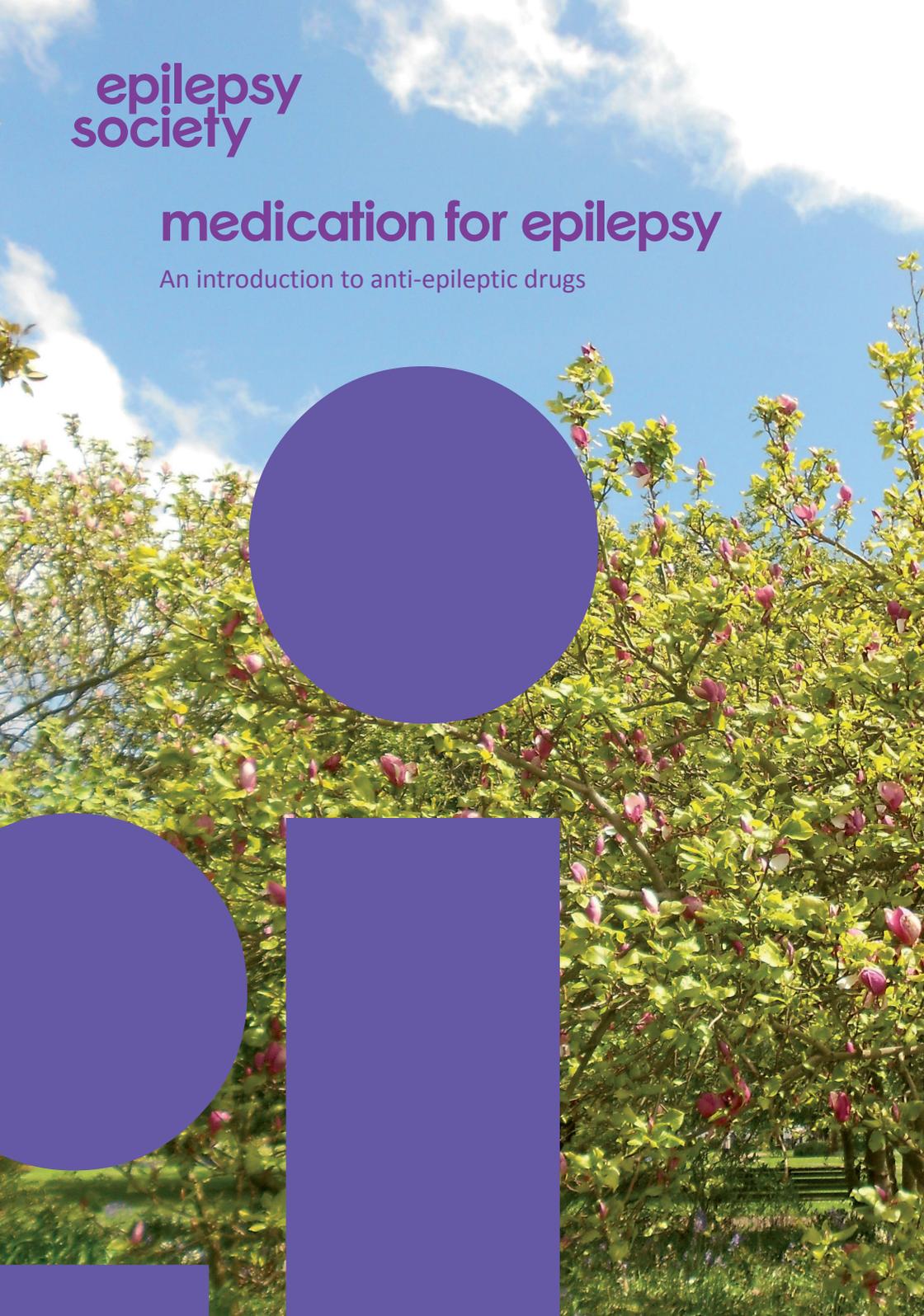


**epilepsy
society**

medication for epilepsy

An introduction to anti-epileptic drugs



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01494 601 400

Monday and Tuesday 9am to 4pm,
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an introduction to anti-epileptic drugs

For most people with epilepsy, the main type of treatment is anti-epileptic drugs (AEDs). Up to 70% (7 in 10) of people could stop having seizures with the right medication.

This booklet has information for both adults and children with epilepsy and answers some questions you might have about anti-epileptic drugs. Where we talk about controlling seizures or 'seizure control' we mean stopping seizures from happening.

about AEDs

What are AEDs and what do they do?

