Epilepsy and leisure

Helpline: 0808 800 2200
www.epilepsyscotland.org.uk
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Activity and leisure are good for you, as we are constantly being reminded these days. Ignorance about epilepsy can put up unnecessary barriers. These may stop you from fully enjoying activities and hobbies you like to do.

Epilepsy Scotland wants to help you enjoy your leisure time. We now know through research that being active means you are less likely to have seizures.

Your epilepsy is as individual as you are, just like the sports or activities you are interested in. Most people with epilepsy have the condition well under control with medication. So there is little that you cannot do. But if you have regular or unpredictable seizures, a bit of extra care should be taken. Always check with your doctor or epilepsy specialist nurse so you can fully and safely benefit from an active lifestyle.

What is epilepsy?

Around 40,000 people in Scotland have epilepsy, that’s one in 130 people. It is the most common serious brain (neurological) condition. Anyone can develop epilepsy at any age. However, it is more common in childhood, teenage years and later life.

Epilepsy means a person tends to have repeated seizures.

Epilepsy and leisure

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Contact sports

Epilepsy should not stop you from playing football or rugby. It never stopped former Hibs player Alen Orman or former Scotland and Lions prop Tom Smith. You can play these sports safely as long as you follow normal safety procedures.

Boxing is one sport that should be avoided. This is because you risk being hit on the head. This could trigger seizures.

Generally, if your epilepsy has been caused by a head injury, you should discuss playing any contact sport with your doctor before you start.
**Gym**

If your seizures are well controlled, you should have no problem using any piece of equipment. If your seizures are a bit unpredictable, you need to be more careful. This is to stop yourself and others from getting injured. Your gym instructor will be able to tell you which equipment is safe for you to use. Also make sure your gym instructor knows what to do if you have a seizure.

**Swimming**

If you are seizure-free or your seizures are well controlled, there is generally very little risk if you swim in a pool that is supervised by a qualified lifeguard. Always tell the lifeguard that you have epilepsy.

If your seizures are frequent and a bit unpredictable, you may want to bring someone with you. Someone who knows what to do if you have a seizure. If possible, stay in the shallow end and swim breadths rather than lengths. Swimming when the pool is quiet is also a good idea. Never swim if you feel unwell.

Swimming in a loch, a river or the sea can be dangerous if you take a seizure. However, if you have someone with you, this may lessen the risk.
“Don’t let your epilepsy put you off doing anything.”
From being paralysed to winning a gold medal at the Sydney Olympics, Maggi McEleny has seen all sides of epilepsy.

The 42-year-old was diagnosed when she was 13 and the seizures led to her being paralysed from the neck down. By 18, she was using a wheelchair. A few years later she was introduced to the Port Glasgow Otter Club to build up strength in her arms in the pool.

Maggi never meant to try the sport competitively, but her coach saw her potential. And she never looked back as she plunged through 15 years of international competition. She attended four Paralympics Games, winning a total of 15 medals. At the Sydney Paralympics in 2000, she was given the honour of being voted by her follow athletes to carry Britain’s flag for the opening ceremony. For this proud moment she was pushed in her wheelchair by her coach.

“There’s no sport you can’t do,” she says. Swimming is the most dangerous sport if you take a seizure. That’s why I have a spotter, someone that watches out for me whilst I swim. If they saw any change in my stroke, they would alert the staff.

“There have been times at major international events that I have taken a seizure even an hour before a race, and the team doctor has wanted me to pull out. But my coach was able to say, ‘give her 15 minutes and she will break the world record’. I’ve done it - 30 minutes after I came out of a seizure and I broke the world record.

“It’s just getting that through to people. There’s still a stigma attached to the condition. I wish we could break down those barriers faster.”

Maggi retired two years ago from competitive swimming and now regularly goes to the gym. But despite a medical setback, Maggi has become the first person in the world to swim with a tracheotomy. She says: “I told my consultant I had to get back into the water. I can only do it once a week, but it keeps my sanity.”

“Don’t let your epilepsy put you off doing anything. For any sport, go for it - make enquiries because there’s ways around everything.”
Climbing and hiking

Any sport that puts you at a height could be dangerous. If you have uncontrolled seizures avoid climbing. But hiking and rambling don’t have the same risk as long as you take sensible precautions. Never go on your own, and make sure the person you are with knows what to do if you have a seizure. Carrying a mobile phone with you will allow your companion to call for help. So check you are in an area where you can get a signal.

