University Hospitals Sussex
NHS Foundation Trust

Seizures and epilepsy

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

Patient information

What is this information about?

This information has advice about different ways to control your seizures, how to monitor your seizures, and changes you can make to your lifestyle to keep you safe and healthy.

Learning how to manage your seizures or epilepsy is an important part of reducing seizures. It will help you to feel more in control and safe.

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 (not being able to control your bowel or bladder)
- impaired or a loss of awareness.

Epilepsy or seizures can start at any age but often begin in:

- people over 65
- early childhood
- 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.

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 or epilepsy has triggers. Something that triggers a seizure in one person may not trigger it in another.

Triggers include:

- Missing anti-seizure medication doses.
- Too much stress.
- Lack of sleep or too much sleep (any change in your usual sleep pattern).
- Infection or an illness that causes a high temperature.
- Menstrual cycle (periods) 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.
- Too much alcohol.
- Illegal or 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 too much stress.
- Keep to a regular sleep pattern, avoid late nights and sleep deprivation.
- If you have a fever, take regular paracetamol and seek help from your GP.
- Keep yourself well hydrated. Drink 1.5 to 2 litres of water per day.
- Avoid skipping meals.

It is a good idea 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 and if you have been drinking heavily and drinking over a short amount of time.

Alcohol may interact with (affect) your epilepsy medication. It will also affect sleep quality, which could also trigger a seizure.

Read NHS UK's alcohol advice and support
www.nhs.uk/live-well/alcohol-advice/alcohol-support

Read epilepsy.org.uk's advice about alcohol and epilepsy
www.epilepsy.org.uk/living/information-on-alcohol-and-epilepsy

How else can I keep myself safe?

Avoid exposing yourself to risky situations especially if you are alone.

Important safety advice. Be aware.

- Do not climb ladders or work at heights.
- Do not swim in open water or if there is no qualified swimming supervisor on site.
- 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 unlocked if you bathe or if you have a shower. Use the shower if you live alone or if you are alone in the house.

Read Epilepsy Action's advice about swimming, sports and leisure
www.epilepsy.org.uk/living/sports-and-leisure

Read Epilepsy Action's safety advice for people with epilepsy
www.epilepsy.org.uk/living/safety

Do I need to take my tablets every day?

Yes. 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 all doses of your medication every day as prescribed. Forgetting medication doses can often lead to seizures.

A useful tip is to set an alarm. If you have difficulty remembering to take your medication you can have it prepared in boxes or blister packs by your chemist or 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.

Be aware

If you run out of your anti-seizure medication by mistake you can get an emergency supply from your pharmacist or any pharmacy if you are away from home. Please see medicines guidance and Charlie's card in the links below:

BNF – Emergency supply of medicines
https://bnf.nice.org.uk/medicines-guidance/emergency-supply-of-medicines/

Charlie Card – SUDEP Action
https://sudep.org/charlie-card/

Charlie-Card
https://sudep.org/wp-content/uploads/2025/06/Charlie-Card.pdf

Do I have to pay for my prescriptions?

If you have a diagnosis of epilepsy or 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.

Am I more at risk of developing osteoporosis (weak, fragile bones)?

People with epilepsy, especially those taking some anti-seizure medicines, may have an increased risk of developing low bone density and osteoporosis. This means they may be more likely to have fractures (broken bones) because their bones are not as strong. Please check with your GP or epilepsy team if you need vitamin D supplements or bone strengthening medication.

Read Epilepsy Action's information about bone health and epilepsy
www.epilepsy.org.uk/info/treatment/osteoporosis-osteomalacia#:~:text=Epilepsy%20medicines%20and%20problems%20with,discuss%20tests%20that%20are%20available

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.

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.

How to apply for a bus pass
www.gov.uk/apply-for-disabled-bus-pass

You may also be entitled to reduced rail fares
www.disabledpersons-railcard.co.uk/are-you-eligible

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
- how often your seizures happen
- the type of work you do
- 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.

Women taking anti-seizure drugs who plan to become pregnant should take 5 mg of folic acid each day. 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 or seizures are advised to take folic acid 5mg per day during their fertile years.

Read NHS UK's information about pregnancy and existing health conditions
www.nhs.uk/pregnancy/related-conditions

It is important to register with the **UK Epilepsy and Pregnancy register.** **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.

Read Epilepsy Action's advice about looking after a baby or young child
www.epilepsy.org.uk/living/parents-and-children/parents-with-epilepsy

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. People who experience seizures during their sleep, especially if these are tonic-clonic seizures (convulsions), are at higher risk of SUDEP. These risks can change over time, and it is important that you discuss them with your epilepsy team.

You might be experiencing tonic clonic seizures (convulsions) at night if you wake up with the following:

- you have bitten or chewed the side of your tongue
- you have lost control of your bladder
- You have a bad headache
- you feel groggy and unable to function properly for a few hours
- your muscles hurt in a similar way to taking an unusual amount of exercise.

If you are uncertain about any symptoms that you wake with, please let your epilepsy team know.

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 for further information and advice.

Status Epilepticus

Managing prolonged tonic clonic seizures (convulsions) or a cluster/serial seizures

If a person has a tonic-clonic seizure (convulsion) lasting longer than 5 minutes or seizures occurring one after another without full recovery in between, this is Status Epilepticus and it is a medical emergency.

If this happens to you or someone you know, call 999 immediately.

If you experience status epilepticus, please let your epilepsy team know as soon as possible as treatment changes may be needed.

Read Epilepsy Action's advice about Status Epilepticus
www.epilepsy.org.uk/info/first-aid/emergency-treatment-seizures-last-long-time

Read the NICE guidelines about treating Status Epilepticus
https://bnf.nice.org.uk/treatment-summaries/status-epilepticus

How can I monitor my epilepsy or 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.

Download a copy of Epilepsy.org.uk's seizure diary
www.epilepsy.org.uk/living/keeping-a-seizure-diary

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.

Brain tumours and seizures

Up to 2 in 3 people with brain tumours experience seizures or epilepsy. They can vary in type and severity.

If you would like more information about this, please talk to your health care professional and see the link to more information below.

Read more information here from The Brain Tumour Charity
www.thebraintumourcharity.org

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

Adult Epilepsy Team
uhsussex.neurologyadminaccount@nhs.net

Please visit for further information and advice:

Sudden Unexplained Death in Epilepsy (SUDEP Action)
https://sudep.org/

Epilepsy Action	www.epilepsy.org
Epilepsy Society	https://epilepsysociety.org.uk
Epilepsy Sussex	www.epilepsysussex.com
NHS.uk	www.nhs.uk/conditions/epilepsy

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

Epilepsy Action Helpline 0808 800 5050

Epilepsy Society Helpline 0149 460 400

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Find out how you can get involved. Visit our website
www.uhsussex.nhs.uk/research-and-innovation/
information-for-patients-and-public
or scan the QR code

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

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