

Living a full and active life





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You can find any further updates at epilepsysociety.org.uk/sport-and-leisure

Call us for a large print version

helpline 01494 601 400

Monday and Tuesday 9am to 4pm, Wednesday 9am to 7.30pm. National call rate.

# living a full and active life

To live full and active lives, and look after our physical and emotional wellbeing, we all need time to rest, relax and exercise. How we spend our leisure time is important and individual to us all, whether or not we have epilepsy.

This leaflet looks at some popular leisure activities, listed alphabetically, and suggests how they might be made safer for people with epilepsy. These are only suggestions, and any decisions about leisure activities need to be made on an individual basis.

### Making choices about leisure activities

Epilepsy is a very individual condition. How it affects you may be very different to how it affects someone else. Most people with epilepsy live full and active lives, and do the leisure activities that they want to.

Some people with epilepsy, especially if they still have seizures, may have concerns about the safety of some activities. If you have concerns, it may be helpful to consider:

- · what your seizures are like;
- · when your seizures happen;
- whether you get any warning (know that a seizure is going to happen); and
- what would help make the activity safer for you.

This may help you to make decisions based on your individual situation and avoid unnecessary restrictions.

If you are making choices on behalf of someone else, such as a child or someone with learning disabilities, it is important to involve them as far as possible. This helps ensure that they are able to take part in the leisure activities they want to, and are not restricted by their epilepsy without good reason.

### Looking at safety

How epilepsy affects safety depends on you and your epilepsy. People who have seizures that are controlled with medication may not need the same safety measures as those who still have seizures.

Some activities do not need to be changed to make them safer for people with epilepsy. For others, simple measures might make them safer. For example, having someone with you who knows how to help if a seizure happens.

One way to think about safety is to do a risk assessment. This looks at what the possible risks are for anyone doing the activity, what it is about your epilepsy that may affect these risks, and what can be done to make the activity safer for you.

Visit epilepsysociety.org.uk/risk-assessments See our leaflets *safety* and *risk*.

### **Equality Act 2010**

Under the Equality Act 2010 people with a disability have rights to use leisure facilities. Epilepsy is a physical, long-term condition and people with epilepsy are protected under the Equality Act even if their seizures are controlled or if they don't consider themselves to be 'disabled'.

Leisure providers may need to make adjustments to make a service more userfriendly. If you have specific needs you may want to talk to the leisure organisation to see how they can help.

Visit equalityhumanrights.com for more information about the Equality Act 2010.

# sport and leisure activities

### Abseiling, climbing and hill walking

Anyone who does abseiling, climbing or hill walking needs the right expert support and safety measures. It is important to assess the possible risks for anyone doing the activity, and then think about how your epilepsy may affect those risks. Having an instructor who knows about your epilepsy means that they can help ensure your safety and the safety of other people with you.

#### Alcohol

The decision to drink alcohol is a personal choice. How alcohol affects someone with epilepsy depends on the individual, whether they are taking anti-epileptic drugs (AEDs), and how much alcohol they drink. For most people with epilepsy, the occasional alcoholic drink does not usually cause a problem. It is usually recommended that people with epilepsy have no more than 1 – 2 units of alcohol per day.

The patient information leaflet that comes with your AEDs may have information about drinking alcohol with that particular medication. It may also be useful to consider the following:

- · alcohol can make the side effects of AEDs worse;
- AEDs may increase the effects of alcohol;
- alcohol can trigger seizures for some people;
- some people may be more likely to have a seizure if they are hungover; and
- alcohol can disrupt sleep patterns, which can make seizures more likely.

### **Combat sports**

Boxing or martial art sports that involve blows to the head are not recommended for people with epilepsy due to the high risk of head injury.

### Cycling

All cyclists are advised to wear reflective clothing and a cycle helmet approved by British safety standards. If you have seizures, it may be safer to avoid cycling on busy roads and to cycle with someone who can help if you have a seizure.

### DIY and gardening

If you have seizures and would like to do your own DIY, it may be helpful to think about the type and frequency of your seizures and the potential risks of each job. Knowing your own abilities may help reduce the risk of accidents or injuries. If you are in doubt about doing a job yourself, or the risks involved, you may want to talk to a professional such as an electrician, gardener, or plumber.

See our leaflet safety.

