

Stiripentol for preventing seizures

This leaflet is about the use of stiripentol to prevent epileptic 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 stiripentol suddenly, as your child may have more seizures.

Name of drug

Stiripentol

Brand name: Diacomit

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

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

What is stiripentol available as?

- **Capsules:** 250 mg, 500 mg
- **Sachets:** 250 mg or 500 mg per sachet


When should I give stiripentol?

You will usually start by giving stiripentol **twice a day**. Ideally, these times are 10–12 hours apart, for example sometime between 7 and 8 am and between 7 and 8 pm.

How much should I give?

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

When you first start giving stiripentol 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?

You need to give your child something to eat with stiripentol, otherwise it may not work properly.

Do not give your child milk or dairy products (e.g. yogurt, cheese), fizzy drinks, fruit juice or foods/drinks that contain caffeine (cola, tea, coffee, hot chocolate) at the same time as stiripentol.



Capsules should be swallowed whole with a glass of water. Your child should not chew the capsule. You can open the capsule and mix the contents into a teaspoonful of soft food (e.g. honey or jam). Make sure your child swallows it straight away, without chewing.



Granules: dissolve the granules in a small glass of water or mix them with a small amount of soft food (e.g. honey or jam). Make sure your child swallows it all straight away, without chewing.

When should the medicine start working?

It may take a few weeks for stiripentol to work properly, so your child may still have seizures for a while. Continue to give the medicine in the way that 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 stiripentol, give them the same dose again.
- If your child is sick more than 30 minutes after having a dose of stiripentol, you **do not** need to give them another dose. Wait until the next normal dose.

What if I forget ?

If you remember within 4 hours, 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 this time, **do not** give the missed dose. Wait until it is time to give the next normal dose.

What if I give too much?

 If you think you may have given your child too much stiripentol, 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 lose their appetite and lose weight, and they may feel sick (nausea). Your child may feel drowsy (sleepy), or they may become irritable or aggressive and have difficulty sleeping. These effects should get better as your child's body gets used to the medicine. If they don't get better after 2–3 weeks, contact your doctor for advice.

Side effects you need to know about

- Your child may also have problems falling asleep at night. This may or may not get better. If it causes problems, or if your child is losing a lot of sleep, contact your doctor for advice.

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 stiripentol?

- 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 this medicine?

- Stiripentol is used mainly for a particular epilepsy syndrome known as severe myoclonic epilepsy in infancy (also called Dravet's syndrome).
- Your doctor may decrease the dose of other medicines that your child is taking for epilepsy when they start taking stiripentol.




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.

Stiripentol and pregnancy

- Stiripentol may harm an unborn baby.
- The oral contraceptive pill can be used safely by women or girls who are taking stiripentol.

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 or your epilepsy nurse.
 - 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.
- Try to give medicines at about the same times every day, to help you remember.
- Do not give extra doses, as you may do harm.
- Only give the medicine(s) to *your* child. Never give them to anyone else, even if their condition appears to be the same, as this 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 should I keep this medicine?

- Keep the medicine in a cupboard, away from heat and direct sunlight. It does not need to be kept in the fridge.
- 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 stiripentol and other medicines used to treat epilepsy.

You can also get useful information from:

England: NHS 111

Tel 111

www.nhs.uk

Scotland: NHS 24

Tel 111

www.nhs24.scot

Wales: NHS Direct

Tel 111

www.111.wales.nhs.uk

Northern Ireland: NI Direct

www.nidirect.gov.uk

Young Epilepsy

Helpline: 01342 831 342

www.youngpilepsy.org.uk

Epilepsy Society

Helpline: 01494 601 400

www.epilepsysociety.org.uk

Epilepsy Action

Helpline: 0808 800 5050

www.epilepsy.org.uk

www.medicinesforchildren.org.uk



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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

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.