

(8) Parents: Anti-epileptic drugs (AEDs)

Epilepsy is most commonly and successfully treated with anti-epileptic drugs. The drugs work by preventing seizures from happening. They do not cure epilepsy. A majority of children can have their seizures controlled by medication.

Different anti-epileptic drugs treat different types of seizures, and your child's specialist will suggest the most effective drug treatment depending on your child's seizure types. If the first drug is not effective or causes side effects, other drugs can be tried. Sometimes children need a combination of drugs. If the first couple of drugs do not control the seizures, the chance of other drugs working becomes much smaller.

The aim of anti-epileptic drugs is to control seizures with the smallest dose possible and to cause as few side effects as possible. If the child's seizures remain controlled, there is usually no need to increase the dose as they grow / get older.

The difference between 'generic' and 'brand' versions of AEDs

Some drugs are available under its usual branded name and under a different, ie generic name. A 'generic' name refers to the chemical name, eg sodium valproate. The 'brand' name is the name given to the drug by the manufacturer, eg Epilim. The active ingredients are the same in both, but there may be small differences, for example, in the coating or binding material used. In some cases, this may make a difference as to how the drug is being absorbed and can lead to a break-through seizure.

There is some disagreement between specialists on this issue with many believing that a switch between a generic and branded drug will not affect seizure control. We at Epilepsy Scotland advocate for staying on the same brand or generic version made by a specific manufacturer where possible to minimise the risk of a breakthrough seizure occurring.

The Medicines and Healthcare products Regulatory Agency (MHRA) has issued further guidelines dividing anti-epileptic drugs into three categories, ie those that should never be substituted, those that can be usually substituted based on clinical judgement, and those that can be substituted.

Different forms of AEDs

Anti-epileptic drugs come in many forms such as tablets, dispersible tablets, slow release pills, liquid, capsules, sprinkle capsules and tiny granules. The doctor or specialist nurse should discuss which preparation is best for your child. If your child is reluctant to take their medication, seek advice from your epilepsy specialist nurse.

Making the most of AEDs

Anti-epileptic drugs should be taken at around the same time each day. Drugs are broken down by the body just like food, so it is important to keep topping it up to maintain enough of the drug(s) in the system to control seizures. If there is too much time between doses the level of drugs in the blood may fall below what is necessary to control seizures. Not taking the drugs regularly is one of the most common reasons why seizures are not well controlled.

What to do if you forget to give a tablet

Do not automatically give your child a double dose next time. Do not stop giving the drug or alter the dosage in any way unless advised to do so by a medical professional.

As a general rule, if your child only takes one tablet a day, give the dose as soon as you remember it. If your child takes tablets twice a day, it is usual to only give the missed dose if you remember within six hours of when your child should have taken the drug. If this is longer, then you may be advised by your child's doctor to wait until the next dose is due. Find out from your child's doctor or specialist nurse in advance, because this could be different for different types of drugs.

To get into a routine of taking drugs roughly the same time every day, try linking it to a regular activity such as mealtimes or brushing teeth, or use a mobile phone alarm as a prompt.

Your local chemist may be able to source pillboxes with a reminder alarm for you. You can also order different pill boxes and a wide selection of helpful gadgets online.

What to do if you have given more than the usual dose

If you have accidentally given your child more than the prescribed dose, phone your child's doctor or NHS 24 on 111. The most likely effect of this overdose will be that your child may be drowsy.

What to do if your child has been sick

If your child has been sick within an hour of taking the drug, this could affect how much of it has been absorbed and may affect seizure control. If this has not been discussed, phone your child's doctor or NHS 24 for advice.

As a general rule, if your child has been sick within an hour of taking the drug, give another dose. However, if it is more than one hour, wait for the next scheduled dose.

Side effects of anti-epileptic drugs

Anti-epileptic drugs are generally tolerated well but some children do experience side effects, especially at the beginning of treatment when the drug is slowly being introduced. Serious side effects are, however, rare. Common side effects include feeling sick, sleepiness, dizziness, headaches and weight gain.

Any drug can have side effects, even an over-the-counter drug such as paracetamol. Each anti-epileptic drug comes with a patient information leaflet, which will have a list of possible side effects. This can be alarming to read, but it is important that you are

familiar with possible side effects. If you are concerned about the way your child is reacting to a drug, please contact the doctor, epilepsy nurse or NHS 24.

It can be sometimes difficult to know if a child experiences side effects particularly if they are very young, have a learning disability or cannot tell you.

