

Living well with epilepsy

Each person experiences epilepsy in different ways depending on the type, frequency, severity and predictability of their seizures. Medication can stop seizures occurring in about 70% of people diagnosed with epilepsy.

With some planning, people with epilepsy can do most things they want to do and enjoy these activities. Epilepsy may have an impact on your life, but you can minimize this by recognizing those issues that affect you and managing them in a positive way. Learning to recognize what might trigger your own seizures will allow you to either avoid them or develop ways to minimize the risk.

1 Your lifestyle

You may improve your seizure control and general wellbeing by getting adequate sleep, having a healthy diet, minimising stress, limiting your intake of alcohol and getting regular exercise.

Sleep

Seizures are much more likely to occur if you are tired or deprived of sleep. It is best to have a regular sleep pattern and to get enough sleep to feel rested. Being asleep during the hours of 11pm to 4am is particularly important if you are prone to seizures due to lack of sleep. If you experience sleep problems discuss this issue with your neurologist or GP.

Healthy diet

Some people are susceptible to seizures if they miss meals and have a low blood sugar level. Regular meals and eating immediately after getting out of bed in the morning will lessen the likelihood of large swings in blood sugar levels.

Caffeine may be a seizure trigger for some people. Limiting consumption of caffeine may also help promote a better sleep pattern. Drinks containing caffeine such as coffee, tea, cola and energy drinks should only be consumed in moderation.

Alcohol

Alcohol interacts with some antiepileptic drugs and may trigger seizures. Check with your doctor to see if it is safe for you to consume small amounts of alcohol. Most people with epilepsy can safely drink a small amount of alcohol, however, some people find even small quantities can trigger seizures. Moderate drinking means having one to two (but no more than two) standard drinks a day. A standard drink is equal to:

- one small glass of wine (100ml)
- one glass of full strength beer (285ml)
- one nip of spirits (30ml).

Be aware of the quantity of alcohol you drink and don't let anyone persuade you to drink more. It is wise to have a minimum of two alcohol free days each week. Alcohol and antiepileptic drugs (AEDs) interact in specific ways. AEDs can make you more sensitive to the sedating effects of alcohol while alcohol reduces the effectiveness of AEDs, making seizures more likely. Drinking large volumes of any liquid causing over hydration can trigger seizures in people with epilepsy. Heavy alcohol consumption can lead to late nights, lack of sleep and forgotten tablets. All of these can make you more likely to have a seizure.

The interaction of alcohol and AEDs makes driving much more hazardous so driving should be avoided when alcohol is consumed, even in small quantities.

Some people mistakenly think it is okay to stop taking their medication for a short time while drinking alcohol; however, this is very dangerous because it can cause a major seizure.

Recreational Drugs

Avoid using drugs such as cocaine, ecstasy, heroin, amphetamines or marijuana as these drugs can provoke seizures in people with epilepsy. Even though some studies have shown marijuana has anti-seizure properties for some people with epilepsy, its irregular supply, imprecise dosage and varying side-effects – as well as the criminal penalties that apply in some parts of the world for using it – make it problematic. Should you be unable to continue to use any drug with which you are controlling seizures, you are at a significantly increased risk of having breakthrough seizures.

Stress management, anxiety and depression

For people with epilepsy, the demands of normal daily living are compounded by the additional stress associated with their condition. Extra stress factors can include the need to take medication regularly, the unpredictable nature of seizures, a fear of injuries, overcoming difficulties in gaining or retaining a driver licence, dependency on others for transport, problems with work or memory and mood disturbances, such as depression. There is an increased incidence of depression and anxiety in people with epilepsy. It is important to seek help at the earliest opportunity from your GP or neurologist if you are experiencing either or both of these conditions.

As well as taking your prescribed medication, stress management techniques including relaxation and breathing, meditation, exercise and anxiety management may help you better manage your epilepsy and reduce the incidence of seizures.

Self-management

It is important that the people around you know what to do if you have a seizure. Having an Epilepsy Management Plan in place will help your family, friends, workmates or teachers to recognise when you are having a seizure and to know what seizure first aid to provide. Plans can be downloaded from www.epinet.org.au.

