

Safety and Lifestyle advice for young people/adults with epilepsy

You may have had epilepsy for as long as you can remember or it may be a new diagnosis. This leaflet is designed to highlight the main safety issues surrounding your epilepsy and give tips on how to minimise those risks and lead as normal a life as possible.

Not everything in this leaflet will apply as it depends on your seizure type and frequency.

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Driving and DVLA

- If you have epilepsy and want to learn to drive you can apply for a driving license if you have been seizure free for 12 months.
- This includes any seizure where you do not have full awareness or full ability to drive a car, so would also include myoclonic jerks and absences.
- If you only have night time seizures or focal seizures that do not affect your consciousness or ability to react then you may be able to drive even if these seizures are still happening. DVLA will advise you.
- If you have a seizure it is your responsibility to inform DVLA that you have had a seizure and stop driving until it has been a year since your last seizure.

- If you continue to drive after you have had a seizure you are putting your life and other people's lives at risk.
- If you continue to drive you will be breaking the law, could face prosecution and your car insurance will not cover you.
- If you are over 17 and cannot drive due to having a seizure in the last year you should be entitled to a free bus pass and can get discounts on train and coach fares. The Epilepsy Society has all the information in their help with travel cost section.

Vocational issues

Most jobs are open to people with epilepsy but there are a few restrictions.

By law people with a diagnosis of epilepsy are not able to work in the following jobs:

- Military forces such as Army, Navy, Royal Marines
- Aircraft pilot

For jobs which involve driving you would need to not be taking any epilepsy medication and be seizure free for 10 years. These jobs include:

- Lorry driver
- Bus driver
- Train driver
- Taxi driver
- Ambulance driver
- Firefighter

There may also be some restrictions if you apply for a job in the police force or prison services.

If you have epilepsy it may not be a good idea to apply for a job working at heights or around open fires.

Alcohol

Alcohol can make seizures more likely to occur and too much alcohol is known to trigger seizures.

- 1-2 units of alcohol are unlikely to be a problem.
- If you have been drinking, seizures are most likely to occur in the 3 days following a drinking session. Your body will be trying to break down the alcohol quickly and in doing so will break down your medicines more quickly meaning they will not be as effective.

- When under the influence of alcohol some people forget to take their regular epilepsy medication.
- Alcohol can also disturb sleep and so provoke seizures.
- Ways to reduce your risk of a seizure if you are having a night out involving alcohol:
 - Eat a substantial meal.
 - Drink plenty of water/soft drinks.
 - If you think there is a possibility you will forget your medication when you get home consider taking it a few hours early before you go out.
 - Remember to take your medication the next morning, set an alarm to wake you and then go back to sleep if necessary.
 - Try not to plan a night out if you need to get up early the next day, and try not to plan 2 nights out in a row, remember that sleep deprivation is the biggest trigger for seizures.

Smoking

There is no evidence to suggest smoking cigarettes will make seizures worse. Smoking will affect your physical health, which will make seizures more likely. There is also a burn and fire risk if you have a seizure whilst smoking.

Drugs

Recreational drugs are illegal and have particular risks for people with epilepsy.

- Drugs can change the brain's chemistry which can lead to seizures.
- Taking drugs can also mean your sleep is disturbed; you are more likely to miss meals and not take your medication on time.
- Drugs also increase the risk of mental and physical health problems, which in turn make seizures more likely.

Medicines and lifestyle

Many health conditions are improved when people lead a healthy lifestyle. For people with epilepsy having a good sleep routine and regular meals can improve your seizure control.

- It is important to take medication at regular times and not miss any doses.
- Incorporate taking your medicines into a daily routine.
- It may be useful to have the tablets in a pill box which is labelled with days of the week.
- Some people find setting an alarm on their phone to remind them twice a day is useful.
- If you vomit within 30 minutes of taking the medication then the full dose can be repeated.

- If you forget your medication:
Twice a day regime:
 - Less than 4 hours late: take the dose and continue the following doses as usual.
 - More than 4 hours late: miss that dose and take the following doses as usual.
Once a day regime:
 - Take the medication for that day if you are less than 12 hours late.

Side effects of medication

Unfortunately medication to control seizures often has side effects, these are usually worse when first commencing on a new medication and then usually settle down to a tolerable level. The most commonly reported side effects are:

- Drowsiness.
- Lack of energy.
- Behaviour change.
- Disturbance in sleep pattern.
- Slowing down of processing speed affecting concentration and memory.

It is common practice that young people who take medication to control their epilepsy are given up to 25% extra time for their exams. The school will need to apply to the exam board.

Each medication will come with a long list of possible side effects. Most of these are very rare but if you are concerned about any side effects speak to your GP or epilepsy nurse for advice.

Bone Health

Studies have shown that long term use of anticonvulsants can affect bone health, so taking a vitamin supplement that has calcium and vitamin D may be helpful. Taking regular exercise and having safe exposure to sunlight is also recommended.

Swimming, sports and other activities

Swimming

Swimming in a pool with a lifeguard is safe for individuals with epilepsy but the lifeguard should always be informed. Ideally everyone with epilepsy should always swim with a family member / friend who would know what to do if you had a seizure.

