



This guide is for pharmacists working in registered pharmacy premises in the UK and has been co-produced by Epilepsy Society and Medway School of Pharmacy.



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## what is epilepsy?

Epilepsy is the tendency to have recurrent seizures caused by a sudden burst of intense electrical activity in the brain. There are over 40 different types of epilepsy, each having a typical cause and seizure type. Epilepsy is the most common serious neurological condition in the UK, affecting more than 600,000 people.

## seizure types

More people experience focal (previously called partial) seizures than generalised seizures. Focal seizures start in one part of the brain. Where in the brain this happens determines the nature of the seizures that occur. During focal seizures a person may be fully aware (focal aware seizures). Others, whilst not unconscious, are not aware of what is happening (focal impaired awareness seizures). A focal seizure may spread from one side to both sides of the brain (focal to bilateral tonic-clonic seizure).

In generalised onset seizures both halves of the brain are involved from the start. These seizures are not preceded by an aura (focal seizure) so there is no warning that a seizure is starting.

## types of generalised seizures

### 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 want to sleep after a seizure.

### Tonic seizures

- The person goes stiff, if they are standing they often fall, usually backwards, causing possible head injuries.
- Seizures usually last less than 20 seconds.

### Atonic seizures (drop attacks)

- The person goes limp and drops to the ground.
- They usually recover quickly, but head injury is a real possibility because they often fall forwards.

## Myoclonic jerks

- These are similar to the sudden hypnic jerks that happen just as we are falling asleep, (but these jerks are not epileptic).
- Seizures may be brief, but do not affect awareness or consciousness.
- 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.
- The child may appear to be daydreaming, look blank and stare, or their eyelids might flutter.
- Seizures 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://epilepsysociety.org.uk/epileptic-seizures)

## treating epilepsy

Complete seizure control is possible for up to 70% of patients with the right anti-epileptic drugs (AEDs). For about 30% of people with epilepsy AEDs do not control seizures satisfactorily. Non pharmacological treatment options may include the following.

- epilepsy surgery (neurosurgery);
- vagus nerve stimulation (VNS) therapy (implantable device);
- the ketogenic diet – a specialist diet that helps control seizures for some children with epilepsy. Dietary treatments are also being trialled in a few clinics in the UK for adults.

Visit [epilepsysociety.org.uk/treatment-for-more-information](https://epilepsysociety.org.uk/treatment-for-more-information).

## epilepsy and anti-epileptic drugs (AEDs)

NICE states <sup>1</sup> that 'AED treatment strategy should be individualised according to the seizure type, epilepsy syndrome, co-medication and co-morbidity, the individual's lifestyle, and the preferences of the individual and their family and/or carers as appropriate'.

Visit [nice.org.uk/guidance/CG137](https://nice.org.uk/guidance/CG137)

- There are around 25 AEDs available.
- AEDs are not a 'cure' for epilepsy as they do not affect the underlying cause.
- AEDs are introduced gradually and increased until seizures are controlled or adverse effects

are unacceptable.

- Ideally individuals should be treated with a single AED (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 AEDs) may be necessary for some individuals.

**For more about indications for use, dosing and side effects see the [British National Formulary \(BNF\)](#) and [British National Formulary for Children \(BNFC\)](#).**

## Factors affecting adherence to AEDs

### Memory problems

- Epilepsy itself, the effect of seizures, and the effect of AEDs, can all affect memory for some people. Medication reminders, alarms or drug wallets may help in some cases. Switching to a twice-daily, slow-release formulation of an AED may be a possibility for some people.

### Consistency of supply

- Differences in bioavailability between products can be an issue for some AEDs 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 AEDs 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 AED with every prescription.**

Some people also prefer to avoid parallel imports for the same reason.

**[Visit epilepsysociety.org.uk/generic-and-branded-anti-epileptic-drugs](http://epilepsysociety.org.uk/generic-and-branded-anti-epileptic-drugs) or [gov.uk/drug-safety-update/antiepileptic-drugs-updated-advice-on-switching-between-different-manufacturers-products](http://gov.uk/drug-safety-update/antiepileptic-drugs-updated-advice-on-switching-between-different-manufacturers-products)**

## Monitoring AEDs

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.

**See our factsheet [monitoring epilepsy](#) for more information.**

## Points to cover with patients taking AEDs

**AEDs are taken as an ongoing preventative treatment. They do not 'cure' epilepsy and are not a 'course of treatment'.** AEDs aim to stop seizures happening, so they need to be taken every day, continuously. AEDs are 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 doctor about slowly withdrawing their medication.

