

Living well with epilepsy

Each person experiences epilepsy in different ways depending on the type, frequency, severity and predictability of their seizures. In up to 70 percent of cases, medication can stop seizures occurring – or at least reduce them dramatically.

From time to time, certain issues will arise and some lifestyle adjustments may need to be made. Epilepsy will have an impact on your life, but you can minimise the impact by recognising those issues that affect you and by managing them in a positive way. You may have a seizure for no obvious reason or you may find certain things seem to trigger your seizures. Common triggers include:

- Forgetting to take your medication
- Lack of sleep
- Too much alcohol
- Feeling ill or hot
- Stress/boredom
- Missing meals
- Dehydration.

You may have photosensitive epilepsy, which means flashing or flickering lights can trigger your seizures. Only about five percent of people with epilepsy are photosensitive.

1. Your lifestyle

A healthy lifestyle can help you control your seizures. By getting adequate sleep, having a good diet, minimising the stress in your life, limiting your intake of alcohol and getting adequate exercise, you may improve your seizure control and general wellbeing.

Sleep

Getting adequate sleep is essential for most people diagnosed with epilepsy and maintaining a regular sleep habit is vital. Sleep deprivation is one of the most common trigger factors and should be avoided. Sleep deprivation occurs when you stay up much later than normal. Sleeping in the next morning after a late night is unlikely to lessen the risk of a seizure. Shift work can create significant problems, especially if you work late during one shift followed by an early start the next morning for your next shift.

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 protect you against large swings in blood sugar levels.

For some people, caffeine is a seizure trigger so drinks containing caffeine, such as coffee, tea, energy drinks and those with cola, should be avoided. Caffeine may trigger seizures if it is consumed in excess as it can lead to sleep deprivation.

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 amounts 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. 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.

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 this action may trigger a major convulsive seizure.

Antiepileptic drugs with other drugs

In addition to being illegal, it is strongly recommended that people with epilepsy refrain from taking recreational drugs such as cocaine, ecstasy, heroin, amphetamines or marijuana because these drugs can provoke seizures. Even though marijuana has been shown to have anti-seizure properties suited to some forms of epilepsy, the risk of psychosis in young people, 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 such a drug to control your 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's licence, dependency on others for transport, problems with work or memory and mood disturbances, such as depression.

As well as taking your prescribed medication, stress management techniques including relaxation and breathing, meditation, exercise, time management, assertiveness training 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 recognise when you are having a seizure and know what seizure first aid to provide.

Download a plan from www.epinet.org.au (Epilepsy Management Plan and Support Package) or contact the Epilepsy Foundation for a copy.

We recommend you keep a record of your seizures. Most people aren't aware during their seizures so ask a witness to write a detailed description whenever your seizures are observed by someone else. Keep the date, time and record of 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 (Epilepsy Management Plan and Support Package). Take it to each doctor's appointment to help your doctor assess the effectiveness of your treatment. If you have had many seizures over an extended period, summarise the information on one page prior to the next appointment with your neurologist.

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 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. People with epilepsy are strongly advised to avoid brand substitution of their medication. Sodium valproate, for example, is sold in Australia as Epilim or Valpro. There are subtle differences in the composition of different brands of the same medication that might cause break through seizures or an exacerbation of side-effects.

There is no way of predicting who might be at risk, so avoiding substitution is the best way to prevent this problem, especially in people with well-controlled epilepsy. Notify your pharmacist if you don't want to change and always check the medication each time it is dispensed. These problems are less likely to occur if you always use the same pharmacy that stocks your brand and get your new script filled at least a few days before your existing medication runs out. Pharmacies can order a branded medication they don't keep in stock but it can take up to three days to get the medication. Make sure you take your own medication whenever you are admitted to hospital because the hospital pharmacy may not stock the brand of your particular medication. It is also a good idea to take your prescriptions.

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 drugs. 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.

Vomiting and diarrhoea can alter the level of medication in your bloodstream required to control your seizures. 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. Sudden withdrawal of medication can lead to increased seizures as well as putting yourself at risk of status epilepticus (prolonged seizures) that can result in 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 as prescribed. 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. To help you remember, keep your tablets on top of your pillow or in the kitchen but out of reach of children. Some people use digital watch alarms to remind them. 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. Always carry two or three doses with you as a backup in case you forget your morning dose or are unable to get home in time to take your evening medication.

Dosette 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 out of the reach of children.

3. Seizures and driving

Being diagnosed with epilepsy and the subsequent suspension of your driver licence can, for a time, throw your life into disarray, particularly if your job involves driving. But it may be for a relatively short period and once your seizures are controlled you will be able to drive again safely and legally.