Seizures are more likely to happen if you are tired or unwell so avoid swimming at these times.

Also avoid swimming at very busy times as it may be more difficult for the life guard to observe you if you have a seizure.

How to deal with a seizure in the water:

Tonic clonic seizure: (unconscious, stiffening and jerking of limbs)

- From behind, tilt the person's head so it is out of the water.
- If possible, move the person to shallow water, while holding their head above water.
- Don't restrain their movements.
- Once jerking movements have stopped move them onto dry land
- Place in recovery position and stay with them until recovered.
- Call an ambulance if you think the person may have swallowed or breathed in water, even if they now appear fine.
 - Or if the seizure lasts longer than is usual for that person or longer than 5 mins.
 - Or if an injury has occurred.

Absence/focal seizure: (vacant episode/mild seizure)

- Protect the person from danger by guiding them away from deep water or holding their head above water.
- When they recover check if they need to get out of the water as they may be drowsy or confused.

Water sports

Life jackets should always be worn when taking part in water sports. Swimming in water such as the sea, lake or river which does not have a lifeguard is not advisable, especially if swimming alone.

Scuba Diving is not recommended at all for people with epilepsy due to the life threatening risk if a seizure happens whilst underwater. The British Sub-Aqua Club currently states that divers must be off anticonvulsants and seizure free for at least 5 years to consider taking part in scuba diving.

Sports

Having the opportunity to take part in sport and leisure activities is important for everyone, including people with epilepsy. With the right support and the relevant safety precautions, there is little that someone with epilepsy would need to avoid. However it is always a good idea to follow the rules and recommendations in terms of safety equipment.

To take part in some sports or activities, a medical form may need to be completed. This information should only be used to help the organiser complete a risk assessment and make reasonable adjustments if necessary

Epilepsy Action has a good webpage on many different sports and what precautions should be taken: www.epilepsy.org.uk/info/sports-leisure

Cycling

- Normal safety precautions include wearing high-visibility clothing and protective head gear are particularly important if you have epilepsy and want to cycle.
- If seizures are not fully controlled avoid cycling on busy roads and by rivers or canals.
- If seizures are frequent it is advisable not to cycle on public roads altogether, until seizures are under better control.

Photosensitivity

Photosensitive epilepsy is when seizures are triggered by flashing lights or contrasting light and dark patterns. Photosensitive epilepsy is not common, approximately only 5% of people with epilepsy are photosensitive. An EEG test can diagnose photosensitivity. This type of epilepsy usually responds well to treatment. Flashing or patterned effects can make people with or without epilepsy feel disorientated, uncomfortable or unwell. This does not necessarily mean they have photosensitive epilepsy.

If you have a diagnosis of photosensitive epilepsy you are unlikely to outgrow your epilepsy so your doctor will suggest that you take medication long term

Between 3-30 hertz (flashes per second) are the common rates to trigger seizures but this varies from person to person. While some people are sensitive at frequencies up to 60 hertz, sensitivity under 3 hertz is not common.

Ofcom regulates material shown on TV in the UK. The regulations restrict the flash rate to 3 hertz or less, a warning will be issued if there is going to be a high level of flashes on a programme. In cinemas due to the size of the screen and the low intensity, it is rare for seizures to be triggered this way. Computer games also have regulations on the flash rate allowed so are unlikely to cause a seizure.

Tips on how to minimise the risk of a seizure:

- Take regular breaks from the screen.
- Sit well back from the screen.
- Watch TV, or play computer games in a well-lit room.

For some, sunlight coming through the trees, blinds or reflecting on water can cause a seizure.



If you are suddenly exposed to a potential risk then covering 1 eye completely with your hand while moving away from the risk can greatly reduce the chance of a seizure.

Contraception

Some methods of hormonal contraception may be less effective in preventing pregnancy in women who take certain anti-epileptic medication. When asking advice from your GP or family planning nurse about suitable contraception, make sure they are aware of what medication you are taking.

Barrier methods and the coil (IUD and IUS) are both safe to use with all anti-epileptic medications.

Planning a Pregnancy

Taking folic acid, before and during pregnancy, reduces the risk of a baby having spina bifida. If you take epilepsy medicine, medical professionals advise that you take a five milligrams daily dose of folic acid. This is instead of the 400 micrograms daily dose of folic acid that most women are advised to take.

It is advisable to take five milligrams of folic acid all the time that there is any chance that you could become pregnant. It is also advisable to take it during the first three months of pregnancy. You will need to get a prescription for this dose from your family doctor.

Most pregnant women with epilepsy have a normal pregnancy and labour.

Ideally pregnancy should be planned if you take anti-epileptic medication as some changes may need to be made to your medication.

Studies of women taking sodium valproate (Epilim) during pregnancy have shown that up to 40% of the children had a form of neurodevelopmental disorder such as ADHD or autism.

Sodium valproate is also known to increase a teenage girl's risk of developing polycystic ovaries. Due to these side effects whenever possible sodium valproate is not given to teenage girls and a different epilepsy medication is used instead.

