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Treating epilepsy with anti-epileptic drugs

The most common way to treat epilepsy is with anti-epileptic drugs (AEDs). Drugs can control seizures but do not cure epilepsy.

How do AEDs work?

Drugs are absorbed into the body and carried in the blood to the brain where they work to stop the spread of unexpected or extra bursts of electrical activity. It is this excessive burst of electrical activities that cause seizures.

AEDs work best if you take them exactly as prescribed. Taking them around the same time each day will ensure that enough of the drug stays in the bloodstream to control seizures. If you miss a dose or take your medication too late, this can lower the drug level in the blood and can lead to seizures. If you take too much of your medication or take it too closely together, you may experience more side effects, such as drowsiness.

AEDs are not addictive.

Different forms of AEDs

AEDs usually come in tablet form. Some AEDs are also available in other forms such as syrups, liquids, sprinkle capsules or soluble tablets which can be helpful for anyone who may have difficulty swallowing.

Some drugs are available as a slow release version. These are absorbed more slowly into the bloodstream which gives your body a more even level of the drug throughout the day.

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Finding the right AED

AEDs have been prescribed for many years. The newer AEDs tend to have fewer side effects than some of the drugs that have been around for 20 or 30 years. These older drugs are, however, still successfully used today. A specialist will choose the right kind of drug for you based on many factors including the type of seizures or epilepsy you have. They will also take into account your medical history, your gender, age, any other prescribed drugs, or your lifestyle to find the drug that works best for you.

Taking just one drug (this is referred to as monotherapy) may be enough to control your seizures. If your seizures are not well controlled your doctor may give you more than one drug (polytherapy).

Many people will respond well to AEDs and will see their seizures completely controlled or at least reduced. For others, it may take some time to find the right drug or combination of drugs to control or reduce their seizures. Generally, between 50 and 60% of people taking AEDs can achieve complete seizure control.

Getting the dosage right

To allow your body to get used to the AED and reduce the likelihood of side effects, your doctor will start you off on a low dosage. This will be increased gradually over a period of time until you reach a dosage which controls your seizures.

With children, doses are usually based on body weight and may need to be increased the older the child gets. Dosages for adults may also need to be adjusted if there is a significant weight increase or decrease.

Sometimes seizures can return after a seizure free period. If this happens, do not automatically increase the dosage you are currently on. Seek medical advice from your GP, neurologist or epilepsy specialist nurse, who may review your medication, may change the dosage, add another drug or switch you to a new drug.

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Generic and branded versions of AEDs

AEDs, like all medications, have two names: a generic name, which is the chemical name (ie levetiracetam), and a brand name, which is the name given to the drug by the manufacturer (ie Keppra). Drugs are often available both as a generic version and a branded version.

The active ingredients (ie the chemicals that control your seizures) in both versions are usually the same but there could be differences, for example, in the binding or coating material used. This can have an impact on how the drug is absorbed by the body and may make a difference to seizure control.

Epilepsy Scotland recommends that the same brand or the same generic version made by a certain manufacturer should be prescribed. This will reduce the risk of possible seizures following a switch between a branded and a generic version, or a switch between two different generic versions. There is more information on this in our factsheet 'Same drug, different names?'.

Side effects

AEDs, like most drugs, prescribed or over-the-counter, can give you side effects. Common side effects of AEDs are tiredness, drowsiness, lack of concentration or weight gain. Most of these side effects are mild and will wear off once the body gets used to the drug. If you notice a skin rash or bruising in unusual places, contact your doctor immediately as this could be a sign that you are allergic to the drug.

If, after an initial period of time, the more severe side effects do not reduce and you find these not acceptable to you, talk to your doctor or epilepsy specialist nurse. They may be able to reduce the dosage or try you on a different drug. There is more about side effects in our separate factsheet 'Side effects of anti-epileptic drugs'.