**It helps to take AEDs at about the same time each day.**

This helps to keep the level of drugs in the body constant, and to set a routine to remember to take them. Stopping or changing AEDs can result in seizures happening.

**Side effects won't necessarily happen, and don't have to be 'put up with'.** Side effects can happen with all types of medicine, including AEDs, but this does not mean that everyone will get them. However, many people assume that they have to put up with side effects.

If someone is having side effects that are intolerable, their prescribing doctor (usually their neurologist) may suggest changing to a different AED.

**For changes to AEDs seek advice from your specialist.**

## Specific issues for girls and women

**In March 2018 MHRA issued strengthened guidance that sodium valproate 'must no longer be used in any woman or girl able to have children unless she has a pregnancy prevention plan in place. This is designed to make sure patients are fully aware of the risk and the need to avoid becoming pregnant.'**

**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/sodium-valproate-guidelines](http://epilepsysociety.org.uk/sodium-valproate-guidelines) or [gov.uk/guidance/valproate-use-by-women-and-girls](http://gov.uk/guidance/valproate-use-by-women-and-girls)**

There are also links between hormones, puberty, contraception, pregnancy and the menopause. For example women (who are not planning a pregnancy) need to be using a contraceptive that does not interact with their AEDs. Enzyme inducing drugs reduce the effectiveness of the pill (in addition the AED lamotrigine can be affected by the pill, leading to possible loss of seizure control). Women taking enzyme-inducing AEDs are also advised against using the progestogen implant. Contraceptive injections, such as Depo-Provera are recommended. Some women with epilepsy have been advised to have the injection repeated every 10 weeks, although this is not recommended by the Faculty of Sexual and Reproductive Health.<sup>2</sup> 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 not user dependent. For this group of patients, even Depo-Provera is considered to be user dependent as it relies on the patient having the injection every twelve weeks and so is not first line.

The IUD or IUS is effective for women taking AEDs, including enzyme inducers and is considered 'highly effective' for women taking valproate. Women taking enzyme inducing AEDs need to have higher doses of emergency hormonal contraception. Only levonorgestrel is recommended for this group.

Visit [epilepsysociety.org.uk/women-and-epilepsy](http://epilepsysociety.org.uk/women-and-epilepsy)

### 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 5 minutes or more without a complete recovery of consciousness. In the UK there are two products containing midazolam for buccal use, Buccolam® and Epistatus®. Buccolam has a licence for children from 3 months to the age of 18 and comes in pre-filled syringes. Epistatus also has a licence for children from age 10 to less than 18 years and is available as a multi-dose bottle and pre-filled single-dose 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.

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

### 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.

### Planning a pregnancy

For women planning a pregnancy, preconceptual care from a specialist is essential. Most AEDs have

teratogenic potential, but strengthened guidance has been issued on sodium valproate. All health care professionals should ensure that women planning a pregnancy have received preconception counselling.

### 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 1000 people die each year from epilepsy related causes. People with uncontrolled epilepsy also have an increased risk of mental health problems, in particular depression. Epilepsy is also associated with significant social problems, including unemployment, problems with relationships, memory, social stigma and isolation.

### getting help

Epilepsy Society provides support for people with epilepsy, their families, friends and carers (and provides resources for professionals). Our confidential epilepsy helpline provides information and support (see below for details).

Epilepsy Society 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/your-rights-and-choices](http://epilepsysociety.org.uk/your-rights-and-choices)

Some areas of the country have GPs with Special Interest (GPwSI) in epilepsy – find out if you have someone in your locality undertaking this role. There may also be a local specialist epilepsy nurse, that you can contact, to get involved and learn more. There is potential in the future for pharmacists to become Pharmacists with Special Interest (PhwSI) in epilepsy too.

### References

1. NICE Guidance CG137. Epilepsies: diagnosis and management. Published January 2012.(Updated April 2018). [nice.org.uk/guidance/cg137](http://nice.org.uk/guidance/cg137)

2. Faculty of Sexual and Reproductive Healthcare. Progestogen only injectable contraception. December 2014 (Updated March 2015)

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[epilepsysociety.org.uk](http://epilepsysociety.org.uk)



helpline

01494 601 400

Monday and Tuesday 9am to 4pm

Wednesday 9am to 7.30pm

Confidential (national call rate)