



living well with epilepsy

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Epilepsy Risk Management

People who continue to have seizures are more susceptible to the potential risks associated with living with epilepsy. Cause, type, and frequency of seizures vary between people. The evaluation and management of risk needs to take into account the persons seizures and their unique circumstances. Ensuring that seizures are correctly diagnosed, that treatment plans are followed and that first aid information is available, minimises risks.

Although many people who witness a seizure fear that the person may be harmed, especially by a generalised convulsion, the risk of brain damage or death from a seizure is low.

Based on a medical assessment, the 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.

Injury

Anything that affects a persons' conscious state, awareness or judgement can increase the risk of accidents. Burn related injuries are often reported in people who experience focal (complex partial) seizures and tonic clonic seizures. Most common are injuries due to scalding in the kitchen or bathroom.

Reducing hot water temperature to 50 Celsius can protect against 3rd degree burns. Similarly strategic placement of indoor heating appliances can minimise the risk of burns in the event of a tonic clonic seizure. A person is at most risk of harm if they are doing something dangerous, such as driving, when a seizure occurs.

Driving

There are laws about driving after seizures and in general, people who have had a seizure are required to notify the licensing body and stop driving until a medical report is supplied. Most people can return safely to driving but the length of time a person must wait varies between individuals.

Swimming and Bathing

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

Check for hazards

Take a few moments to think about your home, work and leisure activities. Consider any risks that your seizures might create. Could you hurt yourself if you had a seizure? Is there a way that you could reduce the risk of harm to yourself or others?

There are many general safety strategies that you may not be using which would be useful. Do you have smoke alarms, fireguards, or power breakers fitted in your home? Is the hot water temperature controlled? Is your shower safe for anyone who falls, not just someone who has a seizure? Do you wear a bicycle helmet when riding? Safety checklists are available from Epilepsy Queensland. See Safety Checklist fact sheet.

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Emergency Identification

Some people choose to wear a medic alert bracelet or pendant with epilepsy information, in case of an accident.

However this is a personal choice and does not appeal to everyone. Another option is to carry medical information in your wallet.

At work or at school

When assessing epilepsy related risks in the workplace or at school, an accurate understanding of the persons condition is required to form the basis of case by case decision making. Strategies need to be realistic, appropriate and practical.

Status epilepticus

Status epilepticus refers to seizures that are prolonged or occur one after the other in quick succession (clusters). In some seizure types status, if untreated, can cause brain damage and can be life threatening. Status is uncommon and the treatment of epilepsy aims to prevent status occurring and, if it occurs, to treat it rapidly.

Some patients who are considered at higher risk of status may be prescribed emergency medication, such as rectal diazepam or intranasal/buccal midazolam, for out of hospital use. 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.

Death

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. Although it is uncommon, a person with epilepsy may die suddenly with no obvious cause of death. The cause of SUDEP is not well understood and estimates of SUDEP vary from 1:1000 to 1:100 people with epilepsy. The higher overall risk appears to relate to a higher frequency of seizures. Key risk factors noted are:

- Young adults
- Generalised tonic clonic seizures
- Seizures at night

- Abrupt and frequent changes of medication in people whose seizures are not well controlled

Deaths occur with many illnesses, from influenza to asthma, however we emphasise that in epilepsy it is uncommon and that working to control any illness is the best way to minimize risk.

If you would like to get a better understanding of SUDEP, a copy of Epilepsy Australia's free publication [Sudden Unexpected Death in Epilepsy: a global conversation](#) is available upon request.

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.

Although every effort has been made to ensure accurate and up to date information is provided, Epilepsy Queensland and its advisors cannot accept any liability in relation to the information provided. It is strongly recommended that you discuss any information with your doctor or other relevant organisations.

This fact sheet was written by Epilepsy Australia and appears on www.epilepsyaustralia.net Epilepsy Queensland is an affiliate of Epilepsy Australia and has permission to print this.

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