### **Extreme sports and adventure sports**

Activities like bungee jumping, hang gliding, snowboarding and whitewater rafting have high levels of excitement, skill, and danger. They often involve speed, height, and a high level of physical energy. It is a good idea to talk to your GP or specialist about what the risks are for you before trying a new sport or activity.

Each sport's governing body can give you information on safety regulations, but they may advise you that the activity is too dangerous for you to do.

Visit sportengland.org/our-work/nationalgoverning-bodies

### Flying a private plane

Flying a private plane is sometimes possible but is usually restricted to smaller aircraft and you will have to meet certain conditions. To apply for a Private Pilot's Licence you need to be seizure free without taking AEDs, for the last five years. For certain aircraft different rules may apply.

Visit the caa.co.uk for more information.

### Go-karting and ATV quad biking

In the UK, you do not need a driving licence to drive a go-kart or an ATV (all terrain vehicle) quad bike on private land.

The National Karting Association (NKA) recommends that you are seizure-free for one year before karting, and that karting venues ask people to declare any medical conditions that could affect their driving.

Some venues may have their own policy on whether people who have seizures are allowed to drive on their circuits.

The British Off-Road Driving Association (BORDA) does not have specific guidelines on quad bikes but most ATV venues would expect you to sign a form to accept your own liability if you have an accident.

It is recommended that anyone karting or quad biking always wears a crash helmet.

### Horse riding

It is recommended that everyone wears an approved British Horse Society (BHS) riding hat for horse riding.

If you have seizures it is also recommended that you ride with someone who knows what to do if you have a seizure.

Riding for the Disabled Association (RDA) has local groups around the UK and can offer special facilities for people with disabilities.



### **Recreational drugs**

Recreational drugs have particular risks for people with epilepsy. Amphetamines (speed), cocaine, ecstasy and heroin have all been shown to increase the frequency of seizures.

Taking cannabis is also not advised if you have epilepsy. Some reports claim cannabis is not harmful, however other research has shown

it can lead to an increase in seizures. This may be partly because cannabis can be made up of different compounds, and so the effects on the brain can vary. (In November 2018 a change in the law meant that specialist doctors in the UK can now prescribe **medicinal** cannabis for some people with epilepsy).

Visit epilepsysociety.org.uk/cannabis-oil-epilepsy for more about medicinal cannabis.

For some people, using recreational drugs could cause epilepsy to start and may increase the risk of triggering mental health problems.

Visit talktofrank.com for more about drugs.

### Sex and relationships

Some people with epilepsy have problems with sex or relationships. Problems such as a low sex drive can happen for a number of different reasons: anxiety, depression, and the side effects of some AEDs can all contribute. Relationships can also be affected by how you or your partner feels about epilepsy.

Talking to your partner and a doctor can help to find the right support and treatment. For example, a doctor may suggest a review of your medication or identify where counselling might be helpful.

See our factsheet *relationships and sex*.

### Skiing and snowboarding

Snowsport England (the governing body for English snowsports) believes that snowsports should be open to everyone, whether or not they have a disability.

They also have a network of adaptive ski clubs and offer disability awareness training courses.

It might be useful to think about what the risk to your safety might be if you were to have a seizure on the slopes or ski lift. Snowsport England suggest this might include wearing a harness and 'clipping on' to chair lifts for safety in the event of a seizure. Other considerations include light flickering through trees, altitude, tiredness, excitement levels and making adjustments when in a different time zone. It may be safer to ski with someone who knows how to help you if you have a seizure.

#### **Team sports**

Team sports such as football or rugby do not necessarily need extra safety measures for someone with epilepsy. However, with any sport that involves contact with other people, there may be a risk of head injuries, which could affect your epilepsy.

It's a good idea if someone on the team or a coach knows about your epilepsy, and how they can help you if you have a seizure.

### **Television and computer games**

Epileptic seizures can sometimes be triggered by certain speeds of flashing or flickering lights, and by some geometric patterns. This is called photosensitive epilepsy and it affects up to 3% of people with epilepsy. For someone with photosensitive epilepsy, triggers can include:

 playing video games or watching moving computer graphics;



 watching a faulty television or other light source that flickers; and strobe lights.

The common rate for a flashing light to trigger seizures is between 3 and 30 hertz (flashes per second).

