

9 Frequently Asked Questions on Antiepileptic Drugs

1. What are antiepileptic drugs?

Antiepileptic drugs (AEDs) are prescribed to control seizures. They do not cure epilepsy and need to be taken regularly exactly as prescribed. It is important not to miss doses of your medication as this can make seizures more likely.

2. When should treatment for seizures be started?

AEDs should not be prescribed until the diagnosis of epilepsy has been confirmed by an epilepsy specialist. Epilepsy can be difficult to diagnose after only one or two seizures particularly if there is no eye-witness account. The epilepsy specialist may advise against starting AED treatment and opt instead to monitor the situation.

3. Will AEDs control my seizures?

Although it can sometimes take a while to find the most appropriate drug and dosage for each individual the majority of people who take AEDs will have their seizures completely controlled. However, sometimes other factors, e.g. illness, hormonal changes, may cause a breakthrough seizure and your medication may then need to be adjusted.

4. What dosage will I be on?

It is likely that you will start on a low dose which, if it does not control your seizures, may then be increased gradually to achieve seizure control with minimum side effects.

All AEDs have their own dose range and these vary greatly. The amount of one drug may sound much higher than another drug but have a similar effect. This is a bit like comparing a measure of whisky with a half pint of beer; the quantities are different but both have the same amount of alcohol.

5. How soon after taking my first dose of medication will it be effective?

It may take some time before AEDs start to take effect as they work by maintaining a steady level of the drug in the bloodstream. Just as missing a dose may not instantly upset the balance, there will also not be an instant response when starting AED treatment.

6. Can you take more than one type of AED at the same time?

The aim of the treatment is to control seizures completely with the lowest possible dose of a single drug. If this is not successful, your doctor may prescribe a combination of AEDs that acts on the brain in different ways to control seizures. Some people may require a combination of up to four AEDs to control seizures.

7. Why do some patients have their blood tested at clinic appointments and others don't?

Blood level testing is not carried out routinely but may be useful in some circumstances and with certain drugs, e.g. to help the doctor adjust dosages and timing of phenytoin, carbamazepine and phenobarbitone, to monitor drug levels in pregnant women, to measure toxic effects and to ensure that the treatment plan is being followed.

8. What about the side effects of AEDs?

Most people will not have any side effects. Tiredness and sleepiness are quite common when starting treatment but often get better after a week or two. Some AEDs can cause weight gain or loss in some people. Some older AEDs, e.g. phenobarbitone, sodium valproate (Epilim), carbamazepine (Tegretol), phenytoin (Epanutin) and primidone (Mysoline) are associated with osteoporosis (bone thinning) and osteomalacia (softening of the bones). To promote bone health, eat a diet high in calcium and Vitamin D, limit alcohol intake, avoid smoking and take regular weight-bearing exercise. Some side effects are potentially serious so if you develop a rash or bruising, particularly in the first weeks of treatment, seek urgent medical attention. It's useful to record any side effects you experience and inform your doctor.

If you think you have experienced negative side-effects from taking AEDs you can report this to the Medicines and Healthcare Products Regulatory Agency (MHRA) using the Yellow Card Scheme. You can report suspected side-effects on www.mhra.gov.uk or by phoning the Yellow Card Hotline on 0808 100 3352. Yellow Cards are also available in GP surgeries and community pharmacies. Your doctor or community pharmacist can advise you how to complete the form. MHRA is a government agency which monitors the use of medicines in the UK.

9. Can AEDs cause loss of libido/impotence?

AEDs (e.g. carbamazepine) can contribute to sexual difficulties but factors such as other medical conditions as well as stress, anxiety and depression can also contribute. Seek advice from your epilepsy specialist, GP or Well Woman/Well Man Clinic or, if you live in the Greater Glasgow and Clyde area, the Sexual Health Clinic, Sandyford Initiative, Tel 0141 211 8601.

10. Is it safe to take AEDs during pregnancy? Will AEDs harm my unborn child?

The majority of pregnant women who are on AEDs have healthy babies. However, there is some increased risk and women who are planning pregnancy are advised to seek medical advice at least 3 months before becoming pregnant. It is usual for women on AEDs to start taking a higher amount of folic acid supplement than is normally prescribed 3 months prior to conception in order to minimise risk of damage to the unborn child. It may also be that other changes to their treatment plan are advised for the duration of the pregnancy.

