

## > **Questions I might ask**

These are just suggestions. Choose any that apply to you – and we've left some space for you to write your own questions below. Or you may want to write on a separate sheet, which you can use for writing down the answers as well.

- How do I know this medicine is helping?
- How can I be sure it's safe for me to take it?
- What side effects are most likely from this medicine?
- What should I do if I get any of these side effects?
- What if I stopped taking it, or took a lower dose?
- Can I drink alcohol with this medicine?
- Does this medicine interfere with the contraceptive pill?
- Why do I need to carry on with this medicine if I am seizure-free?
- Are there any other alternatives, such as a different medicine or another type of treatment?
- Say I forgot to take a dose, what should I do?
- Is there anything that can help to remind me to take my medicines?

## > **Your questions and concerns**

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# Focus on **your** **health**

## for people with epilepsy

*Find out how a review can help* >

Scottish edition



medicines **partnership**



*epilepsy scotland*  
Scotland's voice for epilepsy

## ➤ What this guide is for

**The NHS says that if you have epilepsy, you should have a review meeting with a health professional, at least once a year.**

**You can ask for this meeting with a doctor or nurse** to talk about your epilepsy. Your GP's surgery will arrange for you to see someone. **This is usually called a review.**

If your GP surgery is unable to carry out a review, or if you are unhappy with the advice you are given, you can ask to be referred to a specialist. Or think about changing practices to one that will do epilepsy reviews.

**This guide is to help you get the best from your review.** If you are a carer for someone with epilepsy (for instance, someone with difficulty to control epilepsy, a child, an older person, or someone with learning disabilities), you can read through this booklet with them.

## ➤ What's in this booklet?

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At the back of the booklet are pages that you can fill in: a diary to help you keep track of your epilepsy, and a medicines reminder chart.

## ➤ What is a review?

**A review is a meeting to focus on your epilepsy,** with a health professional – a doctor or nurse. There may be questions that you want answered or worries that are bothering you. The person you meet with may also have changes or questions to raise with you, although you don't have to agree to their suggestions.

**The meeting should be convenient.** It will be booked in advance at a time to suit you and your health professional. How long it lasts depends on how much there is to talk about.

**The meeting is confidential.** Whoever you talk to, the details will be kept private. You can talk openly and your questions or worries will be listened to. A note to say the meeting took place, and any changes agreed to as a result, will be put into your medical notes. So whoever you meet with, your GP will know what you have agreed.

## ➤ Why should I have a review?

**If you have seizures, or problems with medication, a review can help.** Changes to your everyday life, or to your medication, could lead to fewer seizures (sometimes called fits) or fewer side effects.

**Even if you feel well, and aren't having any seizures,** regular review of your epilepsy can help you. A healthy lifestyle and taking the right medication usually means most people with epilepsy can live without seizures. The aim is to enable you to lead as full a life as possible and minimise the risks that seizures and medication can bring.

### **If there is an urgent problem with medicines or your seizures, don't wait for a review**

- **If you have taken too much** of any medicine.
- **If you have an allergic reaction** to a new medicine (such as wheezing, rash, swelling or fainting).
- **If you notice a possible side effect or any unusual symptoms.**
- **If you notice your health getting worse.**

**In any of these cases, talk to a doctor, nurse or pharmacist straight away.**

## ➤ Who will I talk to?

- **A health professional.** The person you meet may be a specialist nurse or doctor, a GP or a specially trained practice nurse.
- **A good listener.** They will be ready to listen to your worries and your questions.
- **Someone you can be open with.** You can say whatever you want in these meetings.

“I just thought that the doctor decided when... now I will go and ask”

### **Don't change your medicines suddenly**

Even quite small changes to the amount of medicine you take can affect your epilepsy and put you at increased risk of seizures.

#### **If you take prescribed tablets for epilepsy:**

- **Take them as your doctor prescribed them.**
- **Don't change your dose without talking to your doctor.**
- **Don't suddenly stop taking your tablets.**

#### **If you get different tablets:**

- **Ask a doctor, nurse or pharmacist if you have been given new or different tablets that you weren't expecting.** That includes different shaped or different coloured tablets or different packaging. There may have been a mistake.

A different make of tablet, even if it contains the same type and quantity of medicine may affect your epilepsy. You can ask for your tablets by brand name to make sure this does not happen.

