

Can I Die From Epilepsy?

Perhaps. Sudden unexpected death is more likely to occur in someone with epilepsy than without, however the risk of Sudden Unexpected Death in Epilepsy (SUDEP) is still low:

- For an adult the rate of SUDEP is one in 3000 people over a one-year period.
- For people with poorly-controlled seizures the risk is one in 100 people over one year.
- In children the risk of SUDEP is even rarer at one in 10,000 people over one year.
- To put these statistics into perspective, keep in mind there is a higher risk of unexpected death with many illnesses including influenza and asthma.

We don't yet know what causes SUDEP but we do know that taking the correct medication in the correct doses will help gain control of seizures and reduce the risk of SUDEP.

A higher overall risk appears to relate to a higher frequency of seizures. Key risk factors noted are:

- young adult.
- generalised tonic-clonic seizures.
- seizures at night.
- abrupt and frequent changes of medication in people whose seizures are not well controlled.

What you can do to help minimise risk factors:

- ensure seizures are correctly diagnosed.
- have regular medical reviews of your epilepsy.
- learn about your epilepsy.
- tell your doctor if you are having seizures.
- follow the treatment plan and ask for advice if you are having unpleasant side effects.
- identify and avoid any seizure triggers for you, such as lack of sleep or excessive alcohol.
- carry out a risk assessment of your home and work environment.
- give accurate first aid information to those who might care for you.
- If you or someone you know has suffered a bereavement due to SUDEP, Epilepsy Tasmania can refer you to experienced counsellors to help you through this time.
- You can also call our helpline on 1300 852 853 or email sudep@epilepsyaustralia.net

Are Seizures Dangerous?

Although someone having a seizure may injure himself or herself externally by knocking into things, the risk of internal injury such as brain damage or even death is very low.

A person is most at risk of injury if doing something potentially dangerous when a seizure occurs. However, based on a medical assessment a doctor will recommend guidelines in relation to driving, the use of dangerous machinery, working above ground level and high-risk activities such as scuba diving.

The risk of accidents and other unwanted outcomes from seizures such as having a seizure in front of work colleagues, having a seizure on public transport or at a special event, can be a source of fear for many people. By remaining aware of the risks and taking reasonable steps

to manage them, people with epilepsy need not cut themselves off from living a fulfilling life.

Ensuring your seizures are correctly diagnosed, your treatment plan is followed and first-aid information is available will minimise your risks.

General Safety Checklist

People who continue to have seizures are more susceptible to the potential risks associated with living with epilepsy.

Ensuring that seizures are correctly diagnosed, that treatment plans are followed and that first aid information is available will minimise risk.

Although it can be frightening to watch someone have a seizure – especially a convulsive one – you should be reassured to know that the risk of brain damage or death is low.

Plan To Reduce Injury

Anything that affects a person's conscious state, awareness or judgement can increase the risk of accidents.

Take a few moments to consider the risks your seizures might create to yourself or others if they were to happen at home, work or during a leisure activity. Our safety checklists below can help you do this.

React Quickly To Cases of 'Status Epilepticus'. Status epilepticus refers to seizures that are prolonged or occur one after the other in quick succession. In some seizure types, status epilepticus when untreated can cause brain damage and be life-threatening.

However, be reassured that status epilepticus is uncommon and treatment of epilepsy aims to prevent it occurring in the first place and treat it rapidly if it does.

Some patients who are considered at high risk of status epilepticus may be prescribed emergency medication, such as rectal diazepam or intranasal midazolam. These medications should be kept in an appropriate safe place, the use by dates should be checked regularly, and training should be provided to anyone who might be required to administer the medications.

Wear Emergency Identification

Some people choose to wear a medical identification bracelet or pendant with epilepsy information in case of an accident. Another option is to carry medical information in your wallet.

Create An Epilepsy Management Plan

An Epilepsy Management Plan is a risk management tool detailing how family members, carers, work colleagues or teachers should respond to the person who is having a seizure.

Epilepsy Management Plans are often required by schools, pre-schools, childcare centres, disability services, supported accommodation and respite services, and disability employment services. Plans help staff recognise seizure activity and provide documented procedures to follow should an emergency arise.

Plans should include the following information:

- type of seizure/s.

- known triggers.
- a description of the seizure pattern.
- who to contact in an emergency.
- name & dose of antiepileptic medication/s, and the time medication is administered.
- step by step instructions from the treating doctor on how to manage the seizure and if emergency intervention treatment is required, the specific circumstances under which it is to be administered, and the time-frame in which an ambulance should be called.
- If the seizure activity requires emergency intervention, ensure that the medication is readily accessible. Intervention medications generally prescribed are rectal diazepam and more often today, midazolam.

Epilepsy Tasmania can provide information and training in the administration of these treatments.

Download an Epilepsy Management Plan:

- Developing an Epilepsy Management Plan
- A template to complete
- Guidelines to Help You Write an Epilepsy Management Plan

Safety Checklist Around the Home

Safety Checklist around the Kitchen:

- consider a microwave instead of stove top or oven.
- if using a stove use the back elements and turn pan handles away from the stove.
- consider a temperature controlled hot water service.
- serve hot dishes from a bench instead of carrying them to the table.
- use cordless electrical appliances with automatic switch off and appliances like food processors rather than using sharp knives.
- use rubber gloves when washing dishes.
- use non breakable crockery and have hot drinks in a mug with a lid.
- if using a dishwasher place points and sharp objects down and close door when not in use.
- consider cupboards with recessed handles.
- minimise the use of knives; Consider buying pre-sliced food.

