

Questions to ask your doctor

When you are first diagnosed with epilepsy you are likely to have lots of questions. Below are some questions you might want to ask a healthcare professional. For some people this might be their GP or epilepsy specialist. For others, it might be an epilepsy specialist nurse. You might also find these questions helpful if you are having a review of your epilepsy.

Suggestions for preparing for your appointment

- Take someone with you, if you can. They can support you and explain exactly what happens when you have a seizure
- If you can't take someone with you, try to take a written description of what happens when you have a seizure
- If possible, ask someone to film you during a seizure. Showing video clips of your seizures to your doctor can be really helpful when they are considering a diagnosis of epilepsy
- Keep a seizure diary and take it to your appointment. Contact Epilepsy Action for a seizure diary
- Organise your thoughts before you go, for example by making brief notes or a list of questions
- Try to make sure your questions are answered. If there's not enough time to cover all your questions, ask for another appointment

Some questions for your doctor

Questions about your epilepsy

- Why do you think I have developed epilepsy now? _____

- Has my epilepsy got a particular name? _____

- What is the outlook for my epilepsy? _____

- Is anyone else in my family likely to be affected? _____

- What possible triggers are there for my seizures? _____

Questions about your treatment

• How does epilepsy medicine work? _____

• When should I take it? _____

• Must I take it exactly as stated? _____

• What are the possible side-effects of my medicine? _____

• Which side-effects are important to see you about? _____

• What will happen if my medicine doesn't work? _____

• What happens if I miss a dose, am sick, or have diarrhoea? _____

• Is my medicine safe to take during pregnancy? _____

Questions about safety

• Would I ever need urgent medical attention for my epilepsy? _____

• How should people around me keep me safe if I have a seizure? _____

• Are there any over-the-counter medicines that I would need to check about before taking them?

• Can you explain how the driving regulations will affect me? _____

• Is there anything it's not safe for me to do? _____

• Am I at risk of sudden unexpected death in epilepsy (SUDEP)? What can I do to reduce the risk?

Epilepsy care plan

You might want to discuss an epilepsy care plan with your doctor. This is a booklet that can be filled in and updated by you and any professionals you see about your epilepsy. You can use it to make a note of things such as:

- What happens to you during a seizure
- How long you take to recover from a seizure
- How long your seizures normally last
- What to do if your seizures last longer than usual
- Anything that makes your seizures more likely
- Which epilepsy medicine you take
- The details of your doctors

You can download an epilepsy care plan booklet from our website or order a paper copy one from our shop.

How often should I see a healthcare professional about my epilepsy?

In England, Wales and Northern Ireland, the National Institute for Health and Care Excellence (NICE) makes recommendations about diagnosing and treating people with epilepsy. NICE recommends that children and young people should have a regular epilepsy review with a doctor or nurse at least once a year.

If you are an adult, NICE says you should have a review at least once a year if any of these things apply:

- You have a learning disability
- You have drug-resistant epilepsy (meaning you have tried 2 or more epilepsy medicines and are still having seizures)
- You are at high risk of sudden unexpected death in epilepsy (SUDEP)
- You have another serious health problem alongside your epilepsy, such as a complex mental health problem
- You are taking epilepsy medicine that has a risk of long-term side effects or interactions with other medicines

- You are able to get pregnant and are taking sodium valproate or another medicine that has a high risk of causing problems if taken during pregnancy

If you are still having seizures, NICE also says you should be offered an appointment with an epilepsy specialist nurse at least twice a year, and after any visits to A&E.

Even if none of these things apply to you, you can still ask for a review of your epilepsy if you have any concerns. Examples of times you might ask for a review include if you:

- Want to discuss stopping or changing your medicine
- Are planning to get pregnant

The Scottish Intercollegiate Guidelines Network (SIGN) Guidelines make recommendations about epilepsy treatment for people in Scotland. The SIGN guidelines say that everyone with epilepsy should have a review once a year.

Guidance from NICE: [nice.org.uk/guidance/cg137](https://www.nice.org.uk/guidance/cg137)

Guidance from SIGN: [sign.ac.uk/our-guidelines/diagnosis-and-management-of-epilepsy-in-adults](https://www.sign.ac.uk/our-guidelines/diagnosis-and-management-of-epilepsy-in-adults)

Where can I get more information about epilepsy?

Visit the advice and information section of our website or call the Epilepsy Action Helpline for lots of information about epilepsy, including:

- What epilepsy is
- Diagnosing epilepsy
- Taking epilepsy medicines
- First aid
- Seizure triggers
- Getting the right treatment and care for your epilepsy
- Safety for people with epilepsy
- Driving and epilepsy
- Epilepsy and your wellbeing
- Epilepsy and having a baby
- Sudden unexpected death in epilepsy (SUDEP)

About this information

This information is written by Epilepsy Action's advice and information team, with guidance and input from people living with epilepsy, and medical experts. If you would like to know where our information is from, or there is anything you would like to say about the information, please contact us at epilepsy.org.uk/feedback

To find out why you can trust Epilepsy Action's information, please contact us or visit epilepsy.org.uk/trust

Disclaimer

Epilepsy Action makes every effort to ensure the accuracy of information in its publications but cannot be held liable for any actions taken based on this information.

Our thanks

Epilepsy Action would like to thank Naomi Baxter, Epilepsy Specialist Nurse at East Suffolk and North Essex Foundation Trust Ipswich Hospital, for her contribution to this information.

Conflict of interest

Naomi Baxter has declared no conflict of interest.

Date: April 2022

Due for review: March 2024

Code: F098.05

Your support

We hope you have found this information helpful. As a charity, we rely on donations to provide our advice and information. If you would like to make a donation, here are some ways you can do this:

- Call the Epilepsy Action fundraising team on 0113 210 8851
- Donate online at epilepsy.org.uk/donate
- Send a cheque payable to Epilepsy Action (see contact details for address)

Did you know you can also become a member of Epilepsy Action from as little as £1 a month? To find out more, visit epilepsy.org.uk/join or call 0113 210 8800.

Epilepsy Action Helpline

Freephone 0808 800 5050, text 07479 638 071, email helpline@epilepsy.org.uk

Contact details

Epilepsy Action, Gate Way Drive, Yeadon, Leeds LS19 7XY, UK, +44 (0)113 210 8800.

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