

## What is epilepsy?



Epilepsy is the tendency to have recurrent seizures that start in the brain. These seizures are caused by abnormal electrical activity in the brain. Epilepsy is usually diagnosed after a person has had two or more unprovoked seizures.

It is also associated with other cognitive problems including memory issues. In the UK, epilepsy affects over 600,000 people.

## Seizure types

### Focal seizures

Around 35% of people with epilepsy experience focal seizures (previously called partial seizures). Focal seizures start in one part of the brain, the 'focus'. Where in the brain the focus is and how far the seizure activity spreads from the focus, determines the nature of the seizures that occur.

During focal seizures, a person may be fully aware and conscious (focal aware seizures) or, if the abnormal activity spreads to both hemispheres of the brain, then consciousness may become impaired (focal impaired awareness seizures). In some cases, the seizure may spread to involve the whole brain and the focal seizure will evolve to a generalised tonic clonic seizure (focal to bilateral tonic clonic seizure).

## Types of generalised seizures

In generalised onset seizures both halves of the brain are affected from the start. The person will not have a warning that a seizure is starting. There are different types of generalised seizure.

### Tonic clonic seizures

- The muscles contract and the body goes stiff, the person may cry out, then lose consciousness and fall to the floor, cyanosed.
- They may bite their tongue, or cheek.
- The clonic phase follows, and muscles alternate between contraction and relaxation, resulting in jerky movements.
- They may be incontinent at this stage.
- After a few minutes they will go limp, then start to come round, often feeling groggy, with aching head and limbs. Some people may then want to sleep.

### Tonic seizures

- There is a prolonged loss of consciousness.
- The person goes stiff and may fall backwards.
- The person may sustain significant injuries due to falling.

### Atonic seizures (drop attacks)

- There is a prolonged loss of consciousness.
- The person goes limp from the start and may flop forward if seated.
- The person may sustain significant injuries as a result of falling.

### Myoclonic jerks

- The loss of consciousness is brief.
- People have sudden short-lasting jerks which can affect some or all of the body.
- Seizures of this type often happen in clusters and are most common in the morning.

### Absence seizures

- These seizures are more common in children than in adults.

This guide has been co-produced by the Epilepsy Society and Medway School of Pharmacy.

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Visit [epilepsysociety.org.uk/helpline](https://epilepsysociety.org.uk/helpline)  
for opening hours.

- The child may appear to be daydreaming, look blank and stare, or their eyelids might flutter.
- The seizures and loss of consciousness are very brief, lasting only a few seconds.
- The child may be having hundreds of absence seizures a day meaning they miss key points in lessons and may find following instructions difficult, creating an impression of bad behaviour.

Visit [epilepsysociety.org.uk/epileptic-seizures](https://www.epilepsysociety.org.uk/epileptic-seizures)

## Treating epilepsy

Complete seizure control is possible for up to 70% of patients with the right anti-seizure medication (ASM). For about 30% of people with epilepsy, ASM does not control seizures satisfactorily. Non pharmacological treatment options may include the following:

- epilepsy surgery (neurosurgery);
- vagus nerve stimulation (VNS) therapy (implantable device); or
- the ketogenic diet – a specialist diet that helps to control seizures.

Visit [epilepsysociety.org.uk/treatment](https://www.epilepsysociety.org.uk/treatment)

## Epilepsy and anti-seizure medication (ASM)

NICE states<sup>1</sup> that the specialist should ‘develop an individualised anti-seizure medication treatment strategy with the person, and their family and carers if appropriate, taking into account: sex, age, seizure type, epilepsy syndrome, whether treatment is needed, risks and benefits of anti-seizure medications, including their importance in reducing the risk of epilepsy-related death, possible interactions with any other medicines taken, any co-morbidities, the preferences of the person, and their family or carers if appropriate’.

Visit [nice.org.uk/guidance/ng217](https://www.nice.org.uk/guidance/ng217)

- There are around 30 ASMs available.
- ASM is not a ‘cure’ for epilepsy as it does not affect the underlying cause.
- ASM is introduced gradually and increased until seizures are controlled or adverse effects are unacceptable.
- Ideally individuals should be treated with a single ASM (monotherapy) wherever possible.

If initial treatment is unsuccessful, monotherapy using another drug may be tried. The changeover period needs to be monitored, so the replacement drug is built up to an adequate or maximum tolerated dose before the first drug is tapered off slowly.

