

**epilepsy
society**

medication for adults

Treatments for adults aged 13 and over



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Words set in **black bold** within the text are explained on pages 17–18.



When you see this symbol, it means further information is available.

For further information about AEDs visit www.medicines.org.uk/guides/epilepsy

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treatment for adults aged 13 and over

Most people with epilepsy take anti-epileptic drugs to stop or reduce the number of seizures they have. This leaflet looks at the drugs available for the treatment of epilepsy in adults. It also answers some of the questions that you may have about anti-epileptic drugs. The leaflet is quite general, so if you have questions or concerns about your epilepsy, your **neurologist** or a pharmacist may be able to help.

what is the aim of anti-epileptic drugs (AEDs)?

Anti-epileptic drugs (**AEDs**) are used to stop seizures happening. They make the brain less likely to have seizures by reducing the excessive electrical activity (or excitability) of the neurones (nerve cells) that normally cause a seizure. They are not used to stop seizures *while* they are happening and they do not cure epilepsy.

Different AEDs work in different ways, but they all aim to stop seizures happening.

Around 70% (70 in 100) of people with epilepsy could get **seizure control** (stop having seizures) with the right medication. This depends on the type of epilepsy they have.

'Optimal therapy' is seizure control using the smallest dose of the fewest AEDs, and with the fewest side effects.

Managing epilepsy can often be a balance between stopping seizures and keeping side effects to a minimum. Also, getting seizure control can sometimes take a while to happen (to find the right drug at the right dose) and this can vary from one person to another.

Some people may not get complete seizure control, even though they have had the most suitable drug treatment. In this case they may need to take more than one type of AED, to reduce seizures as much as possible, while still keeping treatment as simple as possible. This reduces the chances of side effects.

starting AEDs

- Before starting on AEDs, it is important that your neurologist finds out as much as possible about your epilepsy. This is because the AED that they prescribe depends on the type(s) of seizures you have. Some AEDs work better for certain types of seizures, or types of epilepsy, than others.



See our leaflet *seizures*.

- AEDs are taken every day to stop seizures happening. As AEDs may need to be taken over a number of years, the neurologist will take into account any other conditions you have and your lifestyle when prescribing AEDs.
- AEDs come with a **patient information leaflet**. This tells you what the medication is, what it is for, and possible side effects.

- The **National Institute for Health and Clinical Excellence (NICE)** recommends that people with newly diagnosed epilepsy are treated with one drug at a time where possible – this is called **monotherapy**.
- AEDs are divided into two categories: **first line** and **second line** drugs. First line drugs are usually prescribed when treatment is started. If a first line drug does not stop your seizures happening, a different first line drug may be tried. Alternatively, a second line drug may be prescribed alongside the first line drug, so you take two different types of AED each day. This is called **polytherapy**. However, if you still have seizures after trying two different AEDs, then your neurologist may review your diagnosis before suggesting other AEDs to try.
- Usually AEDs are started at a low **dose** that will slowly be increased, if needed, until the most effective dose is found. This varies from one person to another, and is sometimes called an '**individual therapeutic concentration**'. This is done by carefully monitoring your seizures and how you feel on the drug.
- The drug table at the back of this leaflet shows the average range of daily doses of different AEDs. However, the dose you take may be higher or lower than the average dose.
- Suddenly stopping AEDs can cause seizures to start again, or happen more often and last longer than before. Taking extra AEDs can cause side effects. For these reasons, changes to AEDs are best done with your neurologist.

forms of AEDs

Most AEDs have at least two names, a **generic** name (for example carbamazepine) and a **brand**, or trade, name given by the manufacturer (for example Tegretol). Some AEDs have more than one generic form and each form can be given its own name.

For some AEDs, different forms of the generic drug, or different brand forms of a generic drug, can vary slightly and this could affect seizure control. For this reason it is recommended to take the *same form* of AED all the time, whether it is a generic or brand form. This is sometimes called '**consistency of supply**'.

If a prescription only has the generic name of the drug, a pharmacist can give any form of the drug with that generic name. However, if the prescription has the brand name of the drug, the pharmacist has to give that brand. To ensure consistency of supply it might be helpful to get the prescription from the same pharmacist each time.

