

Rufinamide for preventing seizures

This leaflet is about the use of rufinamide 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 rufinamide suddenly, as your child may have more seizures.

Name of drug

Rufinamide

Brand name: Inovelon

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

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

What is rufinamide available as?

Tablets: 100mg, 200mg, 400 mg Liquid medicine: 200 mg in 5 mL

When should I give rufinamide?

You will usually start by giving rufinamide 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.

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 rufinamide (the dose) that is right for your child. The dose will be shown on the medicine label.

When you first start giving rufinamide 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?

Rufinamide should be taken with some food (such as a biscuit, some fruit or a small meal) so that it works properly.



Tablets: These should be swallowed with a glass of water, juice or milk. You can the crush tablet(s) and mix it with about 2 tablespoons of soft food such as yoghurt, honey or jam. Make sure your child swallows it straight away, without chewing.

You can crush the tablet and dissolve it in water or fruit juice. Your doctor will have told you how much liquid to use, and how much of it to give your child. Give the right amount of mixture to your child straight away, using an oral syringe or medicine spoon.



Liquid medicine: Measure out the right amount using an oral syringe or medicine spoon. You can get these from your pharmacist. Do not use a kitchen teaspoon as it will not give the right amount.

When should the medicine start working?

It may take a few weeks for rufinamide 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 vour doctor.

What if my child is sick (vomits)?

- If your child is sick less than 30 minutes after having a dose of rufinamide, give them the same dose again.
- If your child is sick more than 30 minutes after having a dose of rufinamide, 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 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.



Never give a double dose of rufinamide.

What if I give too much?



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

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

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 that you must do something about



If your child gets a fever (high temperature) in the first 2 or 3 weeks of starting rufinamide, they may be reacting to the medicine. Contact your doctor straight away.

Other side-effects you need to know about

Your child may get headaches, feel generally tired, weary or drowsy (sleepy), dizzy, or they may feel sick (nausea) or be sick (vomit). These effects should get better after 2-3 weeks as your child's body gets used to the medicine. If they don't, contact your doctor for advice but continue to give the medicine as usual.

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://yellowcard.mhra.gov.uk.

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

- 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?

- Your doctor may need to reduce the dose of phenytoin if your child is taking this when they start to take rufinamide.
- Your doctor may need to reduce the dose of rufinamide if your child starts to take sodium valproate.

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 thinks that she may be pregnant, it is important that she sees her doctor as early as possible. Your daughter should keep taking her medication until she sees her doctor.

Rufinamide and pregnancy

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

General advice about medicines for epilepsy

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. 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 not change the dose of any drug without talking to your doctor first.



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. 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 rufinamide 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.youngepilepsy.org.uk

Epilepsy Society

Helpline: 01494 601 400 www.epilepsysociety.org.uk

Epilepsy Action

Helpline: 0808 800 5050 www.epilepsy.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