Polytherapy (using two or more ASMs) may be necessary for some individuals.

**For more about indications for use, dosing, and side effects visit the British National Formulary and British National Formulary for Children – [bnf.nice.org.uk](https://www.bnf.nice.org.uk)**

## Factors affecting adherence to ASM

### Memory problems

Because epilepsy is caused by a problem in the brain, other cognitive issues, especially memory problems, commonly occur. The effect of seizures and, in some cases, the effect of ASM, can also interfere with memory. Medication reminders, alarms, or other compliance aids may help some people.

### Consistency of supply

Differences in bioavailability between products can be an issue for some ASM and may result in an adverse drug reaction and/or changes in effectiveness.

The Medicines and Healthcare products Regulatory Agency (MHRA) has issued guidance on when epilepsy medication should be prescribed by brand. Receiving different forms of their usual ASM can confuse some patients or make them feel anxious about taking medication. This may affect seizure control and result in a lack of adherence.

Ideally patients are given exactly the same formulation of ASM with every prescription. Some people also prefer to avoid parallel imports for the same reason.

Visit [epilepsysociety.org.uk/generic-and-branded-ASMs](https://www.epilepsysociety.org.uk/generic-and-branded-ASMs) or [gov.uk/drug-safety-update/antiepileptic-drugs-new-advice-on-switching-between-different-manufacturers-products-for-a-particular-drug](https://www.gov.uk/drug-safety-update/antiepileptic-drugs-new-advice-on-switching-between-different-manufacturers-products-for-a-particular-drug)

## Monitoring ASM

Routine blood monitoring is not usually required if the dose is stable, seizure control is good, and the patient is side effect free. However monitoring is recommended:

- where toxicity is suspected;
- where pharmacokinetic interactions are suspected;
- where other conditions may affect drug levels, e.g. pregnancy or concomitant illness;
- where an adjustment to the dose of phenytoin is required; or
- to confirm potential non-adherence.

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Monitoring can be useful where the dose is stable to establish a benchmark.

[Visit \*\*epilepsysociety.org.uk/monitoring-epilepsy\*\*](https://www.epilepsysociety.org.uk/monitoring-epilepsy)

## Points to cover with patients taking ASM

ASM is taken as an ongoing preventative treatment. It does not 'cure' epilepsy and it is not a 'course of treatment'. ASM aims to stop seizures happening, so it needs to be taken every day, continuously. ASM is usually taken for a few years, and for many people for life. If someone has been seizure free for a few years, they might talk to their specialist about slowly withdrawing their medication.

It is beneficial to take ASM at about the same time each day. This helps to keep the level of drugs in the body constant, and establishes a routine to remember to take them. Stopping or changing ASM can result in seizures happening.

Side effects won't necessarily happen, and don't have to be 'put up with'. However, many patients with epilepsy do live with serious side effects because they have been able to improve seizure control. If someone is having side effects that are intolerable, their prescribing doctor (usually their neurologist) may suggest changing to a different ASM.

This can be a reason why patients are reluctant to mention side effects, for fear of a change to their medication and worsening of seizure control. You can tell them that their specialist may suggest a different ASM which may work just as well and that any change-over will be carefully managed to try to avoid seizure re-emergence.

## Risks in pregnancy

### Sodium Valproate

In January 2024 the MHRA introduced new restrictions on the prescribing of valproate. Valproate is also known as sodium valproate, valproate semisodium, or valproic acid. Brand names include Epilim, Depakote, Convulex, Episenta, Epival, Syonell, Belvo and Dyzantil.

- Men and women under the age of 55 should not be started on valproate without two specialists independently determining the need for valproate is appropriate.
- Women under 55 of child bearing potential already taking valproate will need sign off from two specialists to continue as part of their annual review for a year following the introduction of these changes. After this they will continue to have an annual review from one specialist.

- No-one should stop taking their ASM without consulting their doctor.

The current regulatory measures also mean that no woman or girl of childbearing potential should be prescribed valproate, unless there is no other effective treatment available in which case there should be a pregnancy prevention programme in place.

The MHRA advises that 'If valproate is taken during pregnancy, up to 4 in 10 babies are at risk of developmental disorders, and approximately 1 in 10 are at risk of birth defects.'

