



**University  
Hospitals Sussex**  
NHS Foundation Trust

# Epilepsy and seizures

Information for patients diagnosed with epilepsy and for patients who are suspected to have experienced a seizure or recurrent seizures.

Patient information

## What are seizures and what is epilepsy?

Epilepsy is a common condition that affects the brain and causes recurrent seizures. It has many underlying causes. Seizures are sudden bursts of electrical and chemical activity in between brain cells that temporarily affect brain function. They can cause a wide range of symptoms such as staring, sensations, odd behaviour, stiffening of limbs and jerking, incontinence, with impaired or a loss of awareness.

Epilepsy/Seizures can start at any age, but often begin in people over 65 and in early childhood and adolescence. It is often a lifelong condition, but sometimes can get better over time. Treatment can help most people with epilepsy to have fewer seizures or to stop having seizures completely.

This leaflet has advice about different ways to control your seizures, how to monitor your seizures, and adjustments you can make to your lifestyle to keep you safe and healthy. Learning how to manage your seizures/epilepsy is an important part of reducing seizures, and will help you to feel more in control and safe.

## What are the triggers to my seizures, and what can I do to help control them?

Some things may make it more likely for someone to have a seizure. These are called triggers. Not everyone with seizures/epilepsy has triggers. Something that triggers a seizure in one person may not trigger it in another.

## Triggers include:

- Missing anti-seizure medication doses
- Excessive stress
- Lack of sleep or excessive sleep (any change in your usual sleep pattern).
- Infection or an illness that causes a high temperature.
- Menstrual cycle (or period) due to hormonal changes: some women find that they have seizures at a particular stage of their cycle.
- Flashing lights, bright lights or light patterns. Only 3% of people with epilepsy have this, and your EEG (a recording of brain activity) will indicate whether this is the case for you.
- Excessive use of alcohol.
- Illicit / recreational drugs (especially cocaine and amphetamines) can lead to seizures.

## How can I manage these triggers?

Once you are aware of your triggers, there are some things that you can do to avoid them.

- Always take your anti-seizure medication as prescribed.
- Avoid excessive stress.
- Keep to a regular sleep pattern, avoid late nights and sleep deprivation.
- Take regular paracetamol and seek GP advice if you have a fever. Keep yourself well hydrated- drink 1.5 to 2 L of water per day.
- Avoid skipping meals.

- It is generally advised to avoid drinking alcohol when you are taking anti-seizure medication. However, research shows that a small amount of alcohol is fine. Please keep to the national guidance for safe daily amounts. The risk of having a seizure is highest when the alcohol is leaving your body, if you have been drinking heavily and drinking over a short amount of time. Alcohol may interact with your epilepsy medication. It will also affect sleep quality, which could also trigger a seizure.
- Please see [www.nhs.uk/live-well/alcohol-support/calculating-alcohol-units/](http://www.nhs.uk/live-well/alcohol-support/calculating-alcohol-units/) for further information about alcohol units.
- Please see [www.epilepsy.org.uk/info/daily-life/alcohol](http://www.epilepsy.org.uk/info/daily-life/alcohol) for further information about drinking alcohol and epilepsy.

## How else can I keep myself safe?

Avoid exposing yourself to risky situations especially if you are alone. For example; do not climb ladders or work at heights, do not swim without responsible adult supervision, and do not operate dangerous or heavy machinery. Take care with cooking or handling hot liquids. Using a microwave is safer if you live alone.

**Do not get into a bath** unless a responsible adult is present in your home and knows you are about to get into the water. Remember to keep the bathroom door unlooked if you bathe or you have a shower. Use the shower if you live alone or you are alone in the house.

## Do I need to take my tablets every day?

Most people with a diagnosis of epilepsy are given anti-seizure medication (also known as anti-epileptic drugs) to help control their seizures. **It is very important to take your medications every day as prescribed.** Forgetting medication doses can often lead to seizures.

A useful tip is to set an alarm or if you have difficulty remembering to take your medication you can have your medication prepared in boxes or blister packs via your chemist/pharmacy. If you miss one dose you should take it as soon as you remember. Do not take a double dose. Please do not stop or reduce your medication unless advised by your specialist

If you have a diagnosis of epilepsy/seizures, you do not have to pay for your prescriptions. This is called medical exemption. Ask your GP for a form FP92A. You will be given a medical exemption card, which you need to bring with you when you collect your prescription from the pharmacist.

## Can I still drive?

You must inform the DVLA if you have had a seizure. The usual recommendation is that you cannot drive until one year seizure-free from all seizures. Please look on the DVLA website for more details and further information about driving with epilepsy: [www.gov.uk/epilepsy-and-driving](http://www.gov.uk/epilepsy-and-driving).