Many pharmacists keep patient medication records and can help with questions about prescriptions. Some pharmacists also review medications (called a '**medicines use review**').

If you are not sure if your AEDs are the same as those you normally take, you can check with the pharmacist or doctor.



See our website for up-to-date information on AEDs, and our factsheet *generic and branded anti-epileptic drugs*.

Sometimes medication is labelled in a different language or has different packaging than usual. Often this happens if the drug has been made in another country and brought into the UK (a '**parallel import**'). Some people find that parallel imports affect their seizure control. If you do not want to take medication that has been imported from outside the UK you have the right to refuse it and ask for a supply from within the UK. By always taking the same form of a drug there may be less risk of having a seizure.

taking AEDs

Whether to start taking medication or not is a personal choice. To help you make a decision, you can discuss with your neurologist the possible risks and benefits of taking, or not taking, the medication. Whatever decision you make, if you want to discuss changing your treatment in the future, you can talk to your neurologist about this.

AEDs work best when they are taken regularly. This is because once taken, they start to be broken down and **absorbed** into the bloodstream, and go to the brain to start working. As time passes, the drug leaves the body, so the level of drug in the body goes down. Taking the drugs regularly means that the drug is 'topped up' so there is a steadier level in the body all the time. For most people, missing one dose on a rare occasion is unlikely to result in a seizure happening.

Although the exact timing of doses is not usually crucial, it is helpful to take the right dose around the same time or times each day, and that they are evenly spaced out.

Some drugs are called **chrono** or **retard** (for example, Epilim chrono or Tegretol retard). 'Chrono' and 'retard' mean slow-release (also sometimes called CR or controlled release). In slow-release drugs, the **active ingredient** is released in the digestive system more gradually, and is taken less often, than non-chrono forms.

Some AEDs come in a number of forms: tablets, capsules, syrups or suppositories. There are also versions that can be added to food (such as sprinkles or granules) which can be useful if you have difficulty swallowing tablets. You can talk to your neurologist or a pharmacist about what forms are available for your AED.

Drug wallets

Drug wallets can help you to take the right dose at the right time. They usually have seven containers to keep medication in (one for each day of the week). Each container is divided into sections for the morning, afternoon and evening. Dispersible tablets (that dissolve in water) can't be stored in drug wallets because they react to the air.



Drug wallets are available from us – see back cover for contact details. See also our factsheet *drug wallets and medication aids*.

side effects

All medications can cause side effects, but whether or not someone has them depends on their individual reaction to the medication. Side effects can vary from person to person, and from drug to drug. It is important to balance any side effects against the seizure control the medication gives.

- Some people have *allergic reactions* to medication. This is rare but can be serious. A skin rash is often the first sign of an allergic reaction and usually happens soon after starting treatment. If you think you have an allergic reaction, contact your doctor as soon as possible.
- *Dose-related side effects* happen if the dose is too high. Starting medication at low doses and increasing it slowly may avoid this. Some side effects happen when starting new AEDs, and normally wear off after a few days or weeks. If you have side effects that continue it is worth talking to your doctor about this.
- If drugs are taken for a long time (many years), *long-term side effects* may happen. Keeping drug treatment as simple as possible may lower the risk of these effects.



See the table at the back of this leaflet for examples of common side effects.

The Yellow Card Scheme

The Medicines and Healthcare products Regulatory Agency (MHRA) ensures the safety of medications licensed for use in the UK. The

Yellow Card Scheme is a way of reporting side effects to the MHRA, particularly any not listed on the patient information leaflet. You can get a Yellow Card form from your GP, pharmacy, hospital or NHS drop-in centre. Or call 0808 100 3352 or visit yellowcard.mhra.gov.uk

AEDs and other medication

Some AEDs affect how other medications work, and some other medications can affect how AEDs work. Telling your doctor about any other medication you are taking helps to avoid any possible interactions (when different drugs affect each other). It can be helpful to check with a pharmacist before taking over-the-counter medications, including complementary therapies such as herbal remedies.



See our website for information about complementary therapies.

AEDs and alcohol

Whether to drink alcohol when taking AEDs is a personal choice. How alcohol affects AEDs depends on the AED, the individual and how much they drink.