AEDs are a type of medication that aims to stop seizures from happening. They do not stop a seizure once it has started and they cannot cure epilepsy.

Some medications are taken as a 'course of treatment' to cure a condition (for example, taking a course of antibiotics for an infection). AEDs are different: they are a preventative medication taken every day to try and stop seizures from happening. They do this by reducing the excessive electrical activity in the brain that causes seizures. The way they work is not completely understood, and it is likely that different AEDs work in slightly different ways.

What is the aim of treatment with AEDs?

The aim of treatment is 'optimal therapy'. This means taking the fewest types of AED, at the lowest dose in order to get the best seizure control possible with the fewest side effects.

If optimal therapy cannot be found with one particular AED there are usually several others that can be tried alone or in combination.

When is treatment usually started?

Epilepsy is the tendency to have repeated seizures that start in the brain. Treatment is usually only considered after a diagnosis of epilepsy has been made which usually happens after someone has had repeated seizures.

A diagnosis should be made by a specialist, preferably with expertise in epilepsy. This is recommended by NICE (the National Institute for Health and Care Excellence).

In some rare situations treatment might be considered after just a single seizure. This is usually only when a doctor thinks that it is very likely that you will have further seizures. If this is the case they may suggest starting treatment straightaway.

Who will be involved with my epilepsy care?

If you or your child have been diagnosed with epilepsy, it is likely that you will have seen a neurologist, or a paediatrician or paediatric neurologist. You may already have discussed treatment options with them. They will usually prescribe your AEDs and arrange follow-up appointments to see how you are getting on.

Through the rest of this booklet we refer to a 'specialist'. This means a neurologist for adults and a paediatrician for children. Once a child reaches around 16 to 18 years of age they will usually change from seeing a paediatrician to a neurologist. This is called 'transition'.

The day-to-day management of your epilepsy might be under the care of your GP. For example, they might

organise your prescriptions. They should also have a copy of your treatment plan (see page 26) so you can talk to them about how you get on.

You might also see an epilepsy specialist nurse (ESN). ESNs work alongside the specialist and GP to help you manage your epilepsy. Not all hospitals have an ESN but you can ask about this at your local hospital.

In the longer term, if your seizures become controlled, you might only see your GP to review your epilepsy each year.

How are AEDs chosen?

There are over 20 AEDs and each has a particular type or types of seizures that it works for. The choice of AED firstly depends on the type of seizures you have, and which AED works for these seizures. NICE has recommendations about which AEDs should be used for different types of epilepsy and seizures.



See our factsheet *NICE guideline on AEDs.*

When a drug is chosen, your specialist will take into account any other conditions you have or medication you take. As you may be on drugs for a number of years, they will consider not just what is right for you *right now* but also for the future. For example, when a girl is first prescribed AEDs they will think about when she becomes an adult and may want to start a family.

Some AEDs can affect an unborn baby while it is developing and so these drugs are usually avoided for girls and women who may become pregnant (see page 15).

Although AED recommendations are largely the same for men, women and children, there are some reasons why a particular AED might be chosen or avoided for a particular person. This may be due to possible side effects (see page 7). For example, some AEDs can affect concentration more than others so they might be avoided for a student at school or college.



See our leaflets *women and pregnancy and parenting for more about AED choices for women.*

Starting treatment

You are entitled to free prescriptions for your AEDs and any other prescribed medication. To apply for free prescriptions in England you need to fill in a FP92A form (from your GP surgery or pharmacy). In Scotland, Wales and Northern Ireland all prescriptions are free for everyone.

Treatment is usually started with a first line AED. This is an AED that is tried first and taken on its own, sometimes called monotherapy. Once the most appropriate AED for you has been identified and discussed with you, you will usually start on a very low dose. This helps your body get used to the medication, and makes side effects less likely. The dose is then increased slowly over a number of weeks until it stops your seizures. The right dose for you may be different to what is right for someone else. This is sometimes referred to as your 'individual therapeutic concentration'.

How the body absorbs, uses and removes medication changes with age. For children, AED doses are based on their body weight and so the dose increases as they get older (up to around 12 years of age). For adults, doses are not based on body weight.