Not being able to drive can have a big impact on your life, and initially be very difficult and upsetting. However, you may be entitled to free bus travel. Please see [www.gov.uk/apply-for-disabled-bus-pass](http://www.gov.uk/apply-for-disabled-bus-pass) and for more information and how to apply for a bus pass. You may also be entitled to reduced rail fares: please see [www.disabledpersons-railcard.co.uk/are-you-eligible/](http://www.disabledpersons-railcard.co.uk/are-you-eligible/) for further information and how to apply.

## Will I be able to work?

Whether your epilepsy affects your work depends on whether you continue to have seizures, what your seizures are like and how often these happen. It also depends on the type of work you do, and any risks that having seizures at work might bring. Speak to your employer about making any reasonable adjustments to your work.

## What if I am planning to become pregnant?

Please seek advice from your specialist or epilepsy nurse if you are planning a family. It is advisable that women taking anti-seizure drugs who plan to become pregnant should take 5mg of folic acid daily. These will need to be prescribed for you by your GP, as it is a higher dose that you would be able to buy over the counter.

Women taking medication for Epilepsy /seizures are advised to take folic acid 5mg per day during their fertile years.

Please see [www.nhs.uk/pregnancy/related-conditions/existing-health-conditions/epilepsy/](http://www.nhs.uk/pregnancy/related-conditions/existing-health-conditions/epilepsy/) for further information.

It is important to register with the UK Epilepsy and Pregnancy register at [www.epilepsyandpregnancy.co.uk](http://www.epilepsyandpregnancy.co.uk). This register was established in 1996 for pregnant women in the UK and its aim is to collect and publish information on pregnancy outcomes among women who take Epilepsy medications. This important research may help our knowledge and treatment for future pregnancies.

## What is Sudden Unexplained Death in Epilepsy?

Sudden Unexpected Death in Epilepsy (SUDEP) is rare but occurs when a person with epilepsy dies suddenly and prematurely and no other reason for death is found. The cause of SUDEP is not yet fully understood. Researchers are investigating a range of possibilities such as the effect of seizures on breathing and the heart.

The risk of SUDEP varies from person to person. Risk factors include, for example, not taking your medication, or alcohol and substance abuse. These risks can change over time, and it is important that you discuss them with your clinician. It sounds frightening, but if you know these risks exist, you can do things to keep yourself as safe as possible. Please see [www.sudep.org](http://www.sudep.org) for further information and advice.

## How can I monitor my epilepsy/seizures?

You may find it useful to keep a **Seizure Diary** detailing the following:

- Your patient Trust Hospital ID
- Your NHS number
- Date and time of seizure
- Duration of seizure
- Details of seizure:
  - Were there any identifiable triggers?
  - Did you make any movements during the event/seizure?
  - Did it happen when you were awake or asleep?
  - How long did it take you to recover?
  - Did anyone see it happen and can they describe it to you?
  - Did you need any emergency medications?

You may want to keep a paper diary, or you may want to use an app to record your seizures.

Please see [www.epilepsy.org.uk/info/diagnosis/seizure-diary](http://www.epilepsy.org.uk/info/diagnosis/seizure-diary) for further information, and links to the app.

Bring this diary with you when you have a medical appointment, so your doctor or nurse can discuss it with you. It will also be a good way to identify any triggers that lead to a seizure.

# Who can I speak to if I need any more advice and support?

Please contact: [uhsussex.neurologyadminaccount@nhs.net](mailto:uhsussex.neurologyadminaccount@nhs.net)  
who will forward your query to the adult epilepsy team.

## Please visit for further information and advice:

- Sudden Unexplained Death in Epilepsy (SUDEP Action): [www.Sudep.org](http://www.Sudep.org).
- Epilepsy Action: [www.epilepsy.org](http://www.epilepsy.org)
- Epilepsy Society: [www.epilepsysociety.org.uk](http://www.epilepsysociety.org.uk)
- Epilepsy Sussex: [www.epilepsysussex.com](http://www.epilepsysussex.com)
- NHS.uk: [www.nhs.uk/conditions/epilepsy/](http://www.nhs.uk/conditions/epilepsy/)

**Epilepsy Action Helpline: 0808 800 5050**

Epilepsy Action has a page on their website with details of local support groups which may be in your area.

**Epilepsy Society Helpline: 0149 460 400**

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**This leaflet is intended for patients receiving care in Brighton & Hove or Haywards Heath**

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