Some people find that if they drink too much alcohol it can trigger seizures, especially during a hangover. The patient information leaflet often has guidance on drinking alcohol, or you can talk to your doctor about this.



monitoring AEDs

Monitoring epilepsy involves checking whether your seizures are controlled or how often they happen, and if you have side effects.

If you have **osteoporosis** or a family history of osteoporosis, you may be offered a bone density test. This is because some AEDs may affect bone density for some people.

Before starting AEDs you may be asked to have a blood test. This looks at a number of things, such as how well your liver is working. This test may be repeated every one or two years.

Therapeutic drug concentration monitoring

Therapeutic drug concentration monitoring (**TDM**) is a way of managing epilepsy treatment, and is done by measuring the amount (concentration) of the drug in the blood. This is done to try and get the best seizure control with the least side effects for each person.

There are guidelines or **reference ranges** that tell doctors the range of doses of an AED that is likely to control seizures. However, sometimes people will need doses above or below this range. This is because everyone is different in how they respond to treatment.

Currently, not everyone has TDM as a standard part of their epilepsy management, but there are times when it can be really useful.

TDM can be useful in managing epilepsy if:

- you are starting new a AED when you are already on one;
- you take more than one AED;
- you are still having seizures;
- you have been seizure-free but your seizures start again;
- you have other medical conditions or take other medications, or have poor liver or kidney function;
- you have a learning disability or find it hard to explain how your AEDs make you feel;
- you are pregnant;
- you are over 60 years of age; or
- you are taking phenytoin (an AED that is unusual in how it is distributed around the body and TDM can help to check this).

For some AEDs, an alternative to testing blood levels is testing saliva levels. This may be easier and less painful than a blood test and gives a more accurate measurement of the therapeutic level of the AED. However, drug concentrations are harder to measure this way.



If you have any questions about TDM you can ask your GP or neurologist about it.

See our factsheet *monitoring epilepsy*.

coming off AEDs

Some people may need to take AEDs for a long time, sometimes many years. However, if someone has not had a seizure for two or more years then they may be able to think about **withdrawing** (coming off) their AEDs.

If you are thinking of coming off your AEDs, this is best done with advice from your neurologist. Stopping treatment can lead to seizures starting again, and sometimes they may last longer than they did before. Your neurologist can help you to plan your withdrawal and advise you on what to do if your seizures start again. For most people, if seizures do start again, taking the same AED straight away usually gives the same seizure control as before. But sometimes the AED may not work as well as before.

Considering the impact on your life if your seizures start again, such as the effect on work, leisure and driving, may be an important part of deciding whether to come off your AEDs.

Most people do not have withdrawal symptoms if a drug is withdrawn slowly. However, AEDs that might cause withdrawal symptoms include phenobarbitone, diazepam, clonazepam, clobazam and phenytoin. Symptoms can include anxiety, panic, restlessness and sweating.

contraception, pregnancy and AEDs

Some types of contraception are less effective for women taking some AEDs. This depends on the individual, which AEDs they take and the type of contraception they use.

 See our leaflet *women*.

There is a chance that taking AEDs while pregnant may affect the developing baby. However, these risks need to be carefully considered for each person and balanced against the possibility of seizures happening during pregnancy, which may also affect a developing baby or the safety of the mother.

 See our leaflet *pregnancy and parenting*.

status epilepticus

Usually a seizure will stop by itself. However, if a seizure continues for more than 30 minutes (or one seizure follows another with no recovery in between) this is known as status epilepticus (or 'status').

Status in a tonic clonic (convulsive) seizure is a medical emergency and needs urgent treatment. Seizures that last longer than usual, or an increased number of seizures, often happen before an episode of status. For some, missing doses of AEDs can trigger status.

The emergency medication used for the treatment of status is usually a sedative.

Sedative drugs have a calming effect on the brain and can stop a seizure. The point at which emergency medication is used depends on how long someone's seizures usually last.


The two emergency medications used to treat status are 'diazepam' and 'midazolam'.


- Rectal diazepam – is given rectally (into the bottom).
- Buccal midazolam – is given into the buccal cavity (the side of the mouth between the cheek and the gum).