For most people, once the right AED for them is found, it will stop their seizures. Although for some people it can take time to get this right, the aim is to stop your seizures by just taking one AED. However, if your seizures do not stop when the dose is increased, or you start to have side effects, you may want to talk to your doctor about changing to a different AED. Because different AEDs work in different ways, if one does not control your seizures it doesn't mean that other AEDs won't work. If you change from one AED to another, the second AED is usually added and slowly increased to a dose which is likely to work, and the original drug is slowly reduced.

If your seizures are not controlled with a single AED you may take a combination of AEDs. This is called polytherapy. Some AEDs added to a first line AED are called second line AEDs. This is slightly different for children because AEDs are not split into first and second line for treating children age 12 and under.

Some people continue to have seizures despite taking AEDs. In this case they may continue to take AEDs to reduce their seizures as much as possible and consider trying other types of treatment (see page 28).

side effects and interactions

Side effects are symptoms caused by medical treatment. They are sometimes called 'adverse effects' and are often unwanted or unpleasant. For some people side effects can be positive. For example, side effects that lower your appetite if you are overweight, or that cause sleepiness if you find it hard to sleep.

Do AEDs have side effects?

As with all medications, AEDs can cause side effects and possible side effects vary from one AED to another. Whether you will have side effects or not depends on how you react to the drug (as people can respond differently to the same drug). How important side effects are depends on how important *you feel* they are to you.

Information about side effects is included in the patient information leaflet (PIL) that comes with the packaging for each medication. The list of side effects can be long and off-putting. But listed side effects are only *possible* effects: they do not always happen. They are often listed by how frequently they occur such as 'common' and 'rare'. These terms are the same for all drugs and they show how likely it is that a side effect will happen (how many people will have it). Knowing what these terms mean may help to put side effects into perspective, and help you to make decisions about taking medication or not.

The possible side effects of AEDs may affect the choice of AED. For example, a drug that causes extreme sleepiness might be avoided for a student who needs to be alert in class, or a drug that causes weight gain might be avoided for someone who is overweight. There are also particular issues around AEDs for women and girls who are or may become pregnant (see page 15).

Types of side effects

- Allergic reactions are rare and usually happen very quickly after starting an AED. An itchy skin rash is often the first sign of an allergic reaction. If you have an allergic reaction it is important that you speak to your specialist, a GP, or

pharmacist as soon as possible about what to do. Allergic reactions can be very serious.

- Dose-related side effects happen when the dose of a drug is too high, and usually go away if the dose is reduced. This is why medication is usually started at a low dose and increased slowly.
- ‘Idiosyncratic’ side effects are unique to you (no one else has them).
- Long-term (or ‘chronic’) side effects happen when a drug is taken for a long time, usually many years.

Side effects can be difficult to recognise in babies, children, and people with learning disabilities as they may not be able to say how they are feeling. If your child is taking AEDs and feels unwell you might notice a change in their behaviour.

If you have a side effect which isn’t listed in the PIL, you can report this to the Medicines and Healthcare Products Regulatory Agency (MHRA) – the agency responsible for the safety of medicines in the UK. They run a ‘Yellow Card’ scheme to report side effects which are not listed in the PIL. You can get a Yellow Card by:

- asking your GP, pharmacist, hospital or NHS drop-in centre;
- calling the Yellow Card hotline on 0800 731 6789; or
- visiting yellowcard.mhra.gov.uk

It is important to report side effects to the MHRA so that they are aware of those which need to be added to the medication’s PIL.

Although many people are able to take AEDs without problems, for some, taking AEDs can be about balancing the seizure control the drug gives with any side effects it causes. Some people may 'put up with' side effects if the medication controls their seizures, but if the medication doesn't control their seizures well, they may feel it is not worth putting up with the side effects. If you are having side effects that are causing you concern you can talk to your specialist, ESN or GP.



Visit [medicines.org.uk/emc/browse-medicines](https://www.medicines.org.uk/emc/browse-medicines) for more about side effects.

What are drug interactions?

Some drugs can affect and be affected by other drugs. This is called a 'drug interaction'. When two drugs interact, how one or both drugs work will be affected. Interactions can result in one or both drugs:

- working better (being more effective); or
- working less well, for example, if one prevents the other from working or speeds up how quickly it is eliminated (got rid of) from the body, so it has less time to work.

Drug interactions can happen between different AEDs, and between AEDs and other types of drugs including non-prescription (or 'over the counter') medications including complementary therapies and herbal remedies. For this reason, it is helpful to say if you are taking other drugs before starting AEDs, or that you are taking AEDs before starting any other drugs. Usually, there is no interaction between AEDs and frequently used pain relief medications such as those containing paracetamol or ibuprofen.

