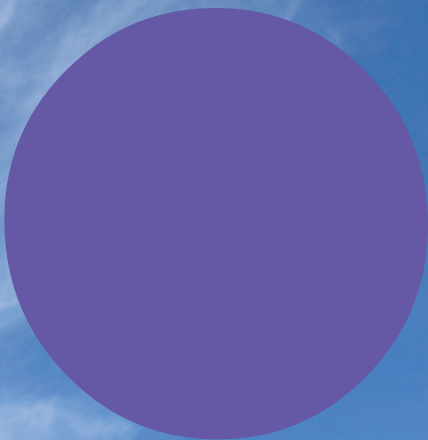


**epilepsy
society**

medication for children

Treatment for children aged 12 and under



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Words set in **black bold** within the text are explained on pages 20–21.



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

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

Call us for a large print version

Epilepsy Society is grateful to Professor Helen Cross of the UCL Institute of Child Health, Great Ormond Street Hospital for Children and the National Centre for Young People with Epilepsy, for her guidance on this leaflet.

helpline

01494 601 400

Monday to Friday 10am to 4pm
(national call rate)

treatment for children aged 12 and under

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 children. 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 child's epilepsy, their **paediatrician** or a pharmacist may be able to help.

what is the aim of anti-epileptic drugs?

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 66% (66 in 100) of children will get **seizure control** (stop having seizures) once the best medication is found for them. 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 least 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 child to another.

Some children 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 the paediatrician finds out as much as possible about your child's epilepsy. This is because the AED that they prescribe depends on the type(s) of seizures your child has. 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 paediatrician will take into account the age and lifestyle of each child when prescribing AEDs.

- How the body **absorbs** and gets rid of medication changes with age. For children under 12, AED doses usually depend on their weight, and so increase as they get older. At about 12 years old, a child will have the same dose as an adult.



See our leaflet *medication for adults*.

- 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**. If the medication needs to be changed, it should be done very gradually. If a child still has seizures after trying two different AEDs, then the paediatrician may review the diagnosis before suggesting other AEDs to try.
- If a single drug does not stop your child's seizures, the paediatrician may add a second drug (so they take two different types of AED each day). This is called **polytherapy**.
- 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 child to another, and is sometimes called their '**individual therapeutic concentration**'. This is done by carefully monitoring the child's seizures and how they feel on the drug.
- Some children will have a **treatment plan**. This records the types, doses and how often AEDs are taken. It may be useful to think about who could be given a copy of this plan (for example, their teachers).

- AEDs come with a **patient information leaflet**. This tells you what the medication is, what it is for, and possible side effects.
- Suddenly stopping AEDs can cause seizures to start again, or happen more often and last longer than before. Also, taking extra AEDs can cause side effects. For these reasons, any changes to AEDs are best done with the paediatrician.

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 can also review medications (called a '**medicines use review**').

If you are not sure if the AEDs you have been given are the same as those your child normally takes, 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 your child 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.

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 children 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 your child has an allergic reaction, contact their 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 your child has side effects that continue it is worth talking to their doctor about them.

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.

What do side effects look like?

Side effects can be difficult to recognise in babies and young children as they can't say how they are feeling. If your child feels unwell but is not able to tell you, you may notice a change in their behaviour.

Some side effects can be particularly important for teenagers, such as weight gain or acne, or those that affect their concentration. Sometimes this means that they don't want to take their medication.

Some side effects are particularly important for girls. Some AEDs can affect a girl's periods, and affect some methods of contraception. Also, some can affect an unborn baby. Even if these issues are not relevant to your daughter *right now*, the paediatrician will usually take this into account if a girl is likely to be on AEDs for some years.

If you are concerned about side effects that your child has, or you think they have, you can talk to their paediatrician. Sometimes AEDs can be swapped or doses altered if side effects are a problem.



See our leaflets *women and pregnancy and parenting* for more information.

What can I do if my child has a side effect that is not listed?

The Yellow Card Scheme is a way of reporting side effects to the Medicines and Healthcare products Regulatory Agency (MHRA), particularly any not listed on the patient information leaflet. The MHRA ensures the safety of medications licensed for use in the UK. You can get a Yellow Card form from your GP, pharmacy, hospital or NHS drop-in centre, by calling 0808 100 3352 or online from yellowcard.mhra.gov.uk

frequently asked questions

Does my child *have* to take AEDs?