Both these drugs are sedatives. Although it is rare, they can cause breathing difficulties so the person must be closely watched until they have fully recovered.

For people who go into status, their doctor may prescribe diazepam or midazolam so that a carer can give it to them. Specialist training is needed to give emergency medication. It is also important that every individual who is prescribed diazepam or midazolam has a written plan (or **protocol**) about when to give the medication.

Epilepsy Society provides emergency medication training for healthcare professionals, delivered by professional trainers.

 **For information about our training call 01494 601 305 or visit www.epilepsysociety.org.uk**

 **Contact us for details of our emergency medication booklets *buccal midazolam* and *rectal diazepam*.**

Epilepsy reviews

Epilepsy is a very individual condition and people respond differently to their treatment. NICE recommends that if you have epilepsy, you should have a review *at least* once a year, with either your GP or neurologist. The review should look at whether you are seizure-free or how well your seizures are controlled by the AEDs you take, any side effects you have and any concerns you may have.



For more about the NICE guideline visit www.epilepsysociety.org.uk/further-resources

further information

Epilepsy Society information

Buccal midazolam

Complementary therapies

Drug wallets and medication aids

Generic and branded anti-epileptic drugs

Monitoring epilepsy

Pregnancy and parenting

Rectal diazepam

Seizures

Women

In England people with epilepsy are entitled to free prescriptions for their AEDs and any other medication (called 'medical exemption'). To apply, fill in an FP92A form from your GP surgery. Everyone in Scotland, Wales and Northern Ireland gets free prescriptions.



summary of terms

Absorb – when the AED is broken down and gets into the blood stream.

Active ingredient – the part of a drug that works to control or treat a condition.

Add-on (or adjunctive) therapy – medication taken in addition to another medication.

AED (Anti-epileptic drug) – medication taken to control epilepsy and stop seizures.

Chrono or retard – slow-release. In these forms, the active ingredient is released more slowly than forms that are not slow-release.

Consistency of supply – getting the same form of medication with each prescription.

Dose – the amount of medication that is taken such as the number and size of tablets.

Effective – when an AED stops seizures.

Enzyme-inducing AEDs – drugs that increase the levels of enzymes in the liver.

First line – drugs that are normally used when first starting treatment.

Focal seizures (also known as ‘partial seizures’) – seizures that affect just part of the brain.

Generalised seizures – seizures that affect both sides of the brain at once.

Generic and brand names – the generic name is the drug’s ‘active’ ingredient, and the brand name is given by a manufacturer. For example, Nurofen is a brand name of the generic drug ibuprofen.

Individual therapeutic concentration – the amount of AED that is effective for a person.

Medicines use review – a review by the pharmacist which looks at your medicines.

Monotherapy – when a single drug is taken.

National Institute for Health and Clinical Excellence (NICE) – an independent organisation that gives guidance on promoting health and treating conditions.

Neurologist – a doctor who specialises in conditions that affect the brain.

Optimal therapy – stopping seizures with the smallest dose of AEDs and fewest side effects.

Osteoporosis – where bones become fragile and are more likely to break.

Parallel imports – a drug made outside the UK and imported back into the UK. Some AEDs are only made outside the UK.

Patient information leaflet – the leaflet that comes with the medication that says what the medication is for and how to take it.

Polytherapy – taking more than one drug.

Protocol – a written list of instructions about how to carry out a particular task.

Reference range – the range of drug doses which are thought to be most likely to work.

Second line – drugs that are usually taken alongside first line drugs (not on their own).

Seizure control – when seizures are completely stopped, usually by taking AEDs.

Therapeutic drug concentration monitoring (TDM) – managing epilepsy treatment by measuring the drug levels in the blood.

Tolerance – when a drug becomes less effective the longer you take it.

Withdrawing – slowly coming off medication.

Every effort is made to ensure that all information is correct. Please note that information may change after printing. This information is not a substitute for advice from your own doctors. Epilepsy Society is not responsible for any actions taken as a result of using this information.

www.epilepsysociety.org.uk

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Epilepsy Society is the working name of The National Society for Epilepsy,
registered charity no. 206186