AEDs and alcohol

Alcohol can affect how well AEDs work and can also trigger (bring on) seizures for some people (particularly during a hangover). This depends on the AED, how much the person drinks and how they react to alcohol. Drinking alcohol when taking AEDs is a personal choice and the PIL or your specialist will be able to tell you more about drinking alcohol with that medication.

When should I take my AEDs?

AEDs work best when they are taken regularly and at about the same time every day. For most AEDs it does not matter when in the day you take them – morning or evening – only that you try to stick to the same time every day. If you take them more than once a day it is useful to try to take them evenly spaced out (for example, at 8am and 8pm).

It is important to take AEDs regularly because this helps to keep the levels in your body ‘topped up’, to stop seizures from happening.



See our factsheet *monitoring epilepsy*.

If you are unsure about when to take your AEDs you could talk to your specialist or pharmacist. The aim of taking AEDs is to make your treatment as simple and convenient as possible so that it fits into your daily routine.

How long will I have to take AEDs for?

How long you need to take AEDs depends on your epilepsy, your seizures and how you respond to the AEDs. Most people will take AEDs for at least several years and sometimes for life.

- For some people, seizures stop or go away on their own (called spontaneous remission). In this case, they might come off their medication with help from their neurologist.
- Some children have an epilepsy syndrome where their seizures stop at a particular age and so they may be able to stop taking their AEDs at that point.
- If someone's epilepsy does not respond to AEDs, they might try other types of treatment as well as their AEDs (see page 28).
- People who continue to have a tendency to have seizures may always take AEDs. If they stop taking the AEDs the seizures will come back.

Are all AEDs the same?

Most AEDs have two names: a generic name (for example carbamazepine) and a brand or trade name given by the manufacturer (for example Tegretol). The generic name refers to the active ingredient in the drug (which works to control or treat the condition it is taken for).

Some AEDs have more than one generic form, each of which has the same active ingredient, and each can be given its own name. For some AEDs different forms may use different ingredients, such as binding or colouring agents, which can affect how they are absorbed and used in the body. Swapping between different forms of AED could

affect seizure control or cause side effects. For this reason it is often recommended that, once you have found a form of AED to control your seizures, you take the same form of this AED all the time (with every prescription) whether it is generic or branded. This is called 'consistency of supply'.

If a prescription only has the generic name of the drug, a pharmacist can give any form of that drug with that generic name. However, if the prescription has the brand name of the drug the pharmacist must give that brand of AED.

It might be a good idea to keep a note of the generic and brand name (if it has one) for any medication that you take. This might make it easier to recognise if you have been given a different form of medication. It is often a good idea to check what you have been given *before* you leave the pharmacy so that, if you have any questions about what you have been given, you can talk to the pharmacist. If you have been given a different form, the pharmacist might be able to change this for you.

Our app allows you to take pictures of your medication so that you can show the pharmacist what you normally take.



Visit epilepsysociety.org.uk/app and our factsheet *generic and branded AEDs*.

Some drugs are made abroad and brought into the UK. Other drugs are made in the UK, exported and brought back to the UK. These are called 'parallel imports'. They are sometimes labelled in a different language or have different packaging from usual. If you are concerned about your medication, you can ask your doctor to write 'no parallel imports' on your prescription.

Although pharmacists don't have to follow this, many will try to ensure that you are happy with your medication.

It may be helpful to get your prescriptions from the same pharmacy each time as most pharmacists keep patient medication records and can help you with questions about prescriptions.

My child has epilepsy: will AEDs affect their behaviour or learning?

The aim of medication is to stop seizures without side effects or impact on behaviour. However, some children may have side effects although these may go away after a few weeks. 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, what happens during the seizure, and how often they happen;
- how the child feels about their 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 AEDs are affecting your child, you could discuss this with their paediatrician.

Many children with epilepsy find that their epilepsy and medication does not impact on their learning. However, for other children it might, for example, due to seizures disrupting their lessons or medication affecting their concentration. Problems with learning could also be due to the cause of

the epilepsy or because they are having seizures. If you are concerned about this you can talk to their paediatrician.

 [See our leaflet *children*.](#)

Are there any special issues for girls and women with epilepsy?

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

Some girls and women have catamenial epilepsy – where their seizures happen at a particular time during their menstrual cycle. They may be prescribed an extra AED, alongside their regular AEDs, to take when seizures are likely to happen.