**If you are worried about the medicines you are taking see a doctor, nurse or pharmacist** before you do anything else.

## ➤ What will we talk about?

- **Your seizures** and any questions about them.
- **Any questions about your epilepsy are OK.** You can raise any of the points in this booklet about living with epilepsy.
- **For women,** questions about contraception and possible pregnancy.
- **Taking your epilepsy medicines** and how you're getting on with them. You may wish to discuss side effects. You may be worried about being given different tablets to your normal ones. The person you meet will also ask you about your medicine taking.
- **Questions about other medicines** are OK, too.

**Speak up about any worries** you have. You may want to discuss getting the right balance between side effects of your medicine and seizure control. You may want to talk about feeling stressed or anxious.

## ➤ How do I ask for a review?

**Call your GP surgery and ask for one.**

“I haven't been for a **yearly** check-up for ages, so perhaps I should go for a **review**”

“**the review** was really very **helpful!**”

## ➤ *Is there anything else I should ask?*

### ● **What risks do you run in everyday life?**

**You may want to ask about safety.** If a seizure affects your awareness or involves falling without warning, you can be at risk of injury or accident. You may want to talk about safely taking part in sports or other activities. You can also ask about safer living, bathing, driving and general safety advice.

### ● **Do you know what brings on your seizures?**

**Ask about triggers.** Some things may trigger seizures. Common triggers include stress, lack of sleep and forgetting to take your tablets. Did you know that recreational drugs or too much alcohol may increase the number of seizures you have?

### ● **Have you been having longer seizures, or having them more often?**

**Ask about the new pattern of seizures.** Sometimes people get seizures that last longer than normal, happen more often or are a different type. This is not very common but it is important that your doctor knows if this has happened to you.

### ● **Have you heard people mention SUDEP?**

**Ask for advice about reducing your risk.** SUDEP means Sudden Unexpected Death in Epilepsy. A small number of people die early from SUDEP each year (about 1 for every 1,000 people with epilepsy in the UK, although some people are more at risk). The better your epilepsy is controlled, the less likely it will happen to you – and there's plenty you can do to reduce your risk. The person you meet with can discuss this with you.

## **These organisations can give you more information and support**

### **Epilepsy Scotland**

www.epilepsyscotland.org.uk  
0808 800 2200 – helpline

### **Epilepsy Action**

www.epilepsy.org.uk  
0808 800 5050 – UK helpline

### **The National Society for Epilepsy**

www.epilepsynse.org.uk  
01494 601400 – UK helpline

### **Epilepsy Bereaved**

www.sudep.org  
01235 772852 – bereavement contact line

### **Joint Epilepsy Council**

www.jointepilepsycouncil.org.uk  
– links to regional groups and more

### **Epilepsy Connections**

www.epilepsyconnections.org.uk  
0141 248 4125

### **Quarriers**

www.quarriers.org.uk  
01505 612224

### **Enlighten**

www.enlighten.org.uk  
0131 226 5458

## ➤ *Can I talk about how epilepsy affects the rest of my life?*

Obviously there's more to life than taking medicines. You can raise anything about the way epilepsy or your medication affects your life.

### ● **Feeling anxious, frustrated or depressed?**

You may be having feelings of anxiety, depression, frustration or anger. People with epilepsy get these feelings just like everybody else, and you can ask for help coping with them.

### ● **Do periods affect your epilepsy?**

Some women find that their seizures are worse around the time of their period. You can discuss this at the meeting.

### ● **Are you pregnant, or might you get pregnant?**

If you want to start a family, you'll need expert advice on medicines. If you are already pregnant, tell the person you meet with.

### ● **Are you on the Pill?**

The Pill can be less reliable when taken with some epilepsy medicines – so it's important to talk about it.

### ● **Lost weight? Gained weight?**

Medicines can cause weight gain or weight loss in some people. If you're unhappy, the doctor or nurse may be able to offer a different medicine. Mention any changes to your weight, especially weight loss, because it can also affect the way medicines work.

### ● **Ask about the menopause and HRT**

These can affect epilepsy. Tell the person you meet with if you have been going through the menopause (the change of life) or are taking hormone replacement therapy (HRT).

### ● **As you get older...**

As you get older, and especially if you take more medicines than before, it's possible that your epilepsy medicine may need adjusting. You may also be more worried about falling.

**If you are a carer for a person with epilepsy** you can make the review as successful as possible by reading through the booklet with them. You can then go to the review with him or her to help in putting their concerns across.

## ➤ What if my epilepsy is already well controlled?

If you are feeling well and you have not had a seizure for a long time – good! But it’s still worth taking the time to have a review.

**Changes in your life** – puberty, getting pregnant, or just getting older – may affect your epilepsy or the medicines that you are taking.