[Visit \*\*epilepsysociety.org.uk/about-epilepsy/sodium-valproate\*\*](https://www.epilepsysociety.org.uk/about-epilepsy/sodium-valproate)

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

### Topiramate

New safety measures have also been introduced for the epilepsy medication, topiramate, also known by the brand name Topamax. These measures follow a major safety review triggered by a European study which showed that children born to mothers who take topiramate during pregnancy face a two to three times higher risk of intellectual disabilities, autism spectrum disorders, and attention deficit hyperactivity disorder (ADHD). The MHRA is advising that:

- Topiramate should no longer be prescribed for epilepsy during pregnancy unless there is no suitable alternative treatment.
- Any woman or girl of childbearing potential newly started on topiramate would be required to take a pregnancy test before it is started to rule out pregnancy.
- Those already taking the medication will need to be using highly effective birth control during treatment.
- Healthcare professionals should discuss the risks associated with the medication with patients and ensure that a risk awareness form is signed.

Some contraceptive methods are less effective than others when using topiramate due to its enzyme inducing potential.

A patient's GP or sexual healthcare practitioner will be able to help advise which form of birth control is right for them.

Regular medication reviews, at least once annually, with a specialist are also recommended for patients taking it for epilepsy. New safety and educational materials have been introduced for patients and healthcare professionals to support the implementation of these measures.

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The introduction of the Pregnancy Prevention Programme will further strengthen the safety measures and aim to reduce the number of topiramate-exposed pregnancies.

Pregnant women or those planning to become pregnant, who currently take topiramate for epilepsy, should **not** stop taking the medication but should seek the advice of a specialist. Stopping medication without supervision may cause their seizures to start again, happen more often, or last longer.

Anyone planning to start a family should make an appointment with their GP to discuss treatment options.

A visual warning symbol will be added to the box of all topiramate medicines. This 'no' symbol will show a pregnant woman in a red circle with a line through it. This will be accompanied by warning text about the risks.

New safety and educational materials have been introduced for patients and healthcare professionals to support the implementation of these measures.

Dispensing pharmacists will also provide a patient card for all females prescribed topiramate and provide advice. Topiramate should be dispensed in its original packaging ideally or with a copy of the package leaflet if it is not for any reason.

**[Visit gov.uk/drug-safety-update/topiramate-topamax-introduction-of-new-safety-measures-including-a-pregnancy-prevention-programme](https://www.gov.uk/drug-safety-update/topiramate-topamax-introduction-of-new-safety-measures-including-a-pregnancy-prevention-programme)**

Suspected adverse drug reactions associated with topiramate, should continue to be reported to the Yellow Card scheme.

**[Visit yellowcard.mhra.gov.uk/](https://www.yellowcard.mhra.gov.uk/)**

## Specific issues for girls and women

Hormone changes can affect the management of epilepsy. This includes at puberty, during and after pregnancy, and the menopause. Consideration of the person's epilepsy and their ASM also has to be taken when, for example, women (who are not planning a pregnancy) need to be using a contraceptive, to ensure it does not interact with their ASM.

Enzyme-inducing drugs reduce the effectiveness of the pill. Women taking enzyme-inducing ASM are also advised against using the progestogen implant. In addition, the ASM lamotrigine can be affected by the oestrogen in the combined hormonal contraceptive pill, and other contraceptives containing oestrogen leading to possible lowering of lamotrigine levels and loss of seizure control.

It is also possible that lamotrigine may affect the efficacy of progestogen containing pills.

Contraceptive injections, such as Depo-Provera are recommended for women with epilepsy as they have good efficacy (if replaced regularly) and do not interact with ASM.

Women of child bearing age taking valproate are advised to use a 'highly effective' method of contraception which is defined as a method that is user independent. For this group of patients, Depo-Provera is only considered 'highly effective' if the woman has the injection without fail every 12 weeks.

Intrauterine devices (IUDs) or Intrauterine systems (IUSs) are effective for women taking ASM, including enzyme-inducers, and are considered 'highly effective' for women taking valproate.

Women taking enzyme-inducing ASM need to have higher doses of emergency hormonal contraception. Only levonorgestrel is recommended for this group.

**[Visit epilepsysociety.org.uk/women-and-girls](https://www.epilepsysociety.org.uk/women-and-girls)**

## Planning a pregnancy

For women planning a pregnancy, preconceptual care from a specialist is essential. Most ASM has teratogenic potential, but strengthened guidance has been issued on sodium valproate and, more recently, on Topiramate (see page 3). All health care professionals should ensure that women planning a pregnancy have received preconception counselling.