Yoga

Many people enjoy yoga and find it helps them relax and feel good. It is therefore unlikely to cause problems for you. There are some forms of yoga, particularly those that involve deep meditation, which may trigger seizures in some people. Yoga Scotland www.yogascotland.org.uk or your yoga teacher can give you more information on this.
**Scuba diving**

This can be a very dangerous sport if you have epilepsy. If you have a tonic-clonic seizure while scuba diving, this could be fatal. Taking anti-epileptic medication can also make you more likely to experience a potentially life-threatening condition (known as “nitrogen narcosis”) than other divers, even at shallow depths. When this happens, you may feel disorientated or excited, or may feel your lips, legs, or feet go numb.

The UK Sport Diving Medical Committee recommends that someone with epilepsy should only scuba dive if it has been five years since they had a seizure without taking anti-epileptic medication. If you only had seizures in your sleep, you can scuba dive after three years instead of five.

**Other water sports**

Whatever water sports you might want to try, it is a good idea to have someone with you who knows what to do if you have a seizure. And always wear a life jacket.
Cycling
We recommend that you always wear a helmet when cycling, whether you have epilepsy or not. If you have poorly controlled seizures, it is best to avoid busy or public roads.

Fishing
Make sure you are always with someone who knows what to do if you have a seizure. Wear a life jacket, in case you have a seizure and fall into the water. It is safer to fish from the river bank rather than a boat or pier.

Riding
Riding can be fun and safe if your seizures are well controlled. As with cycling, we recommend that you always wear a riding helmet. If you have poorly controlled seizures you could fall off the horse. It’s therefore safer if someone walks alongside the horse. Speak to your riding instructor if you have any concerns.

Go-karting
You don’t need a driver’s licence to drive a go-kart. But the National Karting Association recommends that you should be seizure-free for one year before driving a go-kart. Also check with the venue if they have any specific policies or restrictions.
**Theme parks**

Most rides in theme parks are safe to use provided that general safety precautions are in place. Some rides may involve flashing (strobe) lights. These can be a problem if you have photosensitive epilepsy. The park must display a notice if strobe lighting is used during any of the rides or sideshow attractions. It’s best to double check with the operator before you go on any rides. If you are concerned about how strobe lights can affect you, speak to your GP or epilepsy specialist nurse.

**Other sports**

You should always get your GP’s approval first before you have a go at any extreme sports, such as parachuting, bungee jumping, para-gliding or cave diving. You also need to check for any safety regulations with the governing body for each sport.

If you want to ask about other sports not mentioned in this leaflet, contact our Helpline (**0808 800 2200**) or speak to your doctor or epilepsy specialist nurse.
Other leisure activities

Television

Less than five per cent of people with epilepsy have seizures triggered by flashing or flickering lights (photosensitive epilepsy). Television is the most common trigger. So if TV affects you, it helps to sit as far back from the screen as possible. Use a remote control to change channels or turn the TV off and on. Choose a Liquid Crystal Display (LCD) screen as they are safest.

Some programmes or films shown on television may contain flashing lights. Most channels give advance warning if a programme contains flash photography or flickering lights. If it does, the safest thing is to switch off the TV. Phone our Helpline if you want more information about photosensitive epilepsy.

Video and computer games

Some games with patterns of flashing or flickering lights may sometimes trigger seizures in those with photosensitive epilepsy. Computer games may be a better option than video games as a computer screen is safer than a TV screen.

This is because computer screens flash so quickly they very rarely trigger a seizure. If you have any concerns, set the refresh rate of the screen as high as possible. Laptops have an LCD screen, and do not flash at all.

If you are using a TV screen, use the safety tips mentioned above.
Cinema
As with watching TV, some movies may contain flashing lights, and most cinemas now let you know this before the film starts. If you have photosensitive epilepsy, you may want to phone the cinema in advance, just to be sure. If you are in the middle of watching a film and there is unexpected strobe lighting on the screen, look away or try covering one eye with your hand. Some people have found that this reduces the likelihood of having a seizure.