It is a good idea to take regular breaks when watching TV or using a computer, and to watch TV from a distance in a well-lit room. TV programmes, films, and theatre performances often have a warning if they have flashing lights or images.

Video and computer games that have fast moving or flickering images may carry a warning on the packaging. Strobe lighting may be used in nightclubs too.

If you are suddenly exposed to a trigger, covering one eye completely with your hand may help reduce the photosensitive effect.

See our factsheet *photosensitive epilepsy*.

### Theme parks

Many people with epilepsy can go on rides depending on how their epilepsy affects them.

For some people with epilepsy, excitement or stress due to the rides, noise, or crowds could trigger a seizure. Theme parks need to let people know if anything during a ride could make a medical or physical condition worse and have details on their websites, and at the entrance to rides, for disabled guests. For example, some rides may not be suitable for riders with photosensitive epilepsy.

### Yoga

Yoga can have a number of benefits including improving your fitness. The deep breathing involved in many forms of yoga aims to be relaxing. Some forms of yoga involve extreme breathing techniques and may need extra care.

See our factsheet complementary therapies for more about relaxation therapies.

## water sports

Many water sports can be made safer for people with epilepsy by taking the right safety measures. This means considering what risk the activity involves and how your epilepsy affects you.

For example, there may be different risks for water-skiing than for dinghy sailing if you have seizures where you lose consciousness.

Wearing a lifejacket is recommended for most water sports. It is also important to have someone with you who knows how to help if you have a seizure, like a friend or instructor.

### Kayaking and canoeing

There can be additional risks for people with epilepsy, if they have a seizure, when paddling a kavak or canoe.

If a kayak overturns when someone has a seizure they could be trapped underneath, and their buoyancy aid could keep them pressed

up under the kayak. Although this is a risk for anyone who tips over a kayak, it is more of a risk for someone having a seizure as they may be unconscious or partly conscious at the time.

Whether you have epilepsy or not, the most important thing is to learn how to paddle under qualified and experienced coaches.

British Canoeing has a network of clubs, outdoor centres, and qualified coaches.

# Visit britishcanoeing.org.uk

### Scuba diving

Scuba diving carries risks including drowning, as well as conditions caused by breathing different levels of oxygen or nitrogen at depth.

Scuba diving is not recommended for people who have seizures because of the risk of having a seizure underwater. Having a seizure underwater can be life-threatening, and may also endanger the life of the diving buddy or other companions.

Once somebody has well-controlled seizures on medication the risk of further seizures is reduced, but is never removed completely.

The British Sub-Aqua Club (BSAC) recommends that people must be seizure-free for five years without taking AEDs, before they consider scuba diving. (Where seizures only happen during sleep, this can be considered on an individual basis).

See page 18 for BSAC contact details.

### **Swimming**

If you have seizures, seek advice from your doctor or epilepsy nurse about factors that could affect your safety when swimming. It is a good idea to swim with someone who knows about the type of seizures you have, and that they know how to help you if you have a seizure in the water.

Swimming in the sea, a river, or other open water is more risky than in a swimming pool because of currents, tides, sudden changes in depth, and colder water temperatures, even in summer. If you have a seizure in open water, it may also be harder for someone to see that you are having a seizure, or to be able to help you. Some pools, such as hotel pools, may not have lifeguards and so these have extra risk.

At a swimming pool, you could tell the lifeguards how they can help you if you have a seizure. Some people swim during quieter swimming sessions so it is easier for the lifeguards to see them.

If you have a seizure in the water, lifeguards or a friend can help you by supporting your head above the water, and gently towing you to a depth where they can stand up, or to the poolside. They can then support you in the water until the seizure stops. If you are near the poolside, they may need to protect you from hitting the side and injuring yourself.

You may need medical attention to check that you have not inhaled water during the seizure, even if you feel fine. It is also important for someone to stay with you afterwards and check that your breathing has returned to normal.

## travel and holidays

### **Organised holidays**

The organisation Phab runs holiday schemes around the UK, which bring people with and without disabilities together.

See page 19 for contact details.

### Travelling by air

Having epilepsy does not usually prevent people from being able to travel by air. However, some people's seizures are triggered by being very tired (which could happen because of long journeys or 'jet lag'). Seizures can also be triggered by anxiety or excitement, which can affect some people when they are flying.