Around 66% of children will get seizure control with AEDs. But whether to start taking medication or not is a personal choice, and it can be hard to make this choice for another person. You can discuss the possible risks and benefits of your child taking, or not taking, the medication, with their paediatrician. You can also talk about other treatment options. Whatever decision you make, you can talk through with their paediatrician if you have concerns or questions at any time.

Should AEDs be taken regularly?

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.

The exact timing of doses is not usually crucial but it is recommended that the right dose is taken around the same time or times each day, and that they are evenly spaced out. For example:

- if the AED is taken *twice a day*, take a dose every 10–12 hours; or

- if the AED is taken *three times a day*, work back from the child's bedtime to plan the time to take the doses.

Taking AEDs just before or just after a meal can be a useful routine to remember to take them, and also helps the AED to be absorbed into the body.

For most people, missing one dose on a rare occasion is unlikely to result in a seizure. However, *generally* if a dose is missed and the AED is usually taken:

- *once* a day – give the forgotten dose as soon as you remember it; or
- *twice* a day – give the forgotten dose if you remember within six hours of it being due, otherwise, don't take the forgotten dose and just take the next dose at the due time.



The patient information leaflet should have specific instructions for what to do.

How can I help my child take AEDs?

This depends on your child's age and how involved they can be in their epilepsy management. Young children may need help to remember their medication, and setting a routine may help. Encouraging older children to get involved in managing their medication may help them to feel more in control and involved in their epilepsy management.

Drug wallets can help 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*.

What forms of AED are available?

Some AEDs come in a number of forms:

- tablets that can be swallowed whole;
- tablets that can be chewed or crushed;
- tablets that can be dissolved in water, milk or fruit juice;
- liquids like syrups, which may be flavoured to taste nice, and sugar-free so they are kinder to teeth; and
- sprinkles and granules that can be added to food.

For babies, medication that can be dissolved in water can be given in a feeding bottle or with a special oral syringe. Giving medication this way, rather than mixed in with food, means you can check that they have taken all of it even if they don't eat all of their food.



Some drugs are called **chrono** or **retard** (for example, Epilim chrono or Tegretol retard). 'Chrono' and 'retard' mean slow-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.

You can talk to your child's paediatrician or a pharmacist about what forms particular AEDs are available in.

What should I do if my child is sick?

If your child vomits or has diarrhoea this could affect how well the medication is absorbed.

General guidelines are that if your child is sick:

- *within one hour* of taking the medication – you can give another dose; or
- *more than an hour* after taking the medication – wait for the next dose time.



The patient information leaflet should have specific instructions for what to do.

If you are concerned, or if your child is ill for a long time, it may help to talk to their paediatrician or GP about what to do.

What if my child is on other medication?

Some AEDs affect how other medications work and some other medications can affect how AEDs work. There is usually no interaction (when different drugs affect each other) between AEDs and paracetamol, Calpol,

Duprol and Nurofen. However, it is often a good idea to check with the GP, paediatrician or pharmacist before giving any medications, including those you buy over the counter (not on prescription). This helps to avoid possible interactions.

Will AEDs affect my child's behaviour?

The aim of medication is to stop seizures with minimal side effects or impact on behaviour. However, some children may have side effects, even if only short-term (disappearing after a few weeks). Also, if their seizures are not well controlled, the seizures themselves could affect the child's behaviour. Some changes in behaviour could be due to other things, such as:

- where in the brain the seizures happen and what happens during the seizure;
- how often the seizures happen;
- how the child feels about having epilepsy and how it affects them; or
- how other people react to their epilepsy.

However, some changes in behaviour are a normal part of growing up and may not be related to their epilepsy.

If you are concerned about whether the AEDs are affecting your child, you could discuss this with their paediatrician.

Will AEDs affect my child's learning?

Many children with epilepsy find that their epilepsy and medication does not impact on their learning. However, for other children it might. Problems with learning could be due to the cause of the epilepsy or because they are having seizures. If you are concerned about this you can talk to the paediatrician.



See our leaflet *children* for more information.

