SUDEP Action

Making every epilepsy death count

Live well with epilepsy

Managing risk & understanding SUDEP

What is epilepsy?

Epilepsy is a neurological condition that affects the brain and nervous system, causing seizures. Seizures are a burst of electrical activity in the brain that temporarily affect how it works. They can cause a wide range of symptoms.

Epilepsy is a complex condition which can be difficult to understand. Staying safe means having key up-to-date information to make the best decisions possible.

You can lead a great life with epilepsy and knowing the risks associated with the condition can help you do that.

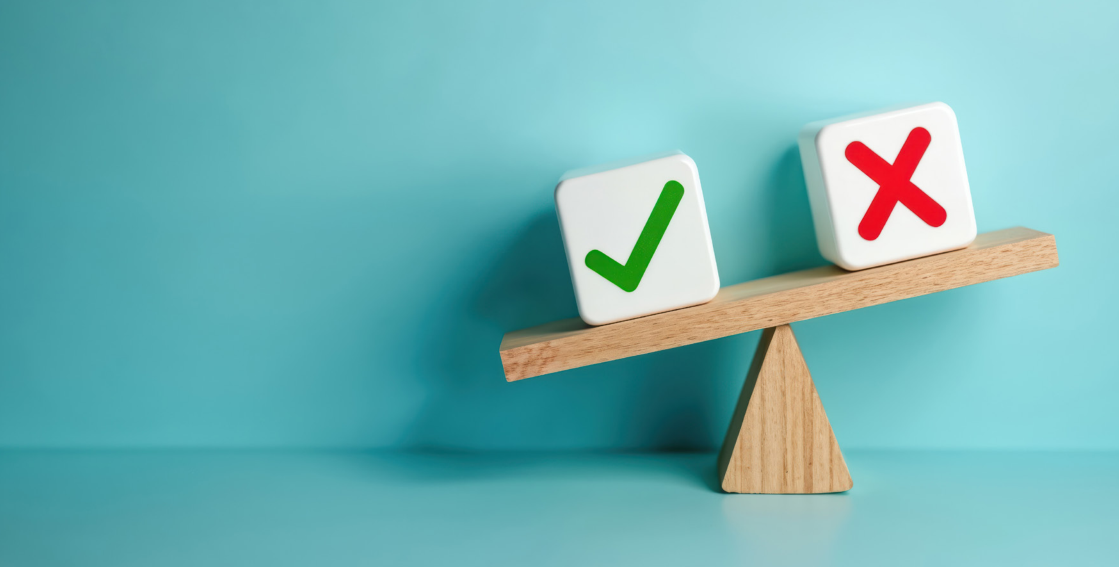
What matters most is understanding YOUR epilepsy and the seizures you have – their type, timing and severity, how well controlled they are, and how they are impacted by lifestyle choices.

One person in 26 will develop epilepsy, which means it is not a rare condition. Seizures look different in different people. Epilepsy is not one thing. It is not the same for everyone.

Be seizure aware

For many, managing epilepsy is possible by medication. Understanding seizure triggers helps with the management of risk.

Although seizures are spontaneous and unpredictable, there are often personal triggers that you come to recognise, for example, stress, alcohol, flashing lights, changes in routines or sleep patterns, or forgetting to take epilepsy medication, also known as anti-seizure medication (ASM) or anti-epileptic medication (AED).



Did you know?

- There are over 20 different types of seizure
- One in 20 people will experience a seizure in their lifetime
- At least 21 people die because of epilepsy each week with most deaths happening at home
- There are over 100,000 emergency department visits a year in the UK because of epilepsy

What is SUDEP?

SUDEP stands for Sudden Unexpected Death in Epilepsy. It's when someone with epilepsy dies and no other cause of death can be found. Many of those who die are often young and otherwise healthy. It's not known what causes SUDEP, but research has shown that actions can be taken to reduce risks for many people with epilepsy. Taking positive steps to reduce seizures as much as possible is the best defence against SUDEP.