Safety Checklist around the Living Room:

- use fixed fireguards around a fireplace.
- consider round rather than square or rectangular coffee tables.
- use shatterproof glass for big windows.
- for photosensitive seizures reduce the contrast of the television screen by turning on the lights in the room and sit at least 3 metres from the set. A quality TV (with 100hz refresh rate), LCD or plasma screens are also useful.
LCD screens for computers are flicker free and useful for people with photosensitive epilepsy.

Safety Checklist in the Bathroom:

- consider a temperature controlled hot water service.
- always turn on cold water first.
- use a handheld shower attachment in the shower and in the bath if no shower available. Remember to leave the plug out.
- consider shower curtains rather than a glass screen or in the case of a glass screen use reinforced glass.
- consider rubber backed mats.
- avoid the use of electrical appliances such as hairdryers and electrical razors near water.
- consider the use of a shower chair.
- in the toilet an outward opening door is very important.
- toilet roll holder on the floor beside or behind the toilet may minimise injury if someone has a seizure while on the toilet.

Safety Checklist around the Bedroom:

- don't sleep on top bunk and if possible use a low bed.
- consider tightly fitted sheets.
- sleep without a pillow or use a firm porous pillow.
- consider bed alarms or other monitor devices.

Safety Checklist in general:

- install smoke alarms.
- minimise clutter.
- you might want to consider walkways are clear before going to bed at night.
- if electrical cords are a consideration, tape them to the floor.
- consider doors that are outward opening, sliding, half doors or doors that are easily removed.
- don't lock internal doors and if using a deadlock leave the key in the lock. Use security sets for bathrooms and toilets if needed. These can be unlocked from the outside if necessary.
- consider having safety switches in the metre box installed by an electrician.
- minimise sharp edges and corners.
- avoid living in accommodation with stairs or consider a safety gate at the top of the stairs.
- wear an Identification bracelet or have information available in case of a seizure.
- keep medications out of reach of children. Store in a cool dry place and do not remove from pillbox or webster pack ahead of time.
- push button phones can be programmed so that pushing a particular button after a seizure alerts a relative or friend that the person may need some help.
- minimise glass for example in doors, cupboards and table tops.
- consider ramps rather than stairs.
- consider chairs rather than bar stools.

Safety Checklist for Leisure Activities

When seizures are under control there is no reason to restrict leisure activities.

However people whose seizures are not under control should consider applying some restrictions, particularly for activities that carry greater risks and must always ensure someone knows where they are and what they are doing.

The following information may be helpful:

- Swimming and Bathing
- Swimming and taking a bath alone are not recommended and special care must be taken when using hot water. Turning on the cold tap first in the shower or basin and lowering the storage temperature of the hot water are good safety hints for any home.
- Showers, baths and running water 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.

In general:

- never swim alone - when participating in water activities take a friend or carer with you.
- let a lifeguard know about your condition.
- wear life-jackets in boats and when fishing.
- avoid scuba diving and high board diving.
- avoid water that is too hot in spas and keep up fluids.

Team and Contact Sports

- consider wearing a helmet whilst participating.
- Cycling - always wear a helmet.
- use bike tracks / lanes if your seizures are not well controlled.
- Rock Climbing - always use a safety harness.
- Horse Riding - always wear a helmet. Try to ride with other people.

Night Clubbing

be aware that strobe or flashing lights can in some people trigger seizures, although this is rare.

High-Risk Activities

- participate in scuba diving only if your seizures are very well controlled.
- participate in boxing only if your seizures are very well controlled.
- bungy jumpy is best avoided altogether if you have epilepsy.

General Leisure Activities

- use protective headgear when participating in activities with a risk of falling or head injury.

- be aware of overexertion or overheating.
- drink plenty of water.
- if possible try to choose activities that take place on softer surfaces such as grass, mats etc.
- consider whether it may be useful to have a gym buddy if using weights, stationary equipment etc.

Safety Checklist for Work / School

When assessing epilepsy-related risks at work or school, it is helpful to have a detailed understanding of the person's individual epilepsy condition.

Strategies need to be realistic, appropriate and practical and questions you should consider include:

- Safety Checklist for Work / School
- what safety considerations are needed?
- have you informed someone that you have epilepsy?
- are policies and procedures in place should a seizure occur?
- is an individual emergency plan necessary?
- have guidelines with driving and use of machinery been understood?
- does the workplace or school need some epilepsy education?
- does the school or workplace have a recovery room?
- are they aware of helpful resources?

Downloadable Resources

The following downloadable resources may be helpful. If you're unable to download the links please ask us for a copy to be sent by post.

- position statement
- transport.tas.gov.au
- Travelling with Epilepsy
- Light and Epilepsy
- Sudden Unexpected Death in Epilepsy (SUDEP)

Seizures:

- First Aid Poster
- All About Seizures - Understanding seizures and first aid responses.
- Seizure Diary
- Diagnosing Epilepsy - An easy to understand booklet answering common questions about epilepsy.