Keep a record of your seizures as you may not be aware when you are having a seizure or remember that one occurred. Ask someone to write a detailed description each time you have a witnessed seizure and keep the date, time and what happened before, during and after the seizure in a diary. This is especially important when someone is newly diagnosed or has had a change of antiepileptic medication. You can use a small notebook or the Seizure Record form which is available at www.epinet.org.au. There are also applications available for use on computers and some mobile phones such as *Seizure Tracker* that many people find helpful. Take the information to each doctor's appointment to help your doctor assess the effectiveness of your treatment. Most doctors will be unable to read through pages of detailed seizure descriptions during a consultation so it is advisable to summarise the information prior to the appointment.

2 Medication

Know your medication and take it as prescribed

It is important to know your medication, its brand name, prescribed strength and dose and to be aware of possible unwanted side-effects. Open discussion with your doctor about what to expect from your medication and the impact of any side-effects on your quality of life is the best way to manage drug therapy.

Taking your medication as prescribed is the cornerstone of your treatment. Changes to your dose should only be made in consultation with your doctor as too much medication can lead to unwanted side-effects while too little can increase seizure frequency. It is important that you take your medication at the specified time/s each day. Taking your medication with fluids and with food may avoid heartburn or indigestion.

Never give your medication to anyone else and nor should you try other people's AEDs. Your medication has been prescribed with your particular seizures or epilepsy syndrome in mind. Other medicines may interact with your medication causing increased, unwanted side-effects or increased seizures. To avoid interactions, tell your doctor, pharmacist or health professional what other medications you are taking, including over-the-counter medications.

Do not change the brand of your medication without consulting your doctor, especially if your seizures are completely controlled. Sodium valproate, for example is available as Epilim and Valpro in Australia. If you started taking Epilim and your seizures are well controlled changing to Valpro may increase your risk of a seizure or side effects due to a slight degree of variation between the two medications. Vomiting and diarrhea may mean you have absorbed less of your medication than usual and may increase your risk of a seizure. If you vomit within 15 minutes of taking your medication, it is advisable to take another dose. If vomiting or diarrhea continues, see your doctor or health professional.

Most importantly, do not stop taking your medication without first seeking medical advice. Sudden withdrawal of medication can lead to prolonged seizures that may cause brain damage or death. Antiepileptic medication should only be withdrawn under medical supervision.

Remembering your medication

Missed doses can lead to increased seizures. Antiepileptic drugs vary in the way they are absorbed, processed and stored in the body. Neurologists agree that you should take the missed dose as soon as you realise you have missed a dose, even if this isn't until the next dose is due so you can catch up. The risk of this is minor over-dosage, but the symptoms are not serious and will last no more than a couple of hours, while the risk of not doing so is a seizure. You should discuss this with your doctor.

At times it may be difficult to remember if you have taken your medication. You are less likely to miss a dose if you make taking your medication part of your daily routine. For example, take it with meals or when you get up and when you go to bed. Some people use digital watch or mobile phone alarms to remind them. For most people it is more important to take your medication when you are more likely to remember than at exact time intervals. However, some people are more prone to seizures with minor variations in the time of day they take their medication and need to have a strict routine.

Pill boxes have separate compartments to place all the tablets required for a week or a day and a glance at the dispenser will reassure you that you have not missed a dose.

People who are unable to manage their own medication can pay a small additional fee to have their pharmacist supply their medication in a Webster pack. The pack is refilled on a weekly basis and lessens the likelihood of missing tablets or getting the dose mixed up.

Storage

Keep adequate supplies of your medication on hand and a spare prescription at home or with your chemist to ensure you don't run out. Keep your medication in a cool, dry place and out of the reach of children.

3 Seizures and driving

If you hold a learner permit or driver licence in Victoria, you are required by law to notify VicRoads if you have or develop any serious or chronic medical condition. This includes blackouts, isolated seizures and epilepsy. If you do not advise VicRoads and you are involved in a motor vehicle accident you could be sued under common law, charged with driving offences and your insurance company may not provide cover.

Being diagnosed with epilepsy and the subsequent suspension of your driver licence can throw your life into disarray, particularly if your job involves driving. The period that you must be free from seizures before driving depends on the type of seizure and the circumstances surrounding it. Driving regulations are now standardized throughout Australia. A conditional private vehicle licence can be issued if there have been no seizures for at least 12 months. Shorter seizure-free periods may be considered by the driving authority in certain circumstances.

