

Seizures

Around 6 in 10 people diagnosed with epilepsy become seizure-free within a few years of starting treatment. Many will not have any more seizures.

However, some people may have occasional breakthrough seizures, side effects from epilepsy medicines, or uncontrolled epilepsy (also called refractory epilepsy).

Whatever your situation, it can be worrying if seizures start happening more often.

Adjusting epilepsy medication may help, but it's also important to think about seizure triggers. If triggers are involved, medication alone might not be enough.

Common seizure triggers

You may be more likely to have a seizure if certain triggers affect you. These vary from person to person, but common triggers include:

- Missing doses of epilepsy medicine
- Not taking medicine as prescribed
- Illness or infection
- High or low body temperature
- Lack of sleep or changes in sleep pattern
- Alcohol
- Recreational drugs (especially stimulants like cocaine or amphetamines)
- Anxiety or stress
- Hormonal changes during the menstrual cycle

- Flashing or flickering lights (photosensitive epilepsy affects about 3% of people with epilepsy)
- Constipation
- Skipping meals or poor nutrition
- Not drinking enough fluids

What to do if you identify a seizure trigger

Avoiding seizure triggers can help reduce the number of seizures you have.

If you think a health issue - such as illness, infection or constipation - may be contributing, speak to your GP first.

You can use the QR code at the end of this leaflet to review common seizure triggers and find support to help manage them.

Recording seizures

Keeping a seizure diary can help you and your epilepsy care team spot patterns and identify possible triggers during periods of increased seizure activity.

A paper diary - Epilepsy Action seizure diary:

<https://www.epilepsy.org.uk/app/uploads/2024/11/EPILEPSY-ACTION-SEIZURE-DIARY-REBRAND-EDITABLE.pdf>

An app - EpSMon App:

<https://sudep.org/about-research/epsmon-app/>

Medications

Take your medicine exactly as prescribed. Missing doses can lead to breakthrough seizures.

If you find it hard to remember your medicine:

- Download the free **Medisafe app**
- Use reminders on your phone or smart devices (for example, Alexa or Google Nest)

If you have difficulty swallowing your medicine or experience side effects, speak to your GP or pharmacist. You can also ask your pharmacist for advice if you often forget to take your medicine.

When to contact us

Contact the team if:

- You or your GP cannot identify a health issue or trigger
- You need help reviewing your seizure diary or care plan

Please note: This service does not provide urgent or emergency advice.

- **Call:** 01603 216021
 - **Email:** eec.epilepsynurses@nhs.net
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Other contacts

- **Emergency services:** Call 999
- **General health advice:** Call 111 or contact your GP
- **Consultant neurologist:** Check your hospital letters or epilepsy care plan for contact details

Additional support from epilepsy charities

Epilepsy Action

- Helpline: 0808 800 5050
- Available Monday to Saturday
- Offers advice on benefits, driving, employment, and general epilepsy support

<https://www.epilepsy.org.uk/>

Epilepsy Society

- Helpline: 01494 601 400
- Available Monday, Tuesday, and Wednesday
- Offers emotional support and a listening service

<https://epilepsysociety.org.uk/>

Sudden Unexpected Death in Epilepsy

SUDEP is a rare risk, but there are steps you can take to reduce it. For more information and guidance on managing your risk:

Call SUDEP Action: 01235 77285

<https://sudep.org/>

Signposting

For further information and advice on seizure triggers, living with epilepsy, advice for managing epilepsy, please see the Epilepsy Specialist Nurse website:

<https://www.eastofenglandcommunityhealthandcare.nhs.uk/our-services/norfolk-communityhealth-and-care-services/norfolk-adult-epilepsy-specialist-nurse-team/>

Accessible formats

If you would like this publication in **large print**, **Braille**, an **alternative format**, or in a **different language**, please contact us on **0800 088 4449** and we will do our best to help.



Feedback

If you have any queries about our services, or would like to provide feedback, please contact our **Patient Advice and Liaison Service (PALS)**:

- **Telephone:** 0800 088 4449
- **Email:** eec.pals@nhs.net
- **Opening hours:** Monday to Friday, 9am–5pm

Ask a member of staff for a **Friends and Family Test form**, or visit:

eastofenglandcommunityhealthandcare.nhs.uk/patient-experience/patient-advice-and-liaison-service-pals/



**East of England
Community Health and Care**
NHS Trust

Your guide to seizure triggers

Delivering great health and care
services in our local communities