

Record and manage your epilepsy using your mobile phone

Many people also use their mobile phone to help manage their condition. Epilepsy Society's free app is available for both iPhones and Android phones. It will enable you to access many useful functions that will help to give you, your friends, family and carers the confidence to deal with your seizures and make sure you receive the appropriate treatment. The app is available in English, Polish, Hindi and Spanish.

What the app provides

Managing epilepsy

A diagnosis of epilepsy can leave you feeling out of control, but learning more about the condition is often a first step in coming to terms with your seizures. This section offers useful suggestions about managing your epilepsy, including talking through any worries and concerns you may have, sourcing reliable information and learning more about the type of seizures you are experiencing.

There is also a useful section about talking to others about your condition and how to get the best out of your appointment with your epilepsy specialist.

Facts about seizures

There are many types of seizures and often they will affect different people in different ways. Here you can find out more about different seizure types and any side effects you may experience from taking anti-epileptic drugs. Problems may include memory issues, tiredness and anxiety.

You can download the app on either phone by scanning this QR code.



My notes

This is a useful page to note questions you may want to ask your GP or epilepsy specialist. Or you might like to use the page to note their answers.

Seizure diary

Keeping a seizure diary can help you and your epilepsy specialist recognise any patterns in your seizures. You can record the date, time and type of seizure using an easy code.

Medication advice

Find out how you can optimise your seizure control by taking your medication regularly as prescribed and by ensuring a consistent supply of your AEDs.

My medication

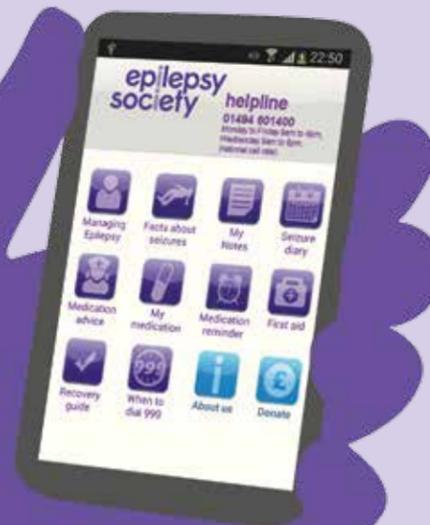
This allows you to record the name, dosage and add a photograph of each AED you are prescribed. This will help ensure you are always prescribed the same version of your drug, rather than being switched between versions.

Medication reminder

This enables you to set alarms to remind you to take your medication at different times of the day. This is especially important if you have memory issues.

First aid

Knowing how to help someone during and after a



seizure may help you and them to feel more confident. If you have seizures, you might choose to share the information with those you spend most time with, either at home or at work. This will give those around you the confidence to support you if you have a seizure.

Recovery guide

Learn how to put someone into the recovery position in seven simple steps. There are easy-to-follow photographs and a link through to a YouTube video.

When to dial 999

When someone has a seizure there is usually no need to call an ambulance. However in some circumstances such as if it is a first seizure, the person has injured themselves, they are having trouble breathing once the seizure has stopped or the seizure lasts longer than five minutes, you should always dial 999. This section will give you, or those around you, the confidence to respond correctly in the event of a seizure.

Downloading your epilepsy app

You can download Epilepsy Society's app from the app store on your phone. If you have an Android phone this is 'Googleplay' and the app is called the Epilepsy Society app.

If you have an iPhone this is the 'App store' and the app is called the epilepsy toolkit. To find out more go to www.epilepsysociety.org.uk/free-epilepsy-smartphone-app



**epilepsy
society
helpline**

01494 601400

Monday to Friday 9am to 4pm
Wednesday 9am to 8pm.
Confidential. National call rate.

Understanding about SUDEP

Sudden Unexpected Death in Epilepsy is rare. For most people, the risk is very low. Dr Greg Rogers explains why talking about SUDEP with an epilepsy specialist can be reassuring and can help you to minimise your own risks

SUDEP – or Sudden Unexpected Death in Epilepsy – it's not an easy conversation to have. A diagnosis of epilepsy can be a lot to take in without having to consider the possibility that in rare cases, it has the potential to be life threatening.

SUDEP is a term used when a person with epilepsy dies suddenly with no known cause. It does not include those cases where a person may die through injury or drowning following a seizure or due to a prolonged and severe seizure as in status epilepticus.

Thankfully, SUDEP is very rare. Every year around 600 people in the UK die from SUDEP. Although initially this figure may seem quite high, when you consider there are over half a million people in the UK with epilepsy, you will see that actually the risk is very low. The risk of SUDEP for those with epilepsy is 1 in 1000. Significantly, every one of those deaths is thought to be potentially preventable. And this is where talking about SUDEP is so important.

Healthcare professionals have been, and often still are, divided on the merits of whether to tell patients about SUDEP, often choosing only to broach the subject with those considered to be at greatest risk. If a person's risk factors are thought to be low, many elect not to burden them with the possibility of something that is unlikely to happen.

Consequently there are many people who have lived with epilepsy all their lives but who have never heard of SUDEP, nor ever had a conversation with their healthcare professional about it. Sadly there are also those who only find out about SUDEP when they lose a loved one to it.