10. Is it safe to take AEDs during pregnancy? Will AEDs harm my unborn child? (cont)

Seizures pose risks to women and their unborn children so following the recommended treatment plan is very important.

Women who are already pregnant should seek advice from an epilepsy specialist as a matter of urgency. For further information and details of support groups contact Epilepsy Connections.

11. Can AEDs affect memory and concentration?

Some AEDs such as phenobarbitone, primidone (Mysoline), phenytoin (Epanutin) and topiramate (Topamax) may affect alertness, concentration and cognition (thinking processes) which in turn can affect memory. Sometimes these problems can be resolved by adjusting the dosage or changing from one AED to another, which should only be done on your doctor's advice. Newer AEDs are less likely to cause problems as a direct side effect but high doses or combinations of several AEDs (polypharmacy) can affect alertness and concentration. Other factors that can affect memory are frequent seizures, anxiety, depression and sleep disturbance. Tell your doctor if you are concerned about your memory. (See Leaflet 14 'Epilepsy and Memory').

12. What should I do if I miss a dose of my medication?

Take the missed dose as soon as you remember. Don't take a double dose unless your doctor has advised you to do so. If unsure, check with your epilepsy specialist or community pharmacist.

13. What if I vomit after taking my AEDs?

Unless vomiting occurs within a few minutes or if you can see your tablet(s) in the vomit, you should not take another dose. Continue with your next dose at the usual time. However, guidance about what to do if you vomit may vary depending on the dosage you are prescribed. Ask your specialist or community pharmacist for advice.

14. What if I have diarrhoea?

Diarrhoea may reduce the amount of your tablets in your system. If you are worried about this, contact your GP. Continue with your normal medication and drink plenty of fluid to counteract dehydration. If you buy an over-the-counter remedy for diarrhoea ask your community pharmacist if it's safe to take with your AEDs.

15. Can being constipated affect my seizures?

Some AEDs can cause constipation. Constipation can lead to a build-up of toxins in the system and may lead to an increase in seizures. Eat a healthy diet high in fruit, vegetables and fibre and low in fat and salt. Drink a reasonable amount of water and take gentle exercise such as walking. If you want to buy an over-the-counter remedy for constipation ask your community pharmacist if it's safe to take it with your AEDs.

16. My child was first prescribed medication in a syrup form but this has been changed to a tablet. Will this have a lessened effect?

The dose will have been adjusted to match your child's weight and age and will have the same effect.

17. For how long will I need to take AEDs?

If you have been seizure free for a minimum of 2 years you may wish to ask your epilepsy specialist about coming off AEDs. Factors to be discussed include the risks of further seizures occurring if treatment is stopped (some types of seizures are more likely to recur than others), the implications for you if seizures recur (driving, employment) and the long-term effects of taking AEDs. If you and your doctor agree to try stopping AEDs, withdrawal should be carried out gradually and under medical supervision. You should not stop taking your AEDs without medical advice. For many people it may be necessary to accept taking AEDs for life.

18. Can a person become addicted to antiepileptic drugs?

This is not a feature of most AEDs however dependency can occur with benzodiazepines and phenobarbitone. Speak to your GP/epilepsy specialist if you are concerned.

19. What would happen if I decided to stop taking my AEDs?

Stopping AEDs can have serious consequences and may lead to status epilepticus. Withdrawal should be carried out under medical supervision.

20. What is emergency medication and when is it used?

Some people with a history of **prolonged seizures, serial seizures or status epilepticus** may be prescribed emergency medication to carry with them.

Diazepam administered rectally is a rapid and effective way to stop such seizures. Midazolam administered nasally or buccally (between the gum and the cheek) is also rapid, effective, easier to give and causes less embarrassment.

Non-medical personnel with appropriate training can administer these drugs as a first aid measure by following written guidelines agreed by the person with epilepsy, their doctor and family/carers.

In the case of tonic clonic seizures, the following situations require medical attention.

Status epilepticus is a medical emergency requiring urgent treatment.

Prolonged seizures: seizures lasting over 5 minutes or 2 minutes longer than usual.

Serial seizures: seizures occurring one after another without full recovery in between.

Status epilepticus: seizure activity persisting for 30 minutes or more without return to normal breathing or full consciousness.

