

Should you change your behaviour?

There are some sensible precautions you can take.

If you go swimming, for instance, take a friend with you or tell the attendant at the pool to keep an eye out for you.

At home, you can reduce the risk in the kitchen by using a microwave. Elsewhere in the house, you can make use of fireguards, smoke alarms, fire retardant materials and power breakers on electrical tools.

You may want to consider having a shower rather than a bath. If you do prefer to use a bath, use a thermostat and keep the water shallow.

An 'occupied' sign may be better than locking the door.

There's evidence that being with someone during a seizure may give you additional protection. Talk to your doctor if you experience seizures during your sleep. More research is needed into the risks of nocturnal seizures, but you may wish to consider sleeping on your back or side. However, if you sleep alone, you could also investigate the pros and cons of different monitors and seizure support dogs. Although there is no data supporting the use of anti-suffocation pillows, they certainly won't do any harm and may prevent obstruction of your airways should you have a seizure.

Responding to seizures: First Aid

Consider carrying identification with you that gives information about your condition, how it affects you and what someone needs to do if you have a seizure. It should also include details of the medication you are taking and any specific allergies. You should also make sure people around you know of about any care plan and what to do in the event of you having a seizure.

If you are with someone who is having a seizure:

Keep calm. Let the seizure run its course and do not try to do anything to stop it.

If possible, put something soft under the person's head and move away objects to prevent injury.

After the seizure, lay the person on their side in the recovery position. Stay until they have recovered. Once their breathing and colour is normal it is good to let them sleep until fully recovered.

Call an ambulance if one of the following circumstances applies:

- The person is injured
- The seizure doesn't stop after a few minutes
- A seizure follows closely after another
- The person has trouble breathing or you are concerned about them



EPILEPSY

Be smart, be safe

Please contact us for further information, details of helplines for people with epilepsy, and details of helplines that can help you improve or maintain your mental wellbeing:

Head Office:
01235 772850
info@sudep.org

SUDEP Action Scotland:
0131 516 7987
www.sudep.org

Support (direct line):
01235 772852
support@sudep.org

SUDEP.ORG

"While finding out about the risks associated with epilepsy was frightening at first, having the conversation with my Doctor gave me the information to feel empowered about my epilepsy. I was able to take positive steps to lower my risk, and my life and that of my family were changed forever for the better"

(Sally, diagnosed at 15 months – now seizure free)

Living with epilepsy

There are approximately half a million people in the UK with epilepsy and around 70% will not have seizures if they're taking the right medication regularly. Others may find they're free of seizures after opting for surgery. Some people, however, will continue to find it difficult to control seizures, which seem to be spontaneous and unpredictable.

Although risk varies widely from person to person – and may relate to your age, type of epilepsy, type of seizures and other factors – it's often possible to identify triggers and to take positive action. This leaflet is designed to help you talk to your doctor or nurse about the options you have.

Being aware of risk

As someone with epilepsy, you may well be aware that having epilepsy and seizures brings a number of risks. They can affect your awareness or judgement, for instance, or lead to a fall. The seizures themselves can be risky too though, particularly if they last a long time, occur in a cluster or interfere with your breathing or heart rhythm. You should be particularly aware of the following types of seizures:

- Generalised tonic-clonic seizures (sometimes called 'grand mal')
- Seizures that take place during sleep and nocturnal seizures
- Seizures lasting 30 minutes or more (called status epilepticus or 'status')
- Seizures that occur in a cluster, one after another

As well as understanding your seizures, take time to be aware of how you are feeling so you can tell your medical team about your overall well-being.

Being aware of the risk of sudden death

Each year, roughly one in every thousand people with epilepsy will die suddenly with no obvious cause. This is what we call Sudden Unexpected Death in epilepsy (SUDEP). The risk is low, and may be less or greater for some people, which is why it's important to talk to your medical team about your own condition. You can visit sudep.org for more information and free downloadable information and resources to help you manage your condition.

What you should ask your medical team

It's useful to know the type of epilepsy and seizures you have, so why not make an appointment to discuss this and the ways in which you can reduce risk? Ask to see a specialist if you haven't yet had the opportunity or you feel your epilepsy is not very well controlled. Together, you can draw up a plan to cut down the number of seizures you have and ideally become seizure-free.

Don't forget to attend your annual review, even if you're not experiencing seizures at the time.

What you should tell your medical team

Tell your healthcare team if you have experienced a seizure which lasts longer than normal or if the number or type of seizures you've experienced has changed. Let them know if you are thinking of stopping or changing your medication. They may also be interested in your lifestyle and if you are feeling depressed or anxious.

What help you can expect

Health professionals can give you a plan which includes informing others what to do when you have a seizure. This seizure plan may also include any epilepsy rescue medications which are used to prevent status epilepticus developing. It may also advise others on when to call the emergency services. In some areas of the UK, there may be a specialist epilepsy nurse as part of the local team, who can play a role in informing your family and friends about first aid.

Health professionals can also help you with managing any depression, anxiety or support you if you are relying heavily on alcohol or taking recreational drugs.

The importance of getting your medication right

Anti-epileptic drug (AED) treatment is recognised as the most effective way to control seizures. Your medical team will need to have precise information about the number, frequency and type of seizures you have, in order to prescribe the correct drug at the appropriate dose. If you continue to have seizures, ask to be referred again to an epilepsy specialist for a review of your diagnosis and treatment options.

Dealing with side effects

A common reason that some people continue to have seizures is that they don't take their medication as prescribed. Sometimes this may be due to the side effects they experience. Before you make a decision to stop taking your medicine, it's important to talk to a specialist to see if there's a possibility of making a change or to look at other treatment options. Your medical team will help you balance control of seizures and the avoidance of side effects.

If you're a woman with epilepsy who is considering becoming pregnant, ask for pre-conception counselling so that your medical team can advise you on how to reduce any risk from seizures and side effects of medications should you become pregnant. It is also important if you find out that you are pregnant and have not had pre-conception counselling that you arrange to see your GP or epilepsy specialist as soon as possible to discuss your changing care needs.

How to avoid seizures

Although seizures can be spontaneous and unpredictable, there may often be triggers that you come to recognise. These may include getting anxious, stressed or excited. Sometimes people are affected by lack of sleep, too much alcohol or the fact that they've taken recreational drugs. Seizures can also be triggered by rapid changes in medication, not taking them regularly as prescribed or if you forget to take your tablets entirely. Because triggers are very individual, it might be a good idea to keep a diary of your seizures and see if you can identify a pattern.