

Frequently Asked Questions on Antiepileptic Drugs (AEDs)

28. 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.

29. 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 detailed record of the seizures and side effects you are experiencing to show your doctor.

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

Yes, and not only your AEDs but ALL prescription medication. Get a copy of the Department of Health leaflet P11 "NHS Prescriptions—How to Get Them Free" from your pharmacist.

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1. **What are antiepileptic drugs?** Antiepileptic drugs (AEDs) are prescribed to control seizures. They do not cure epilepsy.
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 in its early stages, particularly if there is no eye-witness account of seizures, so the epilepsy specialist may advise against starting AED treatment after a single seizure 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.
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.

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

AEDs 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 AED 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 act 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?**

Side effects such as sedation and dizziness are common particularly at the start of treatment and may disappear over time. Some AEDs can cause weight gain or loss. Some side effects are potentially serious so if you develop a rash, bruising or feel sleepy and nauseated 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.

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

Women who are planning to become pregnant or who are already pregnant should seek advice urgently from their doctor. It may be that changes will be made to their treatment plan for the duration of the pregnancy. Seizures pose risks to women and their unborn children and it's advisable for women to follow their treatment plan during pregnancy.

Women who are planning to become pregnant or who are pregnant are advised to take a 5mg supplement of folic acid which may minimise the risk of damage to the unborn baby.

The majority of pregnant women with epilepsy and on AEDs have healthy babies but sometimes there are problems for a few children. For more information about these problems and details of support groups for affected families contact Epilepsy Connections.

26. **For how long will I need to take AEDs?**

If you have been seizure free for 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. For many people it may be necessary to accept taking AEDs for life.

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

It's up to the individual to decide if s/he wants to stop taking medication but this can have serious consequences and may lead to status epilepticus+. Withdrawal should be carried out under medical supervision.

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

Some over-the-counter remedies may interact with AEDs, e.g. antihistamines and some decongestants. Ask your doctor or community pharmacist for advice.

20. **Can vitamin and mineral supplements prevent seizures?**

Some AEDs can lead to vitamin and mineral loss and supplements may be prescribed. Seek your doctor's advice.

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

- Discuss with your GP.
- 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. If you want to try a complementary therapy go to a qualified therapist who knows about epilepsy.

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

Alcohol can cause the liver to break down AEDs more quickly than usual and this could lead to an increase in seizures. For more information about epilepsy and alcohol, see Leaflet 7e 'Epilepsy: Leisure and Pleasure—Safety Issues'.

23. **Would recreational drugs interfere with AEDs?**

Mixing recreational drugs with AEDs is potentially dangerous. See Leaflet 7e for more information.

24. **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 Glasgow, the Sexual Health Clinic, Sandyford Initiative, Tel 0141 211 8601.

9. **Can AEDs affect memory and concentration?**

Some AEDs can cause problems but often these can be resolved by adjusting the dosage of medication or changing the drug for another. Other factors that can affect memory are anxiety and depression, sleep disturbance and frequent seizures.

10. **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. If unsure, check with your specialist or community pharmacist.

11. **What if I vomit after taking my AEDs?**

If vomiting occurs within 1 or 2 hours of taking the medication, then repeat the dose. If vomiting occurs 3 or more hours after taking the medication it will have been absorbed. Continue with your next dose at the usual time. Ask your specialist or community pharmacist for advice.

12. **What if I have diarrhoea?**

Diarrhoea can cause dehydration which can lead to seizures. 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.

13. **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.

14. **What about travelling? How should I take AEDs when I cross time zones? How should I carry my medication when I travel? Can I get AEDs abroad?**

- 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.

15. **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.

16. **What is emergency medication and when is it used?**

Some people with a history of severe, prolonged seizures (i.e. lasting longer than 5 minutes) or serial seizures (i.e. seizures recur without full recovery in between) may be prescribed emergency medication to carry with them.

Diazepam administered rectally is a rapid and effective way to stop prolonged or serial seizures. Midazolam administered nasally or buccally (between the gum and the cheek) is also rapid and effective and is a more socially acceptable alternative. With appropriate training, families and carers can

16. (cont) administer these drugs as a first aid measure by following written guidelines agreed by the person with epilepsy and their doctor.

Status epilepticus is a condition in which seizures persist for 30 minutes or more. It can occur with all types of seizure but with tonic clonic seizures it is a medical emergency requiring immediate medical treatment.

17. **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.

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

- Some AEDs interact with the *contraceptive pill* and make it less effective. To maximise protection, a higher dose contraceptive pill is usually required if taking carbamazepine, phenytoin, phenobarbitone, primidone, high-dose topiramate or oxycarbazepine.
- Some women find that *hormone replacement therapy* helps improve seizure control, but others find their seizures become more frequent after starting HRT. Women on AEDs are at increased risk of osteoporosis and may benefit from taking HRT.
- 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.

Contact your community pharmacist or Epilepsy Connections for more information.