Prolonged seizures, serial seizures and status epilepticus can occur with **all** types of seizure and require medical attention.

21. Can other medication interact with AEDs and affect my seizures?

- Some AEDs interact with the **contraceptive pill** and make it less effective. You will need to take a higher dose contraceptive pill if you are taking carbamazepine, phenytoin, phenobarbitone, primidone, high-dose topiramate or oxycarbazepine.
- **Hormone replacement therapy** can sometimes affect seizures.
- Commonly used **anti-depressants and anti-psychotic drugs** may cause an increase in seizures.
- Some **anti-malarial drugs** are not suitable for people with a history of epilepsy.
- Some **non-steroidal anti-inflammatory drugs** may interact with phenytoin.
- Some **asthma medications** and some **antibiotics** may interact with some older AEDs.

Contact your community pharmacist or Epilepsy Connections for more information.

22. Is it safe to take over-the-counter medicines?

Some over-the-counter remedies may affect AEDs, e.g. antihistamines, antacids. Always ask your doctor or community pharmacist for advice.

23. Is it safe to try complementary therapies when taking AEDs?

- Discuss with your GP if you want to try a complementary therapy and go to a qualified therapist who knows about epilepsy.
- Some **aromatherapy oils** may not be suitable, e.g. rosemary, hyssop, fennel, sage and wormwood.
- **St John's Wort** may interact with AEDs and is not recommended for people with epilepsy.
- **Evening primrose** and **starflower oils** may not be suitable.

24. Is it safe for me to drink alcohol when taking AEDs?

The effect of alcohol on the brain and possible interactions with AEDs can make seizures more likely. Some people find that even moderate use of alcohol can make their seizures worse. Excess alcohol and binge drinking can cause seizures and are associated with common seizure triggers such as late nights, disturbed sleep, missed meals and missed doses of AEDs. However, many people taking AEDs enjoy alcohol in moderation, i.e. up to 1-2 units per day without any problems.

For more information see Leaflet 7e 'Epilepsy: Leisure and Pleasure—Safety Issues'.

25. Would recreational drugs interfere with AEDs?

Recreational drugs can cause seizures. Mixing recreational drugs with AEDs is potentially dangerous.

See Leaflet 7e for more information.

26. What about travelling?

- It's important to take your AEDs at the prescribed intervals. Plan ahead and ask advice from your doctor or community pharmacist to help you adjust to time zone changes.
- Keep medication in its original container or packaging in your hand luggage along with a letter from your GP confirming your prescription.
- Your AEDs may be available abroad depending on your destination, however it's advisable to carry more medication than you expect to need. Some AEDs have different names abroad.

Epilepsy Connections can give you information about the above, and about local epilepsy support organisations in countries to which you are travelling.

27. What if AEDS don't work for me?

There may be other options such as surgery and vagus nerve stimulation implants. These options are not suitable for everyone but are worth investigating. Stress management, relaxation techniques and counselling may help.

28. What if I'm not happy with my treatment?

If you are dissatisfied with your treatment you may wish to ask your GP to refer you to an epilepsy specialist for a re-assessment of your diagnosis and medication. Keep a careful record of your seizures and any side effects you are experiencing, and write down the reasons for your dissatisfaction with your treatment to show the epilepsy specialist.

Ask a relative or friend to attend your appointment with you. They can help by describing what happens during a seizure.

29. Is it true that I can get my AEDs free of charge?

Yes, and not only your AEDs but ALL prescription medication. Ask your doctor for a copy of form EC92A to apply for your exemption certificate.

Leaflets produced by Epilepsy Connections

1. What is Epilepsy? An Introduction
2. Diagnosing Epilepsy
3. Recording Seizures
4. What to do when someone has a seizure
5. Treatment for Epilepsy
6. Antiepileptic Drugs
7. Epilepsy: Balancing Risk and Safety
- 7a. Epilepsy: Safety in the Home
- 7b. Epilepsy: Safety in School, College and University
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10. Epilepsy Checklist
11. Epilepsy and Driving
12. Non-Epileptic Attack Disorder (NEAD)
13. Epilepsy and Dental Health Care for Children and Adults
14. Epilepsy and Memory

Leaflets 1 and 4 are also available in Urdu, Punjabi and Chinese.



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Supporting people with epilepsy

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