Women's issues

Women taking oral contraception and AEDs need to get further advice from their doctor or epilepsy specialist nurse. Some AEDs can interact with the pill and increase the likelihood of becoming pregnant.

If you are planning a family, you should seek further advice from a specialist to make sure the AEDs you are taking are safe for the baby. There are some drugs which need to be avoided (such as Epilim/sodium valproate) as these can cause birth defects including developmental problems. Your specialist will work with you towards maximum seizure control as uncontrolled and frequent seizures during pregnancy can be dangerous to both yourself and the baby.

Pregnant women on AEDs should take a higher dosage (5mg) of folic acid during the first three months of pregnancy. This needs to be prescribed by a doctor.

If you have an unplanned pregnancy, do not stop taking your medication without medical advice, as this could trigger a sudden seizure which could be dangerous to your unborn baby.

You can also contact the UK Epilepsy and Pregnancy Register on 0800 389 1248 to find out more information on the safety of the AED you are taking during pregnancy.

Missed dose or overdose

If you have missed a dose, do not automatically take a double dose the next time. Speak to your doctor or epilepsy specialist nurse and find out what you should do as this may differ from drug to drug. You may need to restrict some 'riskier' activities, such as driving, until you are back to your normal routine in case you have a seizure.

As a general rule, if you only take one tablet a day, take the dose as soon as you remember it. If you take tablets twice a day, take the missed dose if you remember

within six hours of when you should have taken the drug. If it is more than six hours late, your doctor may advise you to wait until the next dose is due.

If you have accidentally taken a small overdose, ie taken your medication twice in a short space of time, contact your doctor or NHS 24 on 111 for further advice. A major deliberate overdose of AEDs is always a medical emergency and requires an ambulance.

To help you remember to take your AED on time, try linking taking your drugs to a regular activity. You can also set your mobile phone alarm or use electronic pill boxes to remind you to take your drugs. Your pharmacist can often advise on what is available.

Vomiting or diarrhoea

If you have been sick within an hour of taking the drug, this could affect as to how much of it has been absorbed and may affect seizure control. This may vary if you take a slow release version of an AED. If you have not discussed this with your doctor or epilepsy specialist nurse, phone them for advice or contact NHS 24.

Generally, if you have been sick within an hour of taking the drug, take another dose. However, if it is more than one hour, wait for the next scheduled dose. You must check this out with your doctor though to make sure you do not accidentally overdose.

If you suffer from diarrhoea, seek medical advice. Common side effects from prolonged diarrhoea such as dehydration or raised temperature can sometimes trigger a seizure.

Changing anti-epileptic drugs

If your seizures are not controlled by your current drug, your specialist may advise you to switch to a different drug. There may be other reasons why a switch is

advised such as interaction with other prescribed drugs. Any switch has to be done slowly and under strict medical supervision. This usually means adding in the second drug and slowly increasing the dosage to a level where it controls seizures, before reducing the first drug. This hopefully reduces the risk of seizures during the switch.

If you drive, you may be advised by your doctor to stop driving during a medication switch until your doctor considers you safe to drive again. This is because there can be a small risk of breakthrough seizures. If you do have a seizure, you will need to stop driving for at least six months and will have to notify the DVLA.

Coming off AEDs

Many people may have to take AEDs for a long period or even throughout their lives. Others may only need to take them for a limited time. This depends on a number of factors such as the type or the cause of the epilepsy and seizures.

If you have been seizure free for two to three years you can talk to your doctor about the possibility of coming off AEDs. There is always a risk that your seizures will return when you come off the drugs. Seek specialist advice first and consider all the consequences of having a breakthrough seizure before you take this important step. For example, you would lose your driving licence for a minimum of six months, which may impact on your work, family or social life.

Should you go ahead, coming off your drugs needs to be done slowly and under strict medical supervision. Our factsheet ‘AEDs – are they for life?’ gives you more information on all the factors to take into account before making this important decision.