Epilepsy: treatment and SUDEP

The aim of this leaflet is to tell you about how epilepsy is treated and how the treatment can help you. More information about all the topics covered is available from Epilepsy Action.

Epilepsy medicines
The most common way epilepsy is treated is with epilepsy medicines. Epilepsy medicines don’t cure epilepsy, but aim to try to stop seizures from happening.

Taking your epilepsy medicines
Epilepsy medicines are usually taken once or twice a day. Occasionally they are taken three times a day. It’s important to take your epilepsy medicines regularly, as prescribed by your doctor. This is to keep as steady a level of the drug in your blood as possible. If you miss taking your epilepsy medicines this can sometimes trigger a seizure.

Doses of epilepsy medicines
When you start taking epilepsy medicines, it’s best to start at a low dose, and gradually build up to a dose that controls your seizures. This allows you to gradually get used to the medicine, and lessens the risk of side effects.

How long it takes for epilepsy medicines to work
Many people with newly diagnosed epilepsy respond well to epilepsy medicines. This means that they have fewer seizures, or their seizures stop altogether. It’s not possible to say how long this will take. Many people find the right medicine and dose very quickly. Sometimes it can take a lot longer. One in three people with a new diagnosis of epilepsy need a combination of different epilepsy medicines to control their seizures.

Side effects of epilepsy medicines
Like most medicines, epilepsy medicines can cause side effects. Every time you collect a prescription, you should get a patient information leaflet (PIL). This lists the possible side-effects of that drug.

There is more risk that you will get side-effects in the early days of taking an epilepsy medicine. Once your body has had a few days or weeks to get used to the medicine, these side-effects may lessen or disappear completely.

Changing epilepsy medicines
If you have been taking epilepsy medicine for a while and you are still having seizures, or side-effects, talk to your GP or epilepsy specialist. They may suggest that you change the dose or try a new epilepsy medicine.

Stopping epilepsy medicines
If you have been seizure-free for at least two years, your epilepsy specialist may talk to you about the benefits and risks of continuing, or stopping your epilepsy medicines. Some of the things to consider are: how long you have been seizure-free, how long it took to get control of your seizures, how many epilepsy medicines you take, the type of seizures that you have, and how you would feel if you started to have seizures again. And the final decision should be a joint one, between you and your epilepsy specialist.
If you and your epilepsy specialist feel that stopping epilepsy medicines is right for you, they will usually tell you to stop taking them very gradually. This may take a few months. If you suddenly stop taking them, this could cause you to have more frequent and severe seizures, or even status epilepticus.

Other ways of treating epilepsy
If epilepsy medicines don’t work well for you, there are other treatments that might help. These include brain surgery, vagus nerve stimulation and deep brain stimulation. For children, there is also a special diet the ketogenic diet that may help.

Sudden unexpected death in epilepsy
Most of the time, people with epilepsy recover perfectly well after a seizure. But some people don’t. And, for a small number of people, there is a risk of dying because of their epilepsy. When there’s no clear reason why a person with epilepsy has died, it is called sudden unexpected death in epilepsy (SUDEP). In the UK, there are around 600,000 people with epilepsy. It’s estimated that about 500 people die of SUDEP each year.

Being aware of the risks of SUDEP gives you the chance to make choices, which may help to reduce the risks. The aim is to have as few seizures as possible. Here are some things you can do to try to reduce the number of seizures you have.

- Always take your epilepsy medicines as prescribed by your doctor.
- Never stop taking your epilepsy medicines, or make changes to them, without talking to your GP or epilepsy specialist first, as this could cause you to have seizures.
- Make sure that you never run out of your epilepsy medicines.
- Ask your epilepsy specialist, or epilepsy specialist nurse, what you should do if you ever forget to take your epilepsy medicines at your usual time.
- If your seizures continue, ask to be referred to an epilepsy specialist for a review of your epilepsy and treatment.
- Avoid things that may trigger your seizures. Common triggers include forgetting to take epilepsy medicines, lack of sleep, and stress. If you drink heavily, there is a real risk of having seizures if you stop drinking suddenly after a long session of heavy drinking.

About this publication
This information is based on information written with input from people with epilepsy and professionals. Epilepsy Action makes every effort to ensure the accuracy of information but cannot be held liable for any actions taken. If you want to know our sources, or give us feedback, contact us.

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