

## Vigabatrin for preventing seizures

This leaflet is about the use of vigabatrin to treat infantile spasms in young children with West syndrome (or West's syndrome). It is also used to prevent epileptic seizures called focal or partial seizures. (Seizures may also be called convulsions or fits.)



This leaflet is for parents and carers about how to use this medicine in children. Our information sometimes differs from that provided by the manufacturers, because their information is usually aimed at adults. Please read this leaflet carefully. Keep it somewhere safe so that you can read it again.

Do not stop giving vigabatrin suddenly, as your child may have more seizures.

### Name of drug

**Vigabatrin**

**Brand name:** Sabril

### Why is it important for my child to take this medicine?

It is important that your child takes vigabatrin regularly so that they have fewer seizures.

### What is vigabatrin available as?

- **Tablets:** 500 mg
- **Powder:** 500 mg (sachets)

### When should I give vigabatrin?

You will usually start by giving vigabatrin **once a day**, while your child gets used to the medicine. This is usually in the evening.


When your child is used to vigabatrin, you will usually give it twice a day: once in the morning and once in the evening. Ideally, these times are 10–12 hours apart, for example sometime between 7 and 8 am and between 7 and 8 pm.

Give the medicine at about the same time(s) each day so that this becomes part of your child's daily routine, which will help you to remember.

### How much should I give?

Your doctor will work out the amount of vigabatrin (the dose) that is right for *your* child. The dose will be shown on the medicine label.

When you first start giving vigabatrin to your child, you will give them a small amount and then increase the dose bit by bit over a few days or weeks. This helps your child to get used to the medicine. Your doctor will explain what to do.

 **It is important that you follow your doctor's instructions about how much to give.**

### How should I give it?



**Tablets** should be swallowed whole with a glass of water, milk or juice. Your child should not chew the tablets. You can crush the tablet and mix it with a small amount of soft food such as yogurt, honey or jam. Make sure your child swallows it straight away, without chewing.



**Powder:** you can dissolve the powder in water, milk or juice. Your doctor or pharmacist will have told you how much liquid to use, and how much to give your child. Give the right amount of mixture to your child straight away, using a medicine spoon or oral syringe.

You may have been told to dissolve the powder in a small amount of water (5 or 10 mL, which is one or two medicine spoons) to give rectally (into the back passage) using a special syringe. Your doctor or epilepsy nurse will show you how to do this.

### When should the medicine start working?

**West (or West's) syndrome:** Your child should start to have fewer spasms within a few days of taking vigabatrin regularly.

**Focal or partial seizures:** It may be a few weeks before vigabatrin works properly, so your child may still have seizures for a while. This is because the amount of medicine has to be increased slowly. Continue to give the medicine as you have been told to by your doctor.

### What if my child is sick (vomits)?


- If your child is sick less than 30 minutes after having a dose of vigabatrin, give them the same dose again.
- If your child is sick more than 30 minutes after having a dose of vigabatrin, you **do not** need to give them another dose. Wait until the next normal dose.

### What if I forget to give it?

- If you remember up to 4 hours after you should have given a dose, give your child the missed dose. For example, if you usually give a dose at 7 am, you can give the missed dose at any time up to 11 am.
- If you remember after that time, do not give the missed dose. Wait until it is time to give the next normal dose.

 **Never give a double dose of vigabatrin.**

### What if I give too much?

 If you think you may have given your child too much vigabatrin, contact your doctor or local NHS services (details at end of leaflet) or take your child to hospital.

Take the medicine container or packaging with you, even if it is empty. This will be useful to the doctor. Have the packaging with you if you telephone for advice.

### Are there any possible side-effects?

We use medicines to make our children better, but sometimes they cause effects that we don't want (side-effects).

#### Side-effects you must do something about

- Your child may be drowsy (sleepy), lethargic (tired, lacking in energy) or confused. This should improve on its own. If it doesn't, contact your doctor.
- Your child may be irritable, agitated or depressed. If this happens, contact your doctor.
- Some people (mostly adults) find that vigabatrin affects their peripheral vision (they can see less at the edges of their vision). This is more likely to happen after taking vigabatrin for at least six to twelve months. You or your child may not notice this effect. However, it can be a significant problem and does not always get better when the medicine is stopped. If your child is aged 8 years or older, your doctor will arrange for a special eye test

to measure their visual field (the amount they can see) before starting vigabatrin, and then every 6 months while they continue to take it. It is not usually possible to test the visual field accurately in children younger than 8 years of age.

#### Other side effects you need to know about

- Your child may be more hungry than usual (increased appetite). Encourage them to eat fruit and vegetables and low-calorie foods, rather than foods that contain a lot of calories (avoid crisps, cakes, biscuits and sweets), and to have plenty of exercise.
- Your child may have difficulty concentrating, or may find that they can't remember things. This usually gets better.