The dominance of the internet, however, is changing the information highway. Until recent times, health information was delivered by GPs, consultants

My inspiration Dr Greg Rogers



'It was Christmas and I was in my fourth year of medical school, attached to a hospital. My girlfriend, Sue, came in to join me for the Christmas party which involved staff and patients. I'm afraid I was a little inattentive of Sue – she is now my wife (above) – and one of the patients, a young woman, stepped in and really looked after her. I was very grateful.

Two weeks later, the same young woman died of SUDEP. It was very poignant. She was only 22. It really brought it home to me just what a devastating effect a condition can have on a person.

That experience sowed the seed for what has become a life-long interest for me in epilepsy and how, as healthcare professionals, we can help to lessen its impact.'

Dr Rogers is GP clinical champion for epilepsy

and specialist nurses. But today we are as likely to go online to supplement our knowledge of health-related issues. Recent research showed that between 2004 and 2013, the volume of Google searches for the term 'epilepsy SUDEP' increased by 5,000 per cent. People want to know more, and indeed understanding about SUDEP and putting it into context can be reassuring.

A recent study in Cornwall, funded by SUDEP Action, looked at 93 epilepsy related deaths from 2004 to 2012. This included 48 cases of SUDEP. The study showed that many of the people who had died had not been in contact with their specialist team despite showing warning signs such as increased seizures before their death. Nor had a significant minority been in contact with their GP. Less than half the SUDEP cases had received an epilepsy medication review.

Researchers concluded that many of the SUDEP deaths might have been preventable with better screening in primary care to identify changes in seizure patterns and referral to specialist services when SUDEP risk factors are present.

In short, the report highlighted the need for healthcare professionals to talk more to their patients about

SUDEP, particularly in the case of those thought to be at greatest risk.

Currently we do not fully understand the causes of SUDEP. Evidence suggests that it seems to happen during or after a seizure, so it is possible that it may be due to a problem with a person's heart or breathing during a seizure. Researchers at Epilepsy Society are trying to identify genes that may increase the risk of SUDEP in some individuals.

Although we are unsure why it happens, it seems that SUDEP is more likely in those with frequent generalised tonic clonic seizures. Young adults in this category seem to be more vulnerable. In people with severe epilepsy (frequent and severe tonic clonic seizures) the risk of SUDEP can rise to around 1 in 200.

Recognising that you may be at risk is a positive first step in minimising that risk. There are several things you can do to reduce your risk (see *Minimising your risks of SUDEP* below).

The important thing to remember is that SUDEP is very rare and the risks are very individual to each person. If you have concerns about your own risk, it is important that you talk them through with your epilepsy specialist, GP or epilepsy specialist nurse.



Caron Robinson lost her daughter Nik to SUDEP last year. She tells her story

'Nik started having seizures two days before her seventh birthday. For eight years she went through 24 medications or combination of medications but nothing worked. At her poorest seizure control she had 200 tonic clonic and complex partial seizures per month.

In 2006 Nik had a final drug change. It was like someone had turned the light back on... her memory became sharper, she could follow simple instructions again. We flew to the US where she fulfilled a lifelong ambition to swim with dolphins.

Nik started to access life once more. She moved into her own bungalow. I was her night-time support and her PA joined her during the day for the gym, swimming, karaoke.

Nikey went to bed at midnight on the 20 March 2013. She shouted through to tell me she had switched her bed alarm on and was doing a word search before going to sleep.

On the 21st at 8am her alarm clock rang. She didn't switch it off. Nik was 23 when she passed to SUDEP. I knew she was at risk, hence she had an anti-suffocation pillow and bed alarm. Her seizure alarm was not triggered and no noise was made. I believe Nik fell asleep... her lights went out.

She was an amazingly brave young lady. We try not to mourn her death but celebrate her life. She leaves a big Nikey shaped hole in our lives. No one will fill it.

Since Nik passed away we have been raising awareness about SUDEP. It amazes me the amount of people who are not aware of SUDEP and whose healthcare professionals don't mention it or say there is no risk. My own GP had never heard of it. She has now.' [facebook.com/groups/NiksShout](https://www.facebook.com/groups/NiksShout)



Abigail Smith was nine years old when she painted this picture, three months before she died of a seizure. www.epilepsysociety.org.uk/artists-and-epilepsy

Minimising your risks of SUDEP

- maximising your seizure control is vital. Make sure you take your epilepsy medication as prescribed, on a daily basis and around the same time each day
- keeping a diary of your seizures will help to identify any changed patterns in your seizures and any avoidable triggers
- if you have active seizures, you might like to ask for a review of your epilepsy with your GP, neurologist or epilepsy specialist nurse
- SUDEP often happens when a person is asleep. If you have asleep (nocturnal) seizures, you might like to consider having a seizure alarm that will alert someone if you are having a seizure. You may also like to use an anti-suffocation pillow.

For more information and support about SUDEP

www.epilepsysociety.org.uk/sudep
Seizure alarms www.epilepsysociety.org.uk/alarms-and-safety-aids
SUDEP Action www.sudep.org provides information and support to those affected by SUDEP.

You can also talk to someone on Epilepsy Society's confidential helpline 01494 601 400 (Monday-Friday 9am-4pm, Wednesday 9am-8pm)
 You can talk to others with epilepsy at <http://forum.epilepsysociety.org.uk>