(7) 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. Up to 70% of children can have their seizures controlled by medication, which leaves around 30% of children who will continue to have seizures.

As a parent or guardian, you have a right to decide whether to agree to drug treatment for your child or not. To help you make an informed decision in the best interest of your child, you need to weigh up possible side effects of the drugs against risks of seizures and possible injury. If your child is old enough, their views should also be taken into account.

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 get bigger/older.

The difference between ‘generic’ and ‘brand’ versions of AEDs

Some drugs are available under its usual branded name as well as under one, or a number of different generic names. 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 to how the drug is being absorbed and can lead to a break-through seizure.
To minimise the risk of such a break-through seizure, the same brand or the same generic version should be prescribed every time. 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.

**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 a sufficient level of drugs 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 the 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 set 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 find different pill boxes and a wide selection of gadgets and suppliers on the internet, such as TabTime [www.tabtime.com](http://www.tabtime.com).

**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 (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**

Most children tolerate anti-epileptic drugs well but some children do experience side effects. However, serious side effects are rare. Generally, any side effects tend to be experienced at the beginning of treatment when the drug is slowly being introduced.

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. Read this carefully but do not be alarmed, as your child is not likely to have all
of these side effects, if any. If you are concerned about the way your child is reacting to a drug, please contact the doctor, epilepsy nurse or NHS 24.

Common side effects include feeling sick, sleepiness, dizziness, headaches and weight gain. It can be sometimes difficult to know if a child experiences side effects particularly if they are very young, have a learning disability or a communication problem and cannot tell you.

A change in a child’s behaviour can often be the first sign something may be wrong. Others 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 or bruising in unexpected areas, ie other than arms and legs.

**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. Just contact our helpline and request your free copy.

Young Epilepsy [www.youngepilepsy.org.uk](http://www.youngepilepsy.org.uk), 01342 831342, have two seizure diaries suitable for younger children and teenagers. This can be a good way of encouraging a child to start taking responsibility by keeping a diary themselves.

An online alternative to a paper diary is Seizure Tracker [www.seizuretracker.com](http://www.seizuretracker.com). Setting up an account is free and you can use this to record your child’s seizures, drug(s) and appointment schedules. You can also turn this data into simple graphs which helps to show how effective the drug is. It is also a good way to get an older child to take more interest in managing their seizures.

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 particular side effect should be reported. They will usually do this on your behalf. For more information, go to [http://yellowcard.mhra.gov.uk/](http://yellowcard.mhra.gov.uk/) or phone the Yellow Card hotline on 0808 100 3352.

**Further research**

If you want to find out more on the particular drug your child is taking or on anti-epileptic drugs in general, there is plenty of information on the internet. Your own research can help you understand different treatment options but it should never replace medical specialist advice.

Reputable sites you can trust include:

- Patient UK ([www.patient.co.uk](http://www.patient.co.uk))
- EMC Medicines Guides ([www.medicines.org.uk/Guides](http://www.medicines.org.uk/Guides))
- Medicines for Children ([www.medicinesforchildren.org.uk](http://www.medicinesforchildren.org.uk))
- British National Formulary ([www.bnf.org](http://www.bnf.org))

For a quick overview of current anti-epileptic drugs used for children, download the Epilepsy Society’s factsheet from their website [www.epilepsysociety.org.uk](http://www.epilepsysociety.org.uk) or call their helpline on 01494 601 400 for a copy.

**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.

**Emergency medication**

Most seizures are self-limiting and last only a few minutes. 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, i.e., seizures which last five to ten minutes or longer, 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 any recovery time 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, but it is fairly straightforward. Having access to emergency medication yourself can be reassuring, particularly if you live in a remote or rural area, as it does away with the need to phone 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 refer to correct storage of 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 the seizures. The decision will need to take into account 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.