Useful information on this topic can be found in the Austroads publication Assessing Fitness to Drive: www.austroads.com.au. The frequency of periodic reviews may vary depending on your doctor's medical report. VicRoads usually accept medical reports from your neurologist rather than GP. For more information download the VicRoads brochure Seizures and Driving at www.epinet.org.au or www.vicroads.vic.gov.au or contact

VicRoads Medical Review

- PO Box 2504, Kew, VIC 3101
- call 13 11 71
- fax (03) 9854 2307
- email: medicalreview@roads.vic.gov.au

4 Sports and Leisure

People with epilepsy are able to undertake most sports and leisure activities, but should exercise extra care in some circumstances.

When choosing a sport or leisure activity, give some consideration to your type of seizures and degree of seizure control. Some activities involve a greater risk than others but with appropriate safety precautions most risks can be minimised. The risk is greater for seizures involving impaired awareness or loss of consciousness. It is also recommended that you discuss any restrictions or risks involved in particular sporting activities with your neurologist.

Swimming and other water sports

Sometimes people with epilepsy avoid swimming, or are barred from swimming, because of fear that they may have a seizure in the water. However, with sensible precautions, people with epilepsy can swim safely.

Always swim with someone else, making sure that your companion knows you have epilepsy and is capable of rescuing you if you have a seizure.

If you are swimming in a public swimming pool, inform the life guard of your epilepsy and how to assist should the need arise. However, be aware that the life guard cannot be relied upon to provide close supervision and could be assisting someone else at the time of a seizure. If your seizures are not fully controlled, one-to-one supervision is advised at all times.

When engaging in any water sport such as boating, canoeing, windsurfing or sailing always wear a life jacket and avoid undertaking these activities solo – always have a spotter or someone in close proximity. Underwater swimming such as scuba diving is not recommended unless you have received a certificate of diving fitness from a medical practitioner certified in diving medicine. It is vital to be completely honest with the assessing doctor about your epilepsy and degree of seizure control. In the event of a seizure, help may not be possible and may increase the risk for the others with you. It is best to avoid situations such as underwater activities, where your chances of survival, should you have a seizure, are greatly reduced.

Team and contact sports

Epilepsy should not stop you from playing team and contact sports unless your epilepsy was caused by a serious head injury and there is a risk of further damage if high impact contact occurs. Some people choose to wear head protection while playing, regardless of whether or not they have epilepsy. It is a good idea to wear protective headgear in contact sports regardless of your health status.

Cycling

Take normal safety precautions when cycling such as wearing a helmet, wearing easily visible clothing and using lights at night. Use designated bike paths to avoid traffic. If your seizures are not well-controlled stick to bike paths and parks rather than cycling on public roads and avoid riding alone.

5 Photosensitivity

Strobe lighting or flashing lights can trigger seizures in some people. This is known as photosensitive epilepsy. Unless you have been diagnosed with photosensitive epilepsy, watching television, using a computer or playing video games should not affect you.

Only about 5-7% of people with epilepsy have photosensitive epilepsy. It is most common in children and usually starts between the ages of 6 and 18 years. Girls are more commonly affected than boys and photosensitive epilepsy is thought to have a genetic cause. Both natural and artificial light sources can trigger seizures in people with photosensitive epilepsy. Natural light sources can include sunlight shining off water, through leaves on trees, or fence railings. Artificial light sources can include television screens, strobe lights and video games.

Most people with photosensitive epilepsy are sensitive to 16-25 Hz. Some people may be sensitive to rates as low as 3 Hz and as high as 60 Hz. The word hertz (Hz) refers to how often something happens in a second. For example, it can mean the number of times something flashes or flickers in one second. It can also mean the number of times the scanning lines on televisions and computer monitors 'refresh' themselves in one second. It is recommended to avoid screens and lights flashing below 100Hz. When faced with a potential risk, covering one eye may reduce the effect of flickering light.

Some people with photosensitive epilepsy have seizures only when exposed to flashing or flickering light sources. Others may find that only some of their seizures are due to photosensitivity. However, if your seizures are triggered by 'photic stimuli' there are things you can do to minimise the risk of seizures.

- Use an LED or LCD television or computer monitor because they are much less likely to trigger seizures in people with photosensitive epilepsy. Watch television in a well-lit room, sit at least 2.5 metres away from the television set and not directly in front of the screen.
- When playing computer games, sit a minimum of 30 cm back from a computer monitor, again in a well-lit room and reduce the brightness of the display. Limit the amount of time you spend on the computer in any one sitting and have frequent breaks.

