

Epilepsy and seizures

Information for patients

This leaflet is for patients diagnosed with epilepsy or who are suspected to have experienced a seizure or seizures. It includes 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. If you have any concerns or questions, please speak to the team caring for you.

Confirming your identity

Before you have a treatment or procedure, our staff will ask you your name and date of birth and check your ID band. If you do not have an ID band we will also ask you to confirm your address. If we do not ask these questions, then please ask us to check. Ensuring your safety is our primary concern.

You have been given this information sheet because your doctor suspects that you have had a seizure or developed epilepsy. A diagnosis of epilepsy is not always straightforward so you will be referred for further assessment and investigations which may include an MRI scan and an EEG (a recording of brain activity).

Not everyone who has had a seizure has epilepsy. It is possible to have a single seizure or seizures triggered by other medical causes that are not epilepsy.

What is epilepsy and what are seizures?

Epilepsy is a common neurological condition that affects the brain and causes recurrent unprovoked seizures. It has many causes.

Seizures are sudden bursts of electrical and chemical activity in between brain cells that temporarily affect brain function.

There are many different types of seizures. The type of seizure depends on which part of your brain is affected, and how far the seizure activity spreads.

In some types of seizure, you may remain conscious but with impaired awareness or you may lose consciousness completely.

Seizures can cause a wide range of symptoms such as staring, sensations, out of character behaviour, stiffening of limbs with jerking, incontinence and changes in awareness.

Epilepsy and seizures can start at any age and can often be lifelong conditions, but sometimes can get better over time. Treatment can help most people with epilepsy to have fewer seizures or to stop having seizures completely. 60 to 70% of patients with epilepsy can become seizure free on medication (anti-epileptic drugs). However, it is very difficult to predict in any 1 patient how easy seizure control will be. We have a long list of anti-epileptic drugs that we can try.

Learning how to manage your seizures or 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 epilepsy has triggers. Something that triggers a seizure in one person may not trigger it in another.

Common 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 (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 will indicate whether this is the case for you
- excessive use of alcohol
- illegal and recreational drugs (especially cocaine and amphetamines)

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 lack of sleep.
- If you are unwell with a high temperature, take regular paracetamol and seek GP advice if you have a fever.
- 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 the NHS website for further information about alcohol units: www.nhs.uk/live-well/alcohol-advice/calculating-alcohol-units/
 - Please see the Epilepsy Action website for further information about drinking alcohol and epilepsy: www.epilepsy.org.uk/info/daily-life/alcohol

How else can I keep myself safe?

Avoid placing yourself in risky situations where a seizure could have serious consequences, especially if you are alone. We offer the following advice:

- showering is preferred and safer than taking a bath, if you do not have this option have a shallow water bath with the door unlocked and someone else around who can check on you
- do not ride a bicycle without a helmet
- avoid working on ladders or at heights
- avoid being by an unguarded open fire or flame
- avoid open water swimming or swimming alone in a pool (inform the lifeguard and have a friend with you if possible)
- avoid operating potentially dangerous or heavy machinery, for example, chain saw, manufacturing equipment
- take care with cooking or handling hot liquids – using a microwave is safer if you live alone

Taking anti-seizure medication

Most people with a diagnosis of epilepsy are given anti-seizure medication to help control their seizures. It is very important to take your medications every day as prescribed.

Forgetting medication doses can increase the risk of 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 you are entitled to free prescriptions. Ask your GP for a form FP92A. You will be given a medical exemption card.

Can I still drive?

You must inform the DVLA if you have had a seizure. You must not drive for at least 6 months (even if you have only had one seizure). The usual recommendation is that you cannot drive until you have been one year free from all seizures. This is for your own safety and that of other road users and pedestrians.

If you have a driving licence, you are required by law to inform the DVLA. Failure to inform the DVLA is a criminal offence and you can be fined up to £1,000.

Please look on the DVLA website for more details and further information about driving with epilepsy: www.gov.uk/epilepsy-and-driving

Not being able to drive can have a big impact on your life, and can be very difficult and upsetting. However, if you have a diagnosis of epilepsy you are entitled to disabled persons bus pass. For more information on how to apply for a bus pass visit www.gov.uk/apply-for-disabled-bus-pass

Will I be able to work?

Your ability to work with epilepsy will depend 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. Pregnancy could affect your epilepsy, and some epilepsy medicines can increase your risk of having a baby with a birth problem. The risk varies, depending on your type of epilepsy, how well your seizures are controlled before pregnancy, and which epilepsy medicine you take. The dose of epilepsy medicine is important too.

Getting specialist support at the right time, particularly if you are at risk of an unplanned pregnancy, may reduce these risks. Ask your consultant or nurse for a pre-conception counselling appointment.

If you are taking anti-seizure medication and there is any chance you could become pregnant, we advise you take 5mg of folic acid each day. To get a 5mg dose you will need a prescription from your GP as it is a higher dose than you can buy over the counter.

What is sudden unexplained death in epilepsy?

Sudden unexplained death in epilepsy (SUDEP) is rare (1 in every 1,000 adults with epilepsy each year). It 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. Research has shown there are some things that can put you at a higher risk.

The biggest risk factor for SUDEP is having uncontrolled tonic-clonic seizures (where you become unconscious and your body becomes stiff, followed by rhythmic jerking of the limbs). SUDEP often happens at night. This suggests that you may be at more risk of SUDEP if you have seizures during sleep. Please see www.sudep.org for further information and advice.

How can I monitor my epilepsy and seizures?

It is useful to keep a seizure diary to record 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 or 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?
- film the seizure if you can on a camera phone

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

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.

Where can I go for more advice and support?

- Epilepsy Action: www.epilepsy.org.uk Helpline: 0808 800 5050
- Epilepsy Society: www.epilepsysociety.org.uk Helpline: 01494 601 400
- UK Epilepsy and Pregnancy Register: www.epilepsyandpregnancy.co.uk
- SUDEP Action: www.sudep.org

Sharing your information

We have teamed up with Guy's and St Thomas' Hospitals in a partnership known as King's Health Partners Academic Health Sciences Centre. We are working together to give our patients the best possible care, so you might find we invite you for appointments at Guy's or St Thomas'. To make sure everyone you meet always has the most up-to-date information about your health, we may share information about you between the hospitals.

Care provided by students

We provide clinical training where our students get practical experience by treating patients. Please tell your doctor or nurse if you do not want students to be involved in your care. Your treatment will not be affected by your decision.

PALS

The Patient Advice and Liaison Service (PALS) is a service that offers support, information and assistance to patients, relatives and visitors. They can also provide help and advice if you have a concern or complaint that staff have not been able to resolve for you. They can also pass on praise or thanks to our teams.

PALS at King's College Hospital, Denmark Hill, London SE5 9RS

Tel: 020 3299 3601

Email: kch-tr.palsdh@nhs.net

PALS at Princess Royal University Hospital, Farnborough Common, Orpington, Kent BR6 8ND

Tel: 01689 863252

Email: kch-tr.palspruh@nhs.net

If you would like the information in this leaflet in a different language or format, please contact our Communications and Interpreting telephone line on 020 3299 4826 or email kch-tr.accessibility@nhs.net