 [See our leaflet *women*.](#)

AEDs and birth defects

Taking AEDs while pregnant may affect a 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.

Research has shown that sodium valproate (including Epilim, Episenta, Epival and Convulex) has greater risks in pregnancy than other AEDs. Therefore it should not be prescribed to girls and women who are pregnant, or who may become pregnant in the future, unless other AEDs are not effective or cause unbearable side effects.

The MHRA has issued guidance and information on the risks of taking sodium valproate during pregnancy.

 [Visit **gov.uk/guidance/valproate-use-by-women-and-girls#toolkit**](https://www.gov.uk/guidance/valproate-use-by-women-and-girls#toolkit)

If you are thinking of starting a family, it is essential that you talk to your neurologist about planning your epilepsy treatment for pregnancy and when your baby arrives. You may have questions about the type of medication you take, the dose, how being pregnant could affect your seizures, and how seizures could affect your unborn baby.

 [See our leaflet *pregnancy and parenting*.](#)

new to epilepsy treatment

Should I start treatment?

Your specialist may recommend that you start treatment but the choice is ultimately yours and will depend on your situation. To help you make a decision the following things may be useful.

- Understanding your condition and how it affects you.
- Understanding what treatment is being suggested and why.
- Understanding how this treatment might affect your life as well as your epilepsy.
- Having enough information to decide what you want to do and being able to discuss this with your specialist.
- Having an agreed treatment plan, and being able to follow it.



To help you decide about taking medication, for you or your child, it can be important to be aware of, and think through, the benefits and risks of taking, or not taking, AEDs. This may depend on how your seizures affect you and how often they happen.

The benefits of taking AEDs	The benefits of not taking AEDs
Reducing or stopping your seizures so that they won't interfere with your day-to-day life	No need to remember to take AEDs
Reducing the chance of accidents and injury caused by seizures	No side effects from AEDs
Reducing your worry that you will have a seizure	
The risks of taking AEDs	The risks of not taking AEDs
Having possible side effects	Continuing to have seizures
Needing to remember to take medication regularly	Accidents and injury from having seizures
	The worry about having seizures

If you need more information to help you to make a decision you can talk to your specialist, ESN or GP. Having the right information and support can help you to make fully-informed and meaningful decisions about managing your condition. Whatever decision you make you can talk this through with your, or your child's, specialist if you have any questions or concerns.

You can also talk it through with our epilepsy helpline.

 **See back cover for contact details.**

If it is your child who has epilepsy you might like to involve them in making decisions about taking medication.

This may depend on their age but encouraging older children to get involved in managing their medication might help them to feel more in control of their condition.

How serious can the risks be?

For most people with epilepsy, seizures last for a short time and stop on their own (without needing medical treatment). Although there is a risk of accident and injury, seizures themselves do not usually cause any lasting harm. However, for some people their seizures can cause serious harm.

Status epilepticus

Status epilepticus (or 'status') is where seizures continue without stopping, or a series of seizures happen without the person recovering in between. This can happen with any seizure type. When status happens in a tonic clonic seizure this is life-threatening and needs urgent treatment with medication. When someone has a prolonged seizure **(lasting more than five minutes)** there is a risk of status happening and the person needs to be given emergency medication to stop the seizure.

The two emergency medications used to prevent status in the community (not in hospital) are midazolam and diazepam. Buccal midazolam is given into the buccal cavity (the side of the mouth between the cheek and the gum). Rectal diazepam is given rectally (into the bottom). Both these drugs are sedatives, which have a calming effect on the brain and can stop a seizure. Although it is rare, these emergency drugs can cause breathing difficulties so the person must be closely watched until they have fully recovered.

For people who are at risk of prolonged seizures, their doctor may prescribe midazolam or diazepam so that a carer can give it to them. Specialist training is needed to give emergency medication. It is important that everyone who is prescribed emergency medication has a current written plan (or protocol) for being given it.

Status can affect the person's oxygen levels and blood pressure, their heart and lungs. This can cause permanent brain damage and can be fatal. For this reason it is important to seek medical help if a seizure is prolonged or repeated.

 **Epilepsy Society can provide emergency medication training. Call us on 01494 601 438 or visit our website epilepsysociety.org.uk/training-courses-epilepsy**

 **See our leaflet *first aid*.**

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 cause status.