## Emergency medication

Buccal midazolam can be given in status epilepticus,<sup>1</sup> a medical emergency where a person has prolonged or repeated seizures that last for five minutes or more without a complete recovery of consciousness. In the UK there are two products containing midazolam for buccal use, Buccolam® and Epistatus®. Both have a licence for children from 3 months to the age of 18 years (3 months to 6 months for in hospital use only) and come in pre-filled syringes.

Other unlicensed named 'specials' are available. Pharmacists should note that Buccolam and Epistatus contain different salts of midazolam and that products are available in different strengths.

Buccolam is 10mg/2mL and Epistatus and 'specials' are 10mg/1mL. Pharmacists need to ensure that the appropriate product is given.

The prescription should be written by brand and that brand only given, as the carer will have been trained to administer that particular product. Substitutions should only be made after consultation with the prescriber.

**[Visit epilepsysociety.org.uk/emergency-medication](https://www.epilepsysociety.org.uk/emergency-medication)**

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## Prognosis and complications

People who have uncontrolled seizures have an increased mortality rate. This relates to an increased risk of accidents, and sudden unexpected death in epilepsy (SUDEP). About 1200 people die each year from epilepsy related causes.

People with uncontrolled epilepsy also have an increased risk of mental health problems, in particular depression and anxiety.

Epilepsy is also associated with significant social problems, including unemployment, problems with relationships, memory, stigma, and isolation.

## When to refer a patient with epilepsy

There may be some specific issues that require a patient with epilepsy to be referred to a GP or specialist including:

- if seizures become worse or more frequent, or if a patient is not under current review with a specialist;
- if there are any signs of adverse drug reactions; or
- if a patient is pregnant or planning a pregnancy.

## Pharmacy support for people with epilepsy

Aside from the role outlined in the MHRA valproate guidance for dispensing pharmacists, the community pharmacist can help patients with epilepsy in lots of other ways.

Many pharmacists think that epilepsy is a very specialist area and believe that the patient will be getting all the medical information they need. If these assumptions are made, there is a real risk that people with epilepsy will miss out on services that other patients get.

Don't underestimate the impact you can have by taking time just to talk to these patients. They will benefit from your input in terms of explaining changes to their medicines, putting a calendar together to help them manage their, often complex, up and down titrations which may be happening simultaneously.

Discussing possible side effects and interactions and advising on over-the-counter medications – things pharmacists do every day, will be very welcome.

In addition, the community pharmacist can help with reminders on when to re-order prescriptions and in trying to ensure consistency of supply where possible.

Pharmacists can also provide an emergency supply, if needed, to avoid the patient going without their ASM, which could lead to dangerous seizure break-through. Remember a pharmacist can give an emergency supply under the Medicines Act without the patient having to go through the Pharmacy First service. The New Medicine Service (NMS) now covers patients with epilepsy as an included group.

Patients with epilepsy who have been in hospital may well benefit from referral to their community pharmacist through the Discharge Medication Service. Practice based pharmacists have a role not only in supporting the valproate initiative but also in carrying out Structured Medication Reviews (SMRs) with this patient group.

Sometimes, there may be issues with medication supplies or shortages. Epilepsy Society has up to date information about issues with supply of ASM.

[Visit epilepsysociety.org.uk/news/medication-updates](https://www.epilepsysociety.org.uk/news/medication-updates)

## Getting help

Epilepsy Society provides support for people with epilepsy, their families, friends, and carers, and provides resources for professionals. The confidential epilepsy helpline provides information and support (see first page for details). Epilepsy Society also has information about the care and treatment that individuals with epilepsy can expect, including access to specialist services and appropriate treatment options.

[Visit epilepsysociety.org.uk/care-and-treatment](https://www.epilepsysociety.org.uk/care-and-treatment)

### References

1. NICE. Epilepsies in children, young people and adults (NG217). Published April 2022 [nice.org.uk/guidance/ng217](https://www.nice.org.uk/guidance/ng217)

Epilepsy Society is grateful to Dr Trudy Thomas, PhD, IP, FRPharmS, Epilepsy Specialist Pharmacist, Kent and Reader in Pharmacy Practice, Medway School of Pharmacy. Universities of Greenwich and Kent at Medway, who reviewed this information.

**For a printed copy of this information contact our helpline.**

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