With the growth in popularity of 3D movies and 3D TV, people have asked if these might trigger seizures. There is no definite answer to this question, however, it has been found that very few photosensitive triggered seizures occur in cinemas, and may in fact be less likely with 3D films. Do not hesitate to leave the cinema if you feel uncomfortable watching a 3D film. Nightclubs generally display warnings if strobe lighting is used. If this is a trigger for you it would be advisable to avoid such clubs. If flashing lights make you feel uncomfortable, covering one eye or turning away from the light source can lessen this discomfort and lessen the likelihood of a seizure in someone who is photosensitive. Wearing wrap around Polaroid sunglasses may also lessen the likelihood of seizures in someone who is photosensitive.

6 Travel

Having a regular supply of medication is important for anyone travelling away from home for any period of time. It is wise to carry your prescription with you – if something unforeseen happens to your medication you can have it replaced immediately.

Travelling overseas requires some extra planning. Arrange to take enough of your medication in its original packaging to last for the duration of your holiday. Pharmacists are able to dispense the full amount of the script, including all the repeats at once, if the doctor endorses the script with the words 'Regulation 24.' Ask your doctor for a letter listing your medications, including their generic (chemical) names, since brand names may vary between countries. Ask your doctor to include information about your epilepsy and any other relevant information. This is useful for Customs and if you need to get tablets while you are away or are admitted to hospital for treatment. Always carry all or most of your medication in your hand luggage because your main luggage may be lost or delayed in transit. Some people prefer to divide their medication between their carry-on luggage and checked luggage, just in case either is lost or stolen. It is advisable to avoid excessive alcohol during the flight and drink plenty of water.

Find out if vaccinations are recommended for the country or countries you intend to visit. Seek advice from a specialist travel clinic as there may be special considerations required if you have epilepsy. Your doctor will also be able to discuss your options with you.

Long distance travel can disrupt your sleep pattern and your medication routine. What to do when changing time zones depends on how many hours the change will entail. If the time at your destination is less than four hours ahead of, or behind, your home time, you probably don't need to worry – just take your medication in the normal way. For those people on longer flights, while in transit take your medication as if you were still at home. Once you have arrived at your destination aim to maintain the same time interval between doses as you would if you were still at home. You may need to make some gradual adjustments over a few days.

Whether you are travelling overseas to visit family, as a tourist, for business or to live, the Department of Foreign Affairs and Trade encourages you to register your plans before you leave Australia. The registration information you provide will help to contact or find you in an emergency - whether it is a natural disaster, civil disturbance or family emergency. It may also be used to pass other information to you such as important travel advice updates, notice of elections and information on other matters relevant to travellers and expatriates. Visit www.smarttraveller.gov.au for more information and to register.

It is highly recommended that you take out travel insurance for the duration of your trip. As epilepsy is considered a pre-existing condition, a higher premium will be charged until your epilepsy has been well-controlled for a time, but you will have peace of mind while travelling. Medical costs incurred outside Australia have the potential to cause financial ruin. The Chronic Illness Alliance has useful information about travel insurance on its website: www.chronicillness.org.au. The Epilepsy Foundation can give you the contact details for overseas epilepsy organisations.

7 Safety

People with epilepsy, especially those with poorly controlled seizures, have an increased risk of injury. If safety is a concern for you or your family, there are some precautions you can take within the home and in the community to minimise these risks. Injuries caused by falls and burns are quite common for people with uncontrolled epilepsy.

The potential risk associated with everyday activities depends very much on the individual nature of your epilepsy. You may need to adjust your lifestyle to minimise or remove these risks.

If you lose awareness or become unconscious during your seizures everyday activities such as climbing ladders, using power tools, taking hot baths or showers, cooking, ironing and standing by the fire may pose a risk. Adopting simple safety measures within the home can minimise many of these risks. Consider obtaining an OT assessment prior to any home modifications or before building a new home.

Identification

The decision to wear or carry some form of medical identification is a very personal one. A medical bracelet or necklace, or a card for your purse or wallet, stating your name, medical condition and emergency contacts, can improve your chances of appropriate first aid and medical treatment if a seizure occurs outside your home. If possible, include your current medication and always ensure the emergency contact details are up to date. There are many products available for purchase and the Epilepsy Foundation can provide you with information about some options.