There may, sometimes, be other side-effects that are not listed above. If you notice anything unusual and are concerned, contact your doctor. You can report any suspected side-effects to a UK safety scheme at <http://www.mhra.gov.uk/yellowcard>.

#### Can other common medicines be given at the same time as vigabatrin?

- You can give your child medicines that contain paracetamol or ibuprofen, unless your doctor has told you not to.
- Check with your doctor or pharmacist **before** giving any other medicines to your child. This includes herbal or complementary medicines.

#### Is there anything else I need to know about vigabatrin?

- If your child is going to have treatment in hospital, it is important to tell the doctor that your child is taking vigabatrin.

#### Epilepsy and pregnancy

- Pregnancy presents a risk to both the mother with epilepsy and her unborn baby. If your daughter has sex, it is essential that she uses adequate contraception to prevent an unplanned pregnancy.
- If your daughter is worried that she may be pregnant, it is important that she sees your family doctor as early as possible. Your daughter should keep taking her medication until she sees her doctor.

#### Vigabatrin and pregnancy

- Doctors don't know yet whether vigabatrin can harm an unborn baby.
- The oral contraceptive pill can be used safely by women or girls who are taking vigabatrin.

#### General advice about medicines for seizures

- ⚠ **Do not** suddenly stop giving any of these medicines to your child, as they may have a seizure. If you are worried, talk to your doctor but carry on giving the medicine to your child as usual.

- ⚠ If your child seems to have more seizures than usual, contact your doctor.

- If your doctor decides to stop a particular medicine, they will discuss this with you. You will usually reduce the dose bit by bit.

- ⚠ **Do not** change the dose of any drug without talking to your doctor first.

- It is best that your child always has the same brand of each medicine, as there may be differences between brands. Keep a record of which medicines your child has. If you have any concerns or questions, speak with your child's doctor or pharmacist.
- Try to give medicines at about the same times every day, to help you remember.
- Only give the medicine(s) to your child. Never give them to anyone else, even if their condition appears to be the same, as it could do harm.

- ⚠ If you think someone else may have taken the medicine by accident, contact your doctor straight away.

- Make sure that you always have enough medicine. Order a new prescription at least 2 weeks before you will run out.
- Make sure that the medicines you have at home have not reached the 'best before' or 'use by' date on the packaging. Give old medicines to your pharmacist to dispose of.

#### Where I should keep this medicine?

- Keep the medicine in a cupboard, away from heat and direct sunlight.
- Make sure that children cannot see or reach the medicine.
- Keep the medicine in the container it came in

#### Who to contact for more information

Your child's hospital doctor, epilepsy nurse or pharmacist will be able to give you more information about vigabatrin and other medicines used to treat epilepsy.

You can also get useful information from:

**England: NHS 111** - Tel 111 - [www.nhs.uk](http://www.nhs.uk)

**Scotland: NHS 24** - Tel 111 - [www.nhs24.scot](http://www.nhs24.scot)

**Wales: NHS Direct** - Tel 111 - [www.111.wales.nhs.uk](http://www.111.wales.nhs.uk)

**Northern Ireland: NI Direct** - [www.nidirect.gov.uk](http://www.nidirect.gov.uk)

**Young Epilepsy Helpline:** 01342 831 342

[www.youngepilepsy.org.uk](http://www.youngepilepsy.org.uk)

**Epilepsy Society Helpline:** 01494 601 400

[www.epilepsysociety.org.uk](http://www.epilepsysociety.org.uk)

**Epilepsy Action Helpline:** 0808 800 5050

[www.epilepsy.org.uk](http://www.epilepsy.org.uk)

[www.medicinesforchildren.org.uk](http://www.medicinesforchildren.org.uk)



Version 2, January 2014. © NPPG, RCPCH and WellChild 2011, all rights reserved. Reviewed by: January 2017.

The primary source for the information in this leaflet is the British National Formulary for Children. For details on any other sources used for this leaflet, please contact us through our website, [www.medicinesforchildren.org.uk](http://www.medicinesforchildren.org.uk)

We take great care to make sure that the information in this leaflet is correct and up-to-date. However, medicines can be used in different ways for different patients. It is important that you ask the advice of your doctor or pharmacist if you are not sure about something. This leaflet is about the use of these medicines in the UK, and may not apply to other countries. The Royal College of Paediatrics and Child Health (RCPCH), the Neonatal and Paediatric Pharmacists Group (NPPG), WellChild and the contributors and editors cannot be held responsible for the accuracy of information, omissions of information, or any actions that may be taken as a consequence of reading this leaflet.