If there is a chance that you might have a seizure on the plane, it is useful for someone travelling with you to know about your epilepsy and how to help if you have a seizure.

Telling the airline about your epilepsy when you book means that they can let the cabin crew know about your seizures, and can tell them anything about your epilepsy that you think may be important for them to know.

It is a good idea to take enough medication in its original packaging with you for your entire holiday. Some drugs may not be available or may have a different name in other countries. Your GP or the drug company may be able to tell you more about this.

Airport security regulations allow you to carry tablets, capsules or liquids up to 100ml in your hand luggage in case your main luggage is lost.

If your medicine is in a container larger than 100ml you will need to contact the airline before you fly. You may need to have a letter from your GP or specialist explaining about your epilepsy and the medication you take.

If you are travelling to a different time zone you may want to gradually adjust when you take your medication, so that you can take it at a manageable time of the day.

#### **Travel insurance**

Travel insurance companies look at each individual's circumstances before giving a quote. Having epilepsy may mean that there is an increase in the premium you pay but this will depend on the type, frequency and severity of your seizures. Giving as much information as possible about your epilepsy may help the insurance company to give you an accurate and fair quote.

As with taking out any insurance policy, it is worth contacting a number of companies to get the best quote for your situation.

Contact our helpline for details of travel insurance companies.

### **European Health Insurance Card (EHIC)**

Most UK residents are entitled to free or reduced cost emergency medical treatment during short visits to other European Union countries (plus Iceland, Lichtenstein, Norway and Switzerland). You will need a European Health Insurance Card (EHIC). An EHIC card does not replace the need for travel insurance.

If the country you are visiting charges for GP consultations, prescriptions or stays in hospital, you will need to pay for these.

Visit the NHS website below for a country by country guide and details on how to apply.

Nisit nhs.uk/using-the-nhs/healthcare-abroad to apply for an EHIC card online or call the EHIC enquiry line on 0300 330 1350.

#### **Travel vaccinations**

Travel vaccinations can protect against infectious diseases when visiting some countries. Most vaccines will not affect a person's epilepsy, anti-epileptic drugs or seizure control. However some anti-malarial medications can trigger seizures and are not suitable for people with epilepsy.

**Visit epilepsyresearch.org.uk for details.** 

If you need to use anti-malarial medication, your GP can advise you which medication will suit you best.

The Department of Health also has general travel advice and useful travel links.

**Nisit gov.uk/foreign-travel-advice** 

## **further information**

### **Epilepsy Society information**

Complementary therapies Photosensitive epilepsy Relationships and sex Risk Risk assessments Safety

## other organisations

#### **British Canoeing**

0300 011 9500 britishcanoeing.org.uk

**British Sub-Aqua Club (BSAC)** 

0151 350 6200 bsac.com

Civil Aviation Authority (CAA) caa.co.uk

### **Equality Advisory Support Service**

Helpline: 0808 800 0082 equalityadvisoryservice.com Information on the Equality Act 2010.

### **Equality and Human Rights Commission**

### equalityhumanrights.com/airtravel

Information on rights for disabled people and those of limited mobility when travelling by air.



#### **Frank**

Helpline 0800 77 66 00 talktofrank.com Confidential helpline providing information

and counselling about drugs.

#### **Phab**

0208 667 9443

phab.org.uk

Runs holidays and activities for people with or without a disability.

### **Riding for the Disabled Association**

01926 492 915

rda.org.uk

Offers horse riding facilities for people with disabilities all over the UK.

Every effort is made to ensure that all information is correct at the time of printing. Please note that information is intended for a UK audience. This information is not a substitute for advice from your own doctors. Epilepsy Society is not responsible for any actions taken as a result of using this information.

# epilepsy society

# epilepsysociety.org.uk

A full life for everyone affected by epilepsy.

### research

Pioneering medical research.

## treatment and care

Individualised medical and care services.

## information

Website, leaflets, factsheets. Call 01494 601 392.

### education

Training for individuals and professionals.

## connect with us





Volunteer, become a member, fundraise.

helpline 01494 601 400 Monday and Tuesday 9am to 4pm, Wednesday 9am to 7.30pm. Confidential, national call rate. Information and emotional support.

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