Will my child *always* be on AEDs?

Some children's seizures stop happening on their own – called **spontaneous remission**. This can happen with some **childhood epilepsy syndromes**. However, some children need to take AEDs for a long time, sometimes many years.

If a child has not had a seizure for two or more years then you may think about them **withdrawing** (coming off) their AEDs, to see if their seizures have stopped. This depends on the child and the type of epilepsy or syndrome they have. In some syndromes seizures are known to stop around a certain age. With others, the seizures are likely to start again if medication is stopped.

Withdrawing from AEDs is best done with advice from the paediatrician as it needs to be done very slowly, often over several months. The paediatrician can advise what to do if the seizures start again. For most children, if seizures start again, taking the same AED straight away gives the same seizure

control as before. But sometimes the AED may not work as well as it did before.

When thinking about coming off AEDs, it is important to consider the impact on your child's life if their seizures start again.

Some types of epilepsy continue into adulthood. If this is the case, your child will usually start to see a neurologist at around 16–18 years of age. Changing from seeing a paediatrician to a **neurologist** is often called '**transition**', and can be a good time to review their epilepsy and its management.

monitoring AEDs

Monitoring your child's epilepsy involves checking whether their seizures are controlled or how often seizures happen, and if they are having side effects.

Therapeutic drug concentration monitoring (TDM) is one 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.

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.

TDM can be useful in certain situations and with certain AEDs, although it is not used routinely in children. If you have any questions about drug monitoring, you can ask your GP or paediatrician.



See our factsheet *monitoring epilepsy*.

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 during 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 people, missing doses of AEDs can trigger status.

Treatment of status (prolonged seizures)

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 children who go into status, their doctor may prescribe diazepam or midazolam so that a parent or 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 more information about our training services call 01494 601 305 or visit www.epilepsysociety.org.uk



If your child has emergency medication contact us for details of our emergency medication booklets *buccal midazolam* wand *rectal diazepam*.

What happens if AEDs don't work

This booklet only covers treatment of epilepsy with medication. If a child does not respond to AEDs, other treatment options may be available. This includes epilepsy surgery, vagus nerve stimulation (VNS) and the ketogenic diet.



See our factsheets *VNS, Surgery and Ketogenic diet* for more information.



further information

Epilepsy Society information leaflets

Buccal midazolam
Children
Medication for adults
Pregnancy and parenting
Rectal diazepam
Seizures
Women

Epilepsy Society factsheets

Drug wallets and medication aids
Generic and branded anti-epileptic drugs
Ketogenic diet
Monitoring epilepsy
Surgery
VNS



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.

Childhood epilepsy syndromes – epilepsy that has a particular pattern, including the age it starts and the types of seizures.

Chrono and **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.

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 with least side effects.

Paediatrician – a doctor specialising in the medical care of children.

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.

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

Spontaneous remission – when seizures stop or go away on their own.

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

Treatment plan (or ‘drug plan’) – a record of the number and types of AEDs taken, when to take them and what to do if they do not work.

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

Transition – when epilepsy management moves from the paediatrician to a neurologist.

Withdrawing – slowly coming off medication.

notes on using the drug table

The drug table opposite shows AEDs available to treat epilepsy in children.

- The table lists the usual total daily doses of AEDs. The starting doses are in black and the usual total daily doses, that are likely to stop seizures, are in purple.
- Doses are usually listed as 'mg/kg/day'. This means milligrams of AED per kg of the child's weight, given each day.
- The total daily dose is the amount given each day. If the AED is given twice a day, then half the total dose is given each time. If it is taken three times a day, a third is given each time.

Examples

- If the total daily dose of carbamazepine tablets prescribed is '20mg/kg/day' for a 15kg child, this would mean their dose is 300mg (20mg for each kg) per day. As this drug is taken twice a day, 150mg will be taken each time.
- The strength of a liquid AED is given on the bottle. For sodium valproate, this is '200mg per 5ml'. This means that every 5ml of liquid has 200mg of AED. The daily dose is listed as the amount of AED (not the amount of liquid). If the total daily dose is 200mg, then 5ml of liquid should be given. If the daily dose is 300mg, then 7.5ml should be given.

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.

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time to talk. Translation is available.

Epilepsy Society

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