SUDEP

On rare occasions people die suddenly for no clear reason. When this happens to someone with epilepsy it may be called sudden unexpected death in epilepsy (or 'SUDEP'). SUDEP is when a person with epilepsy dies and no other cause of death can be found. SUDEP usually happens when the person is asleep and so it is hard to know why it has happened but it is thought to be related to having a seizure and the person stops breathing or their heart stops.

The number of people who die from SUDEP is around 500 – 600 per year in the UK.

There are over half a million people with epilepsy in the UK so the numbers are relatively low. But these figures do not show the risk of SUDEP for an individual because an individual's level of risk will depend on how their epilepsy affects them.

As SUDEP is thought to be related to having seizures, a key way to reduce the risk is to try to get the best seizure control possible. This is usually through taking AEDs.

Although they are rare, status and SUDEP can be very worrying to think about. But, by being aware of these risks and whether they apply to you, you can make an informed decision about managing your epilepsy. You can talk to your specialist about this or you might like to call our confidential helpline (see back page).



See our leaflet *risk*.

if you are taking medication

For anti-epileptic medication to work at its best it needs to be taken regularly at around the same time or times each day.

What is medication adherence and what does it mean for me?

Medication adherence describes how well someone takes their medication compared to the treatment plan they have agreed with their doctors. If you have concerns about taking your medication you can discuss these with your specialist, ESN or GP, or ask them for more information.

Strategies and tools to help

If you have difficulties with taking your medication, the following strategies and tools might be helpful.

It is not uncommon for people to forget to take medication or accidentally miss a dose. This might be forgetting altogether or forgetting at a particular time of day.

Some people with epilepsy have memory problems related to their epilepsy which can make remembering to take medication difficult. Some may also take too much medication if they forget that they have already taken a dose.

For most people, missing one dose on a rare occasion is unlikely to cause a seizure. If you miss a dose, or take too much medication, the patient information leaflet may tell you what to do.

In general, if a dose is missed and the AED is usually taken:

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

It is important that if you miss a dose you do not take twice as much at the next dose time. Taking a larger dose than normal could cause side effects.

If you find that you regularly forget your medication there are several things that might help. These things may also help to ensure you don't take too much medication.

Pill boxes: pill boxes or drug wallets usually have seven containers to keep medication in (one for each day of the week). Some are divided into morning, afternoon and evening sections.

Most medication can be stored in these. However, some, including dispersible tablets (which dissolve in water), react to the air and should not be stored in pill boxes.

Pill boxes allow you to see the medication you need to take and will show if you have forgotten to take it. Some come with in-built alarms.

Some pharmacists are able to make up blister packs (plastic strips where you 'pop' the pill through foil on the back of the strip) where they put together your medication for each day, rather like a pill box. Not all pharmacists offer this service.

Reminders: It might help to set an alarm or reminder for taking your medication. Our app has a function to help you set up reminders for taking your medication, or you could use the alarm on your mobile phone, watch or clock.

 [See epilepsysociety.org.uk/app](https://www.epilepsysociety.org.uk/app)

Routines: having a routine for taking your medication, and linking this to something that you do every day, might help. For example, taking it in the morning and evening when you have a meal.

'If – then' plans: this involves creating a plan to do something and using an action to 'implement' it (to do it). This relies on your intention to do something (take your medication). To create an 'if – then' plan, decide on what you want to do and link this to something meaningful that will remind you to do it.

So, rather than thinking ‘I will remember to take my medication’, you set up a plan that **if** (something happens) **then** you will do something. For example, the plan might be: ‘if it is 7.30am and I have just brushed my teeth then I will take my medication.’

To use this technique try the following.

- Decide on an activity for you to link taking your medication to. It needs to be something you do every day as part of a routine. If you take medication more than once a day you could have a different plan for each time in the day you take it.
- Write down your plan in the form of ‘if this happens then I will take my medication’.
- Say your ‘if – then’ plan out loud and keep repeating it until you can say it without reading it. This will help you to store this information in your memory.

The theory behind this technique is that you make one positive decision to do something (I will take my medication) and link this to an action. Repeatedly saying your plan out loud helps you to store the information in your memory and means that you don’t have to make a decision to take your medication every day.

What can help me get tablets out of the packets?

Medication comes in packaging such as bottles, sachets and blister packs. ‘Pill poppers’ are plastic tools that help you to pop pills out of blister packs. The pills often collect in the handle of the popper so that you don’t lose them.

I find it difficult to take my AEDs – are alternative forms available?

