

Epilepsy: treatment and risks

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.

Anti-epileptic drugs

The most common way epilepsy is treated is with anti-epileptic drugs (AEDs). AEDs do not cure epilepsy, but aim to try and stop seizures from happening.

Taking your anti-epileptic drugs

AEDs are usually taken once or twice a day. Occasionally they are taken three times a day. It's important to take your AEDs 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 AEDs this can sometimes trigger a seizure.

Doses of anti-epileptic drugs

When you start taking AEDs, it's usual to start at a low dose. Your doctor may then gradually increase it to a dose that works well at controlling your seizures. This allows your body to slowly get used to the drug, and lowers the risk of getting side-effects.

How long it takes for anti-epileptic drugs to work

Many people with newly-diagnosed epilepsy respond well to AEDs. This means that they have fewer seizures, or the seizures stop altogether. It's not possible to say how long this will take. Many people find the right AED and dose very quickly. Sometimes it can take a lot longer. About 30 in every 100 people with epilepsy continue to have a number of seizures, even though they have tried two or more AEDs.

Side-effects of anti-epileptic drugs

Like most drugs, AEDs can cause side-effects. Every time you collect a prescription, you should get a patient-information leaflet (PIL). This lists all the possible side-effects of that drug. Although anyone could get any of those side-effects, most people get few or mild side-effects. Some people do not get any side-effects at all.

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

Changing anti-epileptic drugs

If you have been taking an AED for a while and you are still having seizures, or experiencing side-effects, talk to your GP or epilepsy specialist. They may suggest that you change the dose or try a new AED. It is important to never make any changes to your AEDs without following medical advice. This could cause you to have more seizures.

Stopping anti-epileptic drug treatment

You may have to take AEDs for the rest of your life, even if you no longer have seizures. Or you may be able to stop taking AEDs when you have been seizure-free for a few years.

If you want to stop taking your AEDs, you and your epilepsy specialist will need to consider a number of things. These include whether there is a physical cause for your epilepsy and how long it took for your seizures to stop. This can help your specialist decide what the risks of your seizures coming back would be, if you didn't take AEDs.

If your epilepsy specialist recommends that stopping AEDs is right for you, they will usually advise 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.

Other ways of treating epilepsy

If AEDs do not work well for you, there are other treatments that may help. These include brain surgery and vagus nerve stimulation. For children, there is also a special diet that may help.

Sudden unexpected death in epilepsy

Most of the time, people with epilepsy recover perfectly well after a seizure. However, 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 half a million 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 opportunity to make choices, which can help to reduce the risks. The most effective way is to have as few seizures as possible. Here are some things you can do to try and reduce your seizures.

- Always take your AEDs as prescribed by your doctor.
- Never stop taking your AEDs, or make changes to them, without talking to your GP or epilepsy specialist first.
- Make sure that you never run out of your AEDs.
- Ask your epilepsy specialist, or epilepsy specialist nurse, what you should do if you ever forget to take your AEDs at your usual time.
- If your seizures continue, ask to be referred to an epilepsy specialist for a review of your epilepsy.
- Avoid things that may trigger your seizures. Common triggers include forgetting to take AEDs, lack of sleep, stress and alcohol withdrawal.

Word list

AED - Anti-epileptic drug

About this publication

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.

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