Around the home

The living room

Open fires, heaters, sharp edges, a cluttered room and large expanses of window or door glass all pose some risk in the event of a seizure. Having adequate heating and cooling to regulate the internal temperature is vital for many people with epilepsy. You can lessen these risks by:

- placing guards securely in front of fires and heaters. Avoid radiators that have no guards and, when buying a new heater, consider one that can be fixed high on the wall
- placing furniture in front of glass windows
- having oval rather than square tables and furniture without sharp corners
- minimising the furniture in the living room and avoiding having a large coffee table in the centre of the room

The kitchen

Hot liquids, open flames, hot elements, electrical appliances and sharp edges are the main risks in the kitchen. You can lessen these risks by:

- using the back elements of the stove rather than the front ones
- turning saucepan handles to the back of the stove
- using a stove-guard that fits around the top of the stove, which lessens the chance of saucepans being pulled over
- avoiding open-topped jugs
- using a kettle with an automatic off switch and a safety cradle if available
- using a microwave oven rather than a conventional oven

- keeping knives in drawers rather than on benches or in knife blocks
- drinking hot drinks from a closed thermal cup to minimise the risk of burns

The bedroom

Bedheads and bedside tables can contribute to injuries during a seizure, as can a fall from the bed. Pillows may be of concern for some people. You can lessen these risks by:

- moving bedside tables away from the bed and trying to reduce hard or sharp surfaces in the bedroom. If possible, use a bed without a bedhead or have a padded fabric bedhead
- placing the mattress on the floor or sleeping on a futon
- sleeping without a pillow, or buying a porous pillow.

The bathroom

Bathrooms have inherent risks because surfaces are often hard, there can be sharp corners on cabinets and shower screens and the confined space can often restrict assistance in the event of a seizure. Bathing poses its own set of problems in the event of a seizure, with drowning the greatest risk. If the bathroom is very small a sliding or outward opening door is advisable for ease of access. You can lessen these risks by:

- showering rather than bathing
- placing a soft waterproof cover or large mat over hard surfaces
- use a wall or ceiling heater rather than a floor heater
- installing recessed taps if possible
- leaving the door unlocked
- fitting dense foam around the edge of the sink and bath
- ensuring adequate ventilation

Showers are less dangerous than baths because they hold less water and drowning is less likely, but some issues should still be considered:

- toughened safety glass is preferable to shower curtains which can either become entangled around a person or allow them to fall out of the shower
- the shower recess should have a door that opens outwards
- level access or walk-in showers also make for easier access and can reduce the number of hard edges to fall against
- non-slip shower mats can also help reduce injuries during falls
- people prone to seizures in showers may need to use a shower chair

Seizures in a toilet can cause injuries and can make it difficult for people to reach you. You can lessen the risk by leaving the door unlocked and devising another way to ensure privacy. Replace an inward opening door with a sliding or outward opening door.

8 A word about SUDEP

Most people in the community are unaware that a small percentage of people with epilepsy can die suddenly of SUDEP.

SUDEP is sudden unexpected death in someone with epilepsy, who was otherwise well, and in whom no other cause for death can be found, despite thorough post mortem examination and blood tests. The definition excludes people dying from status epilepticus and those who drown.

Most people with newly diagnosed epilepsy will stop having seizures, and SUDEP is very rare amongst them. The cause of death in SUDEP is currently, by definition, unknown but various risk factors have been suggested. These include young adulthood, presence of convulsive attacks, poor seizure control and poor adherence to antiepileptic drugs (AEDs).¹

People with epilepsy can try to minimise the risk by taking medication as prescribed, being aware of lifestyle factors that can provoke seizures, minimizing or eliminating any trigger factors and seeking medical assistance when required.

The Epilepsy Australia publications *Sudden Unexpected Death in Epilepsy: a global conversation and continuing the global conversation* provide more information on the subject of SUDEP. If you would like to find out more about SUDEP the full text can be accessed online at www.epilepsyaustralia.net

To discuss SUDEP with an epilepsy support worker, contact the Epilepsy Foundation of Victoria on 1300 852 853.

¹ Chapman D., Moss B., Panelli R. and Pollard R., *Sudden Unexpected Death in Epilepsy: a global conversation*, Epilepsy Australia Ltd, Epilepsy Bereaved, 2005, p2.

Further information:

For more information, contact the Epilepsy Foundation of Victoria on 1300 852 853 or visit www.epinet.org.au

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