Your specialist or pharmacist can tell you whether there are alternative forms for your AED. Some AEDs come as tablets, and capsules, liquids and syrups, sprinkles and granules (which can be added to food), and suppositories. Some AEDs are available as ‘slow release’ forms which release their active ingredient more slowly in your body than non-slow release forms. Some tablets can be crushed into a powder to be sprinkled onto food or in a drink, and it may be worth asking your pharmacist if this is possible with your medication.

For babies, medication that can be dissolved in water can be given in a feeding bottle or with a special oral syringe. Giving it 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. You can ask your pharmacist about how medication can be taken.

It is difficult to get to the pharmacy to collect my medication, or to my GP for a repeat prescription – what might help me?

Some surgeries and pharmacies offer services that might help.

- Repeat prescriptions – where you can re-order your medication from the GP and collect it from your GP’s surgery or the pharmacist.
- Repeat dispensing – a pharmacist gets a six month prescription for medication from the GP and they dispense it to you each month.
- Some pharmacies offer home deliveries for medication.
- You can talk to your pharmacist about what to do if you forget to order your prescription and you need an urgent supply.

My prescription looks different – what should I do?

If your medication looks different – either the packaging or the medication itself – you may have been given a different version. This sometimes happens if your prescription only has the generic name of the drug (see page 12). If this happens you can ask your pharmacist whether they are able to replace it with your usual version.

For this reason it is a good idea to check your medication before leaving the pharmacy. A pharmacist may not be able to change your medication if you have left the pharmacy and then try and return it.

You can download a letter to give to your GP or specialist about the importance of being prescribed the same version of your medication (unless a change is advised for medical reasons).



Visit [epilepsysociety.org.uk/antiepileptic-drugs](https://www.epilepsysociety.org.uk/antiepileptic-drugs)

Should I take another dose if I'm sick?

If you have been sick or have diarrhoea this can affect how well your medication will work. Whether you should take the dose of medication again may depend on how soon after taking your medication you were sick. In general:

- if you are sick within one hour of taking medication take another dose; or
- if you are sick more than one hour after taking medication, wait until your next dose is due before taking it.

The PIL for your medication may have more information or you could talk to your pharmacist about what to do.

managing your treatment

Care and treatment plans

A care plan is an overview of your epilepsy and its treatment and management. It includes information about your epilepsy and seizures, and covers other issues that may be important to you such as education, work, driving, leisure activities and starting a family. You should be offered a care plan, particularly if your epilepsy is recently diagnosed. This might be part of the letter that your specialist will write following an appointment. If you are not offered a care plan you can ask for one.

Part of a care plan includes a treatment (or medication) plan. This sets out how your epilepsy will be treated and usually includes how to start and increase your medication and what to do if it does not work or you have side effects.

Your care plan is made by you and your specialist together, and you might want to involve your family, carers or anyone else important to you who helps you to make decisions about your epilepsy. Developing a plan together means that you can make informed choices about your epilepsy and know what to do if things change. You should be given a copy of the plan which is usually also given to your GP so that they know how to manage your prescriptions. It should be reviewed and updated when needed.

How do I know if treatment is working?

Often the best way to measure how well treatment is working is to look at whether your seizures have stopped or you are having fewer seizures. If you have very frequent seizures, it might be easy to see if your seizures have reduced

or if they have stopped. But if your seizures were infrequent, it can take longer to see whether the treatment is working.

Keeping a seizure diary can help to record how many seizures you are having, when they happen, if anything triggers them and if your medication is reducing or stopping them.



Contact us for a free *seizure diary*.

monitoring epilepsy

Epilepsy reviews

You should be offered regular reviews of your epilepsy. If you are still having seizures a review should be at least every six months with your specialist but, if your seizures become well controlled, you might have annual reviews with your GP.

Reviews are an opportunity to look at how well any treatment is working, and whether you are having any side effects. They should also look at your lifestyle. This could be anything from how well you are sleeping to how you feel about going out, from leisure activities to employment. Your review is your chance to ask any questions, or talk about anything that is concerning you. You might like to make a note of any questions you want to ask during your next review.



See our factsheet *epilepsy review checklist*.

AEDs and osteoporosis

Some AEDs affect bone density in some people. If you have osteoporosis or a family history of osteoporosis you may be offered a bone density test, and to have your calcium and vitamin D levels checked.