Nightclubs
Strobe lights can trigger seizures if you have photosensitive epilepsy but it depends on the speed of the flashes. Remember, only a few people have photosensitive epilepsy. The most common flash rates that produce seizures are between 12 and 24 flashes per second. Not all nightclubs have strobe lights so it’s worth checking which clubs do.
Jane wants to lead a full and active life. But she’s always aware that she lives with epilepsy. “I get a lot of people assuming I can’t drink or go to clubs, but I do drink – and dance badly when I do! I was advised to only have one or two drinks. So at first I was really worried about it and didn’t drink much or at all. I have never had a seizure because of alcohol, but it can affect the medication. This can then trigger a seizure. It all depends on what type of epilepsy you have.

“My friends and I have perfected the hands-over-the-eyes dance,” says Jane. “We dance with one hand over each others’ eyes when they put on strobe lights because I have photosensitive epilepsy. You only need to cover one eye.

“I have asked bars not to use strobe lights, but they never ever leave them off. It’s usually my friends who ask for me - they are well versed in my epilepsy. But there is still a lot of ignorance out there.”

Jane says her epilepsy is very predictable. She gets some warning before she has a seizure. They normally happen when she’s just woken up, or when she’s very tired. She says it doesn’t prevent her from doing anything. But it affected one of her early passions when she was diagnosed at the age of 12:

“I was a figure skater for seven years. After I was diagnosed I went back,” she explains. “My lessons were at 7am on a Saturday and I had seizures on the ice, so I had to give that up. It devastated me because I loved ice skating. If I could have practiced figure skating other than in the morning, it would have been fine.”

But the loss of figure skating led Jane to writing. She now aspires to be a publisher and eventually a full-time writer. She says: “I would not let epilepsy stop me. You have epilepsy but you’re no different than anyone else.”
“You have epilepsy but you’re no different than anyone else.”
Alcohol and drugs

Both alcohol and drugs (prescribed and non-prescribed) can affect how your epilepsy medication works. This means control is reduced and you may have more seizures. It can also make it harder to recognise the warning signs of a seizure coming on. Talk to your doctor or epilepsy specialist nurse about this. You can also phone our Helpline for more detailed information on how alcohol or drugs can affect your epilepsy.

Travel

Always take a full supply of your epilepsy medication, especially when you travel abroad. Keep the drugs in their original containers. And if you’re flying, it is worth putting a supply of anti-epileptic drugs in your hand luggage, in case your suitcase goes missing or is delayed. You should also carry a letter from your doctor stating the name and the dose of your medication, and a prescription in case of emergencies.

Flying in itself is not known to trigger seizures. However, it is important to be aware of other factors while flying that could affect you. This may be missing sleep or meals or becoming dehydrated.
If you are travelling across a different time zone, you might want to speak to your doctor about the best time to take your medication. If you need to take your medication at the same time every day, it helps to carry two watches. Set one to the local time and the other to the time back home.

Insurance companies should not charge you extra for travel insurance simply because you have epilepsy. It depends how well your seizures are controlled. If you want information or have problems getting travel insurance, contact our Helpline.
**Beauty treatments**

Sometimes people are concerned that certain beauty treatments, especially those that involve light or electricity, could trigger a seizure. However, there is no evidence for this. Nor is there evidence that it would be dangerous if you had a seizure during treatment. It is possible though that pain triggers a seizure in some people, so it is worth bearing this in mind.

**Electrolysis** (hair removal): before you start your treatment, talk to salon staff about any risk of harm, if, for example, you moved suddenly because of a seizure during electrolysis. It’s also important to let them know if pain is a seizure trigger for you.

**Laserbeam hair removal:** there is no evidence that laser use triggers seizures. Even if you have photosensitive epilepsy, there is no risk as the beam of light used is very small and does not flicker.

**Sunbeds:** some people think that sunbeds could trigger a seizure because of flickering lights. Even if you have photosensitive epilepsy, this would not be the case. This is because the light used in sunbeds does not flicker, unless it is faulty. If you are worried about this, you should speak to the tanning salon and ask them to confirm that the lights are working properly.

**Foot spas:** you may have seen warnings on foot spas, particularly detox foot spas, that you should not use them if you have epilepsy. However, there is no evidence to suggest that using them could trigger a seizure.
Further information

Epilepsy Scotland can give you further information on:

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We also have information leaflets designed for people with learning difficulties. These include:

• All about epilepsy
• Safety and epilepsy
• Living with epilepsy

If you have questions after reading this leaflet, please call our Helpline. Our trained staff are available during office hours and until 6pm on Thursdays.

If you would like this leaflet in a different format or language, please call 0808 800 2200.
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