It's vital you talk directly with your clinician about SUDEP and YOUR SUDEP risks.

Understanding seizures

It’s important to understand and recognise your own type and pattern of seizures. You should discuss this with your clinician – because there are different risks, according to the type and pattern of your seizures.

For example:

Generalised Tonic-Clonic Seizures (GTCS)

These seizures are what most people picture when they think of a seizure and can be the most severe. They are when a person loses consciousness, becomes stiff (often falling to the ground) and shakes or convulses.

Sleep-related (nocturnal) Seizures

These happen when a person is asleep, or shortly after waking. This type of seizure puts people at a higher risk of death compared to other seizure types.

Status Epilepticus

Status epilepticus is when a seizure lasts a long time or when you have one seizure after another without recovering in between. Rescue medications are used to stop the seizures.

Cluster Seizures

There is no single definition for cluster seizures but it’s generally when a group of seizures happen more often than you’re used to within a certain span of time.

Managing seizures

If you have epilepsy it's important you continue to look after yourself and have regular reviews, **at least yearly**, to check:

- **There are no changes to your epilepsy, health or wellbeing**
- **You are still on the right medication for you**

If you are seizure free but notice any changes to your health, speak with your clinician in case it is related to your epilepsy or your medication.

Anyone having seizures, whether one a year or many a day, is considered to have active epilepsy. If this is you, it's important to have regular reviews with your clinician. This may be a GP, neurologist, epilepsy specialist nurse or learning disability nurse.

Regular reviews are important

Clinical guidelines such as the NICE Guidelines (UK) recommend that people with epilepsy have regular reviews of their epilepsy yearly, and are given information about risk. This is not law, but you should ask for a review if one isn't offered to you. Not taking prescribed medication, even for a short time, can increase your risks of seizure and injury / death. If you are experiencing side effects from medication or have any concerns, talk to your clinician.

When someone has a general convulsive seizure

You may wish to tell friends and family what they should do if you have a seizure. Perhaps give them a copy of this booklet so they know how to help you.

What to do...

- ✓ Stay calm and talk reassuringly to them.
- ✓ Turn them on their side to prevent choking and into the recovery position after the seizure.
- ✓ Loosen tight clothing and place something soft under their head if you can.
- ✓ Avoid putting anything in their mouth.
- ✓ Time how long the seizure lasts.
- ✓ Stay with them until they are awake and alert, or help arrives. Do not give them anything to eat or drink until they are fully alert.

Remember...

- ✓ Do not restrain or try to move someone whilst they are having a seizure (unless they are in danger).
- ✓ Call an ambulance if you are concerned. Call 999 and ask for an ambulance if it's the first time someone has had a seizure, the seizure lasts longer than is usual for them or if the seizure lasts more than five minutes. Also ask your doctor / nurse for a plan, when to seek emergency help.

Stress / mental wellbeing

It is thought that one in four people will have a mental health condition at some point in their lives. This includes anxiety and feeling depressed. For people living with long-term conditions such as epilepsy, this risk is higher. Whatever you are experiencing, help is available so please be reassured that things can be done to improve how you are feeling.

Please speak to your clinician / clinical team if you have any concerns or questions.

Medication & seizure control

- ✓ Ensure medications are taken as prescribed and you get prescriptions on time.
- ✓ If you feel your medication isn’t right, speak to a clinician as soon as possible. Ask questions. And be prepared to ask them again if you aren’t satisfied with the response.
- ✓ Getting the best seizure control possible for you should be your priority.
- ✓ Understand your personal seizure triggers.
  Know what you need to do to stay safe and what to avoid.
- ✓ Prioritise your personal wellbeing and try to reduce stress.
- ✓ Speak to a clinician if you notice any changes in your seizures, medication side effects or mood.