**If you are having side effects**, there may be new medicines to discuss.

**If you have had no seizures for three years or more**, you may want to talk about gradually cutting down treatment. There is still a risk of seizures coming back – this is a chance to talk it over.

## ➤ What if I have already had a review?

You may still benefit from looking at your epilepsy, your lifestyle and your medicine. If the review was over 12 months ago, it’s definitely worth thinking about another one.

“if you need it adjusted,  
if it’s not agreeing with you,  
go back and have it reviewed”

### **If you would like further information about medicines for epilepsy** see the following leaflets and websites:

- *Treatment factsheet*, Epilepsy Scotland (see page 6). This leaflet includes information on antiepileptic drugs (plus table) and other treatments.
- *Epilepsy – medication for adults*, The National Society for Epilepsy (see page 6 for contact details). This leaflet includes a table of drugs and possible side effects.
- *The treatment of epilepsy*, Epilepsy Action (see page 6).
- Go to this web site for information about medicines used in epilepsy. It also has links to NHS Direct online information about epilepsy.  
<http://medguides.medicines.org.uk>

## ➤ How should I prepare for my review?

- **Keep an epilepsy diary** (see pages 10-13). This is not just a diary of your seizures but should include all the things you notice leading up to a seizure. You might find there is something that is triggering seizures and which can be avoided. The diary will also help when discussing any side effects of the tablets you are taking.
- **Fill in the medicines reminder chart** (pages 14-15).
- **Think about your questions**, concerns and suggestions, and write them down. There’s a list that might help you on the back cover.
- **Make sure you know when, where and who** you are meeting for your review.

## ➤ What happens after a review meeting?

- **You and the person you meet may agree to try some changes** – to your life or to the medicines you are prescribed. No changes will be made if you don’t want them.
- **If necessary, the person you talk to will make suggestions to your GP**. A summary of the meeting will be written into your medical notes.
- **You may need to be referred to a specialist**.
- **If you are not happy with your review** you can ask to see someone else.

## ➤ Questions I might ask

See the back cover >

### **If you have epilepsy you are entitled to free prescriptions for any medicines**, not just medicines for epilepsy:

- Ask your GP surgery for details of form EC92A.

## What's an epilepsy diary?

Use an epilepsy diary to record your seizures and your general well-being. This will help you to get the best from your review meeting.

## How to use the diary

Read the notes below and then use the blank version over the page.

### Month/Date

Fill in the month and the date.

### Time

Write down the times the seizures happened.

### Awake/Asleep

Write down the number of seizures. Do this for both your waking and sleeping hours.

### Triggers

Write down anything you experienced before the seizure that you think may be useful.

### Notes

Write in any other things that might affect your health or mood. For example, if you are feeling run down or stressed, if you have exams to take, or there is anything that has particularly distressed you.

Write down your mood – good or bad.

### Possible side effects of tablets

Write down any possible side effects that you have noticed.

Take your diary to review meetings.

## Epilepsy diary

Name:

Month: August

Date	Time	Awake	Asleep	Triggers	Notes	Possible side effects of tablets
1st			1	had several late nights	very tired, grumpy	
2nd	2pm	1		did n't sleep well	tired, cross	feeling sick,
3rd	10 am	1				
4th					argued with steve, worried about work	
5th	8am, 12am	2		period started	headache	
6th					stressed about work	feeling sick again
7th						? tired and slow
8th						

“I didn't realise what triggered it until I kept a diary”



# Medicine reminder chart

Medicine name (not just prescribed medicines, see right)	What I call it	What it's for	How much to take, when				Date started
			Breakfast	Midday meal	Evening meal	Bed time	
<b>Epilepsy tablets</b>							
<b>Other medicines</b>							

## How do you take your medicines?

This chart is to help you remember when to take your medicines. It's only meant for medicines that you need to take regularly. So there's no need to write down anything you only take now and then (such as a headache tablet), unless there's a problem with it.

Please show the chart to anyone who prescribes you medicine, and **take it to a review meeting.**

**If you go to hospital** take the chart.

Name: \_\_\_\_\_

Next of kin: \_\_\_\_\_

GP: \_\_\_\_\_

Allergies: \_\_\_\_\_

## Medicine doesn't just mean tablets

When we use the word "medicine" here, it includes lots of things:

- Vitamins, herbal products or other supplements from the pharmacy, health shop or supermarket
- Over the counter medicines, like painkillers or cough syrup
- Liquid medicines or tonics
- Creams and ointments
- Inhalers or other devices