Therapeutic drug concentration monitoring

Some people have therapeutic drug concentration monitoring (TDM) to help manage their epilepsy. This involves measuring the amount (level) of AED in their blood or saliva. This can help to get the best seizure control, with fewest side effects, for each person. Reference ranges tell doctors the range of doses of an AED that is likely to control seizures. Some people will need doses above or below this range because everyone is different in how they respond to treatment. Although not everyone has TDM as part of their epilepsy management, there are times when it can be really useful.



See our factsheet *monitoring epilepsy*.

if medication doesn't work

Most people's seizures are controlled with medication. That is why medication is usually the type of treatment that is tried first. But if medication doesn't stop all your seizures, or only stops some of them, there are other types of treatment that might be considered. This might be instead of, or alongside, AEDs. Rather than waiting until you have tried lots of different AEDs, your specialist might talk to you about alternatives if two or three AEDs have not worked for you.

- Epilepsy surgery involves removing the part of the brain where the seizures start. Surgery is only possible for people whose epilepsy comes from a distinct part of the brain which can be found and safely removed. For some people surgery can stop their seizures and they may be able to stop taking their AEDs.
- Vagus nerve stimulation (VNS) therapy involves implanting a small device (like a heart pacemaker) into the upper chest and connecting this to the left vagus nerve in the neck.

- The device sends regular electrical stimulation, via the vagus nerve, into the brain. VNS is usually used alongside AEDs.
- The ketogenic diet is a medical treatment that is a high fat, low carbohydrate and controlled protein diet. This is generally only used for children although dietary treatments for adults are available on a limited basis in the UK. It is a medical treatment and needs to be supervised by medical specialists and dietitians. It is usually started alongside AEDs.
- Deep brain stimulation (DBS) therapy involves implanting electrodes into specific areas of the brain which give direct electrical stimulation to the part of the brain where the seizures start. Like VNS therapy, this aims to reduce the number, length or severity of seizures and is usually used alongside AEDs. Currently, there is no NHS funding for DBS therapy in the UK, but specialists can make special arrangements with their Clinical Commissioning Group (CCG) if they want their patient to be offered DBS therapy.
- Some people consider using complementary therapies alongside AEDs. Most complementary therapies are not used to treat epilepsy but some people find them useful to manage stress, or feel more in control of their life.



See our factsheets [epilepsy surgery](#), [VNS therapy](#), [deep brain stimulation therapy](#), [ketogenic diet](#) and [complementary therapies](#).

If your seizures are not controlled with medication, your specialist may want to review your diagnosis to check that it is correct, to confirm the type of epilepsy or seizures you have, and to review the treatment you have had so far. They may refer you to a tertiary service (a specialist hospital or unit that focuses on specific care for different conditions) if they feel that more specialist treatment would be appropriate for you.

coming off treatment

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

If you are thinking of coming off your AEDs this is best done with advice from your specialist. Suddenly stopping treatment can cause seizures to start again or happen more often and last longer than before. With your specialist you can plan how to come off the medication slowly and decide what to do if your seizures start again. If seizures do start again, taking the same AED straightaway usually gives the same seizure control as before. However, sometimes the AED may not work as well as before.

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

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

If you are considering coming off your AEDs, the DVLA (the Driver and Vehicle Licensing Agency) has specific guidelines on this. As there is a risk of seizures happening when coming off medication, your specialist is likely to advise you to stop driving while you are coming off your AEDs and for six months afterwards. If you have a seizure you will have to meet the driving standards for epilepsy before being able to drive again.

This might be an important part of making a decision about whether to come off your medication.

 **See our leaflet *driving and travel*.**

who can I talk to?

You might want to talk to your specialist, ESN or GP, about your epilepsy. You might also want to talk to your pharmacist about your treatment. Your pharmacist may be able to carry out a 'Medicines use review' each year, when you can talk to them about your medication.

Our confidential helpline provides information and emotional support.

 **See back page for contact details.**

Self Management UK runs courses for people with long-term conditions. The courses cover topics such as making the most of your appointments and managing your medication.

 **Visit selfmanagementuk.org**

Every effort is made to ensure that all information is correct at the time of printing. Please note that information is intended for a UK audience. 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.

epilepsysociety.org.uk

A full life for everyone affected by epilepsy.

research

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treatment and care

Individualised medical and care services.

information

Website, leaflets, factsheets, app – call 01494 601 392.

education

Awareness, training for professionals.

connect with us



Volunteer, become a member, fundraise.

helpline 01494 601 400

Monday and Tuesday 9am to 4pm, Wednesday 9am to 7.30pm.

Confidential, national call rate.

Information and emotional support.

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