The period that you must be free from seizures before driving depends on the type of seizure and the circumstances surrounding it. The frequency of periodic reviews may vary depending on your doctor's medical report.

See the Epilepsy Foundation website for more information or to download the VicRoads brochure *Seizures and Driving*, which explains the rules.

If you hold a current learner permit or driver licence you are required by law to notify VicRoads if you have or develop any serious or chronic medical condition. This includes epilepsy and seizures.

If you drive with a serious or chronic medical condition without notifying VicRoads, and you are involved in a crash, you could be sued under common law and/or charged with driving offences. In addition, your insurance company may not provide cover.

For VicRoads information 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 advisable to have a family member or friend accompany the person with epilepsy in some of the riskier sports, so they are on hand to help in the event the person has a seizure. 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 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 your companions know you have epilepsy and are capable of rescuing you if you have a seizure.

If you are swimming in a public swimming pool, inform the lifeguard of your epilepsy and how to assist should the need arise. However, be aware that the lifeguard cannot be relied upon to provide close supervision and could be assisting someone else at the time of a seizure.

When engaging in any water sport such as boating, canoeing, windsurfing or sailing always wear a life jacket and avoid undertaking these activities solo – and 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.

Cycling

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

Horse riding

Wear a riding helmet and try to ride with other people.

Photosensitivity and epilepsy

Strobe lighting or flashing lights can trigger seizures in some people. This is known as photosensitive epilepsy. However, it only affects about five percent of people with epilepsy.

Unless you have been diagnosed with photosensitive epilepsy, watching television, using a computer or playing video games should not affect you. However, if your seizures are triggered by 'photic stimuli' there are things you can do to minimise the risk of seizures.

Watch television in a well-lit room, do not sit too close or directly in front of the screen and use the remote control.

When playing computer games, sit 2.5 metres from the screen, again in a well-lit room and reduce the brightness of the display. A seizure is more likely to happen within the first 30 minutes of play. Limit the amount of time you spend on the computer in any one sitting and have frequent breaks.

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. There is some evidence that blue cross polarized sun glasses may be even more helpful for people who have photosensitive epilepsy. Contact the Epilepsy Foundation of Victoria for more information about this option.

5. 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 the 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 luggage is lost or stolen.

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 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.

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 can cause financial ruin.

It is advisable to avoid alcohol during the flight and drink plenty of water.

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.

6. Safety

Some 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 when out in the community to minimise these risks.

The potential risk in everyday activities depends very much on the individual nature of your epilepsy. You may need to adjust your lifestyle to minimise or remove the risks that epilepsy can bring for you or those you support.

If you lose awareness during your seizures and they are not fully controlled or are unpredictable, 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.

The following are suggestions only and they may not apply to everyone.

Identification

The decision about whether 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, address and medical condition, can improve your chances of appropriate first aid and medical treatment in the event of a seizure occurring outside your home. If you use a card, include emergency contact details and a list of your current medications. There are many products available for purchase and the Epilepsy Foundation can provide you with information about some options. We also have a limited range of products for sale.

Helmets

If you have frequent seizures and a tendency to fall, you may choose to wear a specially-designed helmet to help protect your head from injury. However, if the helmet is not fitted properly, it may not give you enough protection. You can consider having a helmet custom-made to your requirements.

Around the home

The living room

Open fires, heaters, sharp edges of furniture, 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, if you are buying a new heater, consider the fan type or a heater 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
- drinking hot drinks from a closed thermal cup to minimise the risk of burns.

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 switch off and a safety cradle if available
- using a microwave oven rather than a conventional oven.

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
- 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 in that the 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
- using a non-slip mat in the shower or bath
- placing a soft waterproof cover or large mat over hard surfaces
- unplugging all electrical appliances as soon as you have finished with them and making sure they are off the floor
- leaving the door unlocked
- using a soft shower curtain instead of glass
- using a shower chair
- fitting dense foam around the edge of the sink and bath
- ensuring adequate ventilation
- avoiding excessively hot showers
- reduce the maximum temperature of your hot water system by adjusting the thermostat to lessen the likelihood of burns.

The toilet

Seizures within this confined space can cause injuries and can make it difficult for people to reach you. You can lessen these risks by:

- leaving the door unlocked and devising another system to ensure your privacy
- replacing an inward-opening door with a sliding or outward-opening door.

7. 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 (or those caring for a child or adult with epilepsy), can try to minimise the risk by taking medication as prescribed, being aware of lifestyle factors that can provoke seizures and ways these factors can be better managed and seeking medical assistance when required.

The Epilepsy Australia publication *Sudden Unexpected Death in Epilepsy: a global conversation* provides 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 counsellor, contact the Epilepsy Foundation of Victoria on 1300 852 853.

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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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.