding circumstances or substances known to increase the risk of seizures.

A person who has a motor vehicle accident during the recommended non-driving period will be treated as an unlicensed driver and will not be covered by insurance. Obtaining insurance in the future may also be difficult. They could also be charged with driving offences such as dangerous driving or be sued under common law. The regulations for holders of commercial licences are much more stringent.

A non-driving period can disrupt your daily routine but a number of strategies can be helpful. Most friends, neighbours or colleagues are happy to offer assistance if you are willing to ask. Join a local carpool or arrange a lift with a friend. Public transport maybe an option in your area. You may also be able to access community transport.

Employment

During the early stages of diagnosis it is important to consider any adjustments that

may need to be made to current duties at work. This is especially important:

- ♦ When a person is commencing epilepsy medication and their seizures are not yet under control or they are experiencing unwanted effects from the medication, such as lack of concentration or incoordination.
- ♦ During the non-driving period. Telling an employer is not always mandatory. However your employer cannot make reasonable adjustments if they do not know. Under the Occupational Health and Safety Act, an employer is only held responsible for safety measures if they are aware of the condition.

Staying safe

For the majority of people with epilepsy, seizures will be well controlled by medication. However it is worth being prepared in case a seizure does occur. Tell your family, friends, colleagues about your type of epilepsy, what to expect should you experience a seizure and how they can help. Have seizure first aid posters displayed in easily accessible places at home or in the office.

With a few extra precautions, people with epilepsy can safely enjoy a full range of sporting and recreational activities both inside and outside the home.

While accidents can happen to anyone at any time, the risks for people with epilepsy can be different. This is due to the unpredictable nature of epilepsy. Try to gain an awareness of potential risks and how these can be lessened.

Injuries can occur as a result of seizures such as cuts and abrasions, broken teeth, burns, fractures or even drowning. As with many other conditions, loss of life can result although this is very rare indeed. It may occur because of an injury sustained during a seizure or as a direct result of seizure activity.

Improving management of seizures, being compliant with medication regimes and avoiding circumstances or identified triggers that increase seizure frequency will reduce potential risk factors.

It is important to remember that the majority of people with epilepsy gain good seizure control and live full and active lives.

Accurate information and knowing what to do can give you and those around you a greater sense of confidence and control.

Need help?

Support from a community group can help if you or a family member has recently been diagnosed with epilepsy. For more information phone 1300 EPILEPSY (37 45 37).





EPILEPSY ACTION
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This information is given to provide accurate, general information about epilepsy. Medical information and knowledge changes rapidly and you should consult your doctor for more detailed information. This is not medical advice and you should not make any medication or treatment changes without consulting your doctor.