Plan ahead

When seizures occur:

- Keep a seizure record to help spot patterns or changes.
- Put emergency contacts into your phone’s directory.
- Modify or arrange your home to make it as safe as possible should you have a seizure.
- Ensure you carry key information with you about your epilepsy (perhaps wear a medical ID bracelet or carry an information card).
- Use your support network, involving family, friends, carers, health professionals and people at work.
- Take extra medication with you, if possible, when you travel or go away. If you are holidaying abroad, get proper advice before you go away, such as when to take medication in different time zones.
- Avoid unsupervised baths. Showers are a safer alternative. Consider life jackets & lifeguard supervision for activities.

Contraception and family-planning

Women with epilepsy should speak to their clinician about the best form of contraception as some anti-seizure medications (ASMs) can interfere with some types of contraception. This could affect how your contraception works and might make your seizures worse.

It's important that women have ongoing discussions with their epilepsy clinician about contraception, sex and pregnancy (also known as pre-conception counselling). These discussions should take place even when there are no plans for pregnancy. It's important to have personal discussions so you can make personal choices, which provide the best outcomes for you.

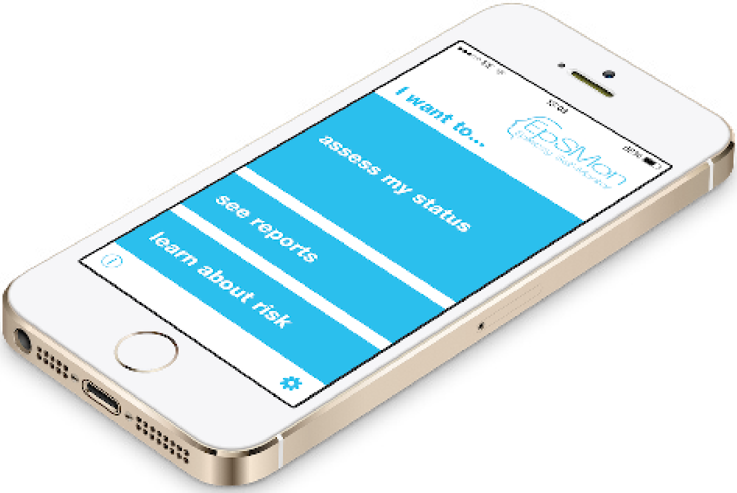
When you discover you are pregnant it is vital you DO NOT stop taking your epilepsy medication. However, talk to your doctor / clinician to ensure the safest possible care for both you and your baby. If you are taking Epilim (sodium valproate) or Topiramate you must talk to your doctor as soon as possible.

Pregnancy

To ensure a healthy pregnancy, it's important to have balanced information and to receive personal medical advice before you become pregnant. This is known as pre-conception counselling.

Some epilepsy medicines are not recommended during pregnancy but stopping them could affect how well your seizures are controlled. It's therefore vital that expert advice is sought to minimise any risks to both mother and child.

Having a baby could also affect dosages and your seizures may change too. These changes may continue until the baby is born. Again, your clinician can help with advice on this. Continue to take your medication as prescribed by your clinician – because maintaining control over your seizures is one of the best ways to keep both you and your baby safe.



The EpSMon app

Our EpSMon app (for over-16s) is designed to help you understand your own personal epilepsy risks so you can make informed decisions about when to book GP appointments and review your care plan.

EpSMon provides key information for you and your clinician – helping you better understand your condition and when you need to take positive action to live more safely.

Download from the App Store or get it at Google Play. More at our website www.sudep.org

Other tools

We also have tools for health professionals to use in discussion with patients. Find out more about:

- The SUDEP & Seizure Safety Checklist
- The Children's SUDEP & Seizure Safety Checklist

Go to www.sudep.org for more details

SUDEP Action

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SUDEP Action's website has more information and resources about living well with epilepsy, reducing risks, and providing support to anyone bereaved by epilepsy:

www.sudep.org

SUDEP Action provides all resources, tools and information, including our EpSMon app, to people for free. However, if you would like to support our work we would welcome any donation, large or small.

Go to sudep.org and click on the 'donate' link, or scan the QR code

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