A change in a child's behaviour can often be the first sign of a side effect. Other signs are more obvious, such as a skin rash. If you spot a skin rash, phone your doctor immediately. Also keep an eye on sudden bruises in areas where you would not normally expect them.

Monitoring drugs and side effects

When a new drug is introduced, it is helpful for both you and your child's doctor to monitor your child for side effects and seizures. A seizure diary can be useful to record any changes noticed in a child. We have our own seizure diaries for parents to complete, which we can send out on request. Contact our helpline and request your free copy.

There are also online resources and apps that allow you to record seizures in a diary.

A blood test may occasionally need to be done to check the level of drug or monitor liver function. This is usually the case for only a couple of the older anti-epileptic drugs. There may, however, be other reasons why a doctor occasionally wants to do a blood test, and this will be explained to you when this is necessary.

Yellow card reporting scheme

Anyone can report an unusual suspected side effect by using the yellow card reporting scheme. You can also ask your doctor or epilepsy nurse whether a side effect should be reported. They can do this on your behalf. For more information, go to <http://yellowcard.mhra.gov.uk/> or phone the Yellow Card hotline on 0808 100 3352.

Online searches

Never solely rely on what you read online, information is often presented in a biased way which is not helpful and can make anyone anxious. It does not always help to compare experiences with other parents as every child is unique and reacts to medication in a different way.

If you have any concerns about your child's medication or want to find out more, speak to your child's specialist, epilepsy specialist nurse, GP, or your pharmacist.

Interaction with other drugs

If your child already takes prescribed medication for another medical condition, or takes any over-the-counter medication including vitamins, supplements, or herbal remedies, the doctor will carefully check that the anti-epileptic drug(s) will not interfere with this and vice versa.

Cannabis based drugs

As of 1 November 2018, cannabis-based medications can now be legally prescribed by the NHS. This includes medications containing only CBD (cannabidiol) or both CBD and the psychoactive component THC (tetrahydrocannabinol). Clinical guidelines, however, currently only recommend cannabis-based medicines which have undergone strict clinical trials.

There is one licensed drug called Epidyolex, which is based on CBD (cannabidiol) oil only. Epidyolex is recommended to be used for children affected by two severe epilepsy childhood syndromes, ie Dravet syndrome and Lennox Gastaut syndrome. For more information and latest update on cannabis-based medications, please see our separate factsheet 'Cannabis and epilepsy'.

Emergency medication

Most seizures last only a few minutes and stop on their own. A small proportion of children, however, have seizures which last longer and may require emergency medication to stop them.

If a child has prolonged seizures, ie seizures which last two minutes longer than normal or five minutes in total, the doctor or epilepsy nurse may consider prescribing emergency medication. This can also be prescribed if a child has many seizures a day, particularly if a child goes from one seizure to another without full recovery in between.

If your child has been prescribed emergency medication, your child's doctor or epilepsy specialist nurse will show you how to administer this, and under what circumstances to call an ambulance. Having access to emergency medication yourself can be reassuring, particularly if you live in a remote or rural area, as it reduces your reliance on an ambulance every time your child has a seizure.

Unlike anti-epileptic drugs which prevent seizures from happening, emergency medication stops a prolonged seizure. This is usually **midazolam**, which is dripped into the side of the cheek or the nose. Occasionally, **diazepam** is used and given rectally (into the anus) using a specially prepared tube. A small number of children use **paraldehyde** rectally if midazolam or rectal diazepam does not work for them.

If other adults regularly look after your child, such as nursery assistants, teachers, or babysitters, they also need to know how to administer emergency medication and under what circumstances to call an ambulance. You will need to give them written consent and arrange for them to get training from an epilepsy specialist nurse.

If emergency medication is prescribed, your child's epilepsy specialist nurse or doctor will draw up a care plan. This has a clear protocol (written instructions) of what to do and when. The plan spells out the exact circumstances when you need to give emergency medication. It also tells you how much should be given initially, if

and after how long a second dose can be given, and the maximum amount over a 24 hour period. The care plan will also include information about how to correctly store the medication.

Are anti-epileptic drugs forever?

If your child's seizures are controlled for around two years, you can discuss with your child's doctor or epilepsy nurse whether to reduce or stop the medication to see if your child has outgrown their seizures. A decision is based on the type of epilepsy, the risk of seizures returning, how your child and you feel about this risk, and the best time to do this.

If your child is a teenager and is looking forward to driving, the possibility of stopping treatment should be discussed well before they can apply for a provisional driving licence. The best time is when they are aged 14-15. This will give everyone enough time to try and reduce or come off the medication safely. Your child's doctor or specialist nurse will be able to guide you through the considerations you and your child need to make.