If sodium valproate is the only medication which will control your seizures, effective contraception should be used. Speak to your doctor or specialist if you are planning a baby.

If you do get pregnant continue to take your medication and contact your specialist immediately to discuss your drug treatment. Do not alter your drug treatment or

stop taking your medication without specialist advice. This is because a severe seizure in pregnancy could result in harm or injury to you or your baby.

Holidays and travel insurance

When booking travel insurance it is important to let the insurance company know that you have epilepsy. If a hospital admission is required due to the epilepsy whilst on holiday and the insurance company was not aware it could cost you a lot of money that you won't be able to claim back.

Always pack any medication in your hand luggage. Suitcases can get lost. Pack extra medication in case there are any delays. Try to take medication at usual UK time if possible.

Dealing with anxiety

It is very common for young people with epilepsy or any long term health condition to have anxiety. Having a supportive family and friends that you can talk to are really useful. But please do seek help if you are struggling.

Have a look at the mental health a wellbeing leaflet which has details of the support available in your local area.

Safety in the home

If your seizures are controlled with treatments, or you retain awareness during your seizures, your safety may not be affected. But for people that have the potential to have a seizure with no warning it is a good idea to think about ways you can minimise risk in the home environment.

In the bathroom

All individuals with epilepsy need to take extra care when bathing due to the risk of drowning during a seizure.

- A shower is safer than a bath as the water runs away.
- If a bath is the only option keep the bath water very shallow.
- Having an adult in the bathroom is the safest option but is obviously not ideal as you are getting older. Having someone just outside or using a portable baby monitor would allow for privacy but would mean that someone could hear if a seizure happened and act quickly.
- Bathroom doors should not be locked. Have a sign that can be hung on the door to let other people know that the bathroom is in use.
- A bathroom door that opens outwards is safer in case you have a seizure by the door.



Bedroom and living areas

If possible avoid very hard flooring. More cushioned flooring such as carpets or lino will provide a softer landing if you fall during a seizure. A soft rug or carpet at the bottom of the stairs may be useful to cushion any fall. Edge and corner guards are widely available to cover any sharp corners on furniture that may be a risk.

If you have seizures at night consider having a bed lower to the floor to reduce the risk of injury and make sure the area around your bed is safe from hazards if you fall out.

Kitchen

Make sure you have a smoke alarm and the battery is checked regularly. It is safer to use a microwave than the oven or hob, especially if you are unsupervised in the kitchen.

The link below offers suggestions on other ways to keep safe at home that could be useful for someone with epilepsy:

<https://epilepsysociety.org.uk/wellbeing/safeathome>

Safety outside the home

Heights

If your seizures are not well controlled it would be best not to climb ladders, trees or have a job working with heights involved.

Climbing activities with a harness such as abseiling or rock climbing are fine for people with epilepsy. You would need to let the organiser know you have epilepsy so they can supervise you more closely.

Sudden Unexpected Death in Epilepsy (SUDEP)

In rare instances, a person with epilepsy dies during the night for no obvious reason. This is called Sudden Unexpected Death in Epilepsy (SUDEP). No one knows what causes SUDEP, there may be evidence that a person had a seizure but this is not always the case.

Recent studies estimate the incidence of SUDEP as 1 death in every 1000 epilepsy patients per year.

Although we don't know for certain why it happens, there are some situations that are thought to make SUDEP more likely in certain people:

- SUDEP is thought to happen during or following a seizure, so uncontrolled or poorly controlled seizures are a risk.
- SUDEP is thought to be more likely in people with frequent seizures, particularly generalised tonic clonic seizures, than in people with infrequent seizures.
- Young males seem to be more at risk than other age groups.

How to minimise the risk of SUDEP

- Maximising seizure control is vital. Make sure anti-epileptic medications are taken as prescribed on a daily basis and around the same time each day.
- Have a healthy lifestyle, sleep well, do not take illegal drugs or drink alcohol in excess.
- Anti-suffocation pillows which have holes in to aid breathing are available but there is no evidence to prove that they prevent SUDEP.
- Bed alarms which can alert parents/carer to a seizure are also available but again there is no evidence to support their use in preventing SUDEP. They may not alarm to every seizure and also may produce false alarms when there is no seizure activity.

Additional information

We have a paediatric epilepsy webpage which can be accessed from the Royal United Hospital website by entering 'paediatric epilepsy' into the search box. Or you can scan the QR code below. The website has useful information on mental health resources, sleep and many other topics.



SCAN ME

I hope the information in this leaflet is useful. Please contact us if you have any questions or would like more information.

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The majority of this information was taken from the following 3 websites and was correct at the time of publication. (Jan 2022)

Epilepsy Society: www.epilepsysociety.org.uk

Epilepsy Action: www.epilepsy.org.uk

Young Epilepsy: www.youngpilepsy.org.uk



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Please contact the Patient Advice and Liaison Service (PALS) if you require this leaflet in a different format, or would like to feedback your experience of the hospital. Email ruh-tr.pals@nhs.net or telephone 01225 825656/ 826319.