

Ciclosporin for nephrotic syndrome

This leaflet is about the use of ciclosporin for nephrotic syndrome in children.



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.

Name of drug


Ciclosporin

Brand names: Capimune, Deximune, Neoral

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

Your doctor may recommend this treatment if your child's nephrotic syndrome doesn't get better with steroid treatment or keeps coming back. Ciclosporin should help to make the nephrotic syndrome get better (go into and stay in remission).

What is ciclosporin available as?

 Your child should stay on the same brand (e.g. Neoral) of ciclosporin (unless your doctor tells you otherwise). Always check the packet and ask the pharmacist if you are given a different brand.

- **Deximune capsules (grey):** 25 mg, 50 mg, 100 mg
- **Neoral capsules:** 10 mg (yellow/white), 25 mg (blue/grey), 50 mg (yellow/white), 100 mg (blue/grey)
- **Capimune capsules:** 25 mg (grey), 50 mg (white), 100 mg (grey)
- **Liquid medicine:** 500 mg in 5 mL

Ciclosporin preparations contain a small amount of alcohol. If you have any concerns or questions, speak with your child's doctor or pharmacist.

When should I give ciclosporin?


Ciclosporin is usually given **twice** each day, once in the morning and once in the evening. Ideally, these times are 10–12 hours apart, for example some time between 7 and 8 am, and between 7 and 8 pm.

It is very important to give the medicine at about the same times 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 ciclosporin (the dose) that is right for *your* child. The dose will be shown on the medicine label.

Your doctor will measure the amount of ciclosporin in your child's blood, usually in the morning. On the day of the blood test, delay the ciclosporin morning dose until after the blood test.

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

How should I give it?




Capsules should be swallowed with a glass of water, milk or juice (not grapefruit juice). Your child should not chew the capsule.



Liquid medicine: Measure out the right amount using an oral syringe or dropper. Your pharmacist will make sure you have the right device for measuring out the correct dose for your child.

Do not use a kitchen teaspoon as it will not give the right amount. Dry the dropper or syringe after use, but do not rinse it out.

To hide the taste of the liquid medicine, you can add the dose into a small glass of milk or fruit juice (preferably at room temperature). Do not use grapefruit juice, as this affects the ciclosporin level. Your child should drink all the mixture straight away. Then add some more juice or milk to the glass, swirl it round and ask your child to drink the liquid so they get all the medicine.

 Your child should not eat grapefruit or drink grapefruit juice for at least 1 hour before giving ciclosporin, as it may interfere with the medicine.

When should the medicine start working?

It may take up some weeks or even months for ciclosporin to work properly. Your child may need to take ciclosporin for many months or some years.


What if my child is sick (vomits)?

- If your child is sick less than 30 minutes after having a dose of ciclosporin, give them the same dose again.
- If your child is sick more than 30 minutes after having a dose of ciclosporin, 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 about 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 the next normal dose. You do not need to wake up a sleeping child to give a missed dose.

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

What if I give too much?

 It may be dangerous to give too much ciclosporin.

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

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


Are there any possible side-effects?

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

Side-effects you must do something about



Contact your doctor straight away if your child has fever (temperature above 38°C), with a sore throat or a cough, or if they have unusual bleeding that is difficult to stop, or severe bruising.

 Very rarely, children can have headaches and visual disturbances. If this happens, contact your doctor straight away.

Other side-effects you need to know about

- Your child may get stomach cramps, nausea (feeling sick), be sick (vomit), or get diarrhoea or headaches when they first start taking ciclosporin. These effects should wear off as your child gets used to the medicine. If they are still a problem after 2 weeks, contact your doctor.
- Your child may get a burning feeling or tingling in the hands or feet during the first week of taking ciclosporin.
- Your child's gums may become tender or swollen, and may bleed when they brush their teeth. You can help prevent this by making sure that your child brushes and flosses their teeth regularly and massages their gums. Contact your doctor or dentist if you are concerned.
- Your child is more likely to get infections and they may take longer than usual to fight these off. They may also become ill very quickly, in which case you should contact your doctor.
- Your child's skin may become more sensitive to sunlight. Keep them out of strong sun. When outdoors, they should wear a long-sleeved top, trousers and a hat and should use a high-factor sun screen (at least SPF 30). Your child may also experience an increase in the growth of hair on their body.
- Your child may be more tired than usual or develop tremor (shakiness), muscle cramps, or pins and needles.
- Girls may find their periods become irregular or stop but they will return to normal after stopping the treatment.

There may, sometimes, be other side-effects that are not listed above. If you notice anything unusual and are concerned, contact your doctor.

Can other medicines be given at the same time as ciclosporin?

- You can give your child medicines that contain paracetamol or ibuprofen, unless your doctor has told you not to.
- Ciclosporin should not be taken with some medicines that you get on prescription. Tell your doctor and pharmacist about any other medicines your child is taking **before** giving ciclosporin.
- 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 will test your child's blood regularly to check that ciclosporin has not affected their liver, kidneys or blood.
- Your doctor will check your child's blood pressure regularly.
- Your child should not eat grapefruit or drink grapefruit juice in the hour before taking ciclosporin.



If your child comes into contact with anyone who has measles, chickenpox or shingles, contact your doctor straight away, as they may need special preventative treatment.

- Ciclosporin is also used for chemotherapy in cancer, but at a higher dose and for a longer time. You may have heard about some serious side-effects associated with chemotherapy. These are very rare when used for nephrotic syndrome. Talk to your doctor if you are worried.
- Ciclosporin may, rarely, cause infertility in males and females who have reached puberty, but this is very unlikely as it is only used for a short period in nephrotic syndrome.
- If ciclosporin is taken for a long time, it may damage the kidneys or skin and there is a low risk of some forms of blood cancer. Your doctor will discuss this with you before starting this medicine and will do regular blood tests to check for these effects. However, the benefit of taking the medicine is greater than the risk of these effects.
- Ciclosporin may harm an unborn baby. If your daughter is sexually active, it is vital that she uses adequate contraception to prevent unplanned pregnancy and continues it for at least 1 month after stopping the treatment. If your daughter wants to use the oral contraceptive pill, she must discuss this with her doctor, as this may increase the ciclosporin levels. If your daughter thinks that she may be pregnant, it is important that she sees your family doctor as soon as possible. She should keep taking her medicine until she sees her doctor.



It is important that your child always has the same brand of ciclosporin, as there may be differences between brands.

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General advice about medicines

- Try to give medicines at about the same times each day, to help you remember.
- If you are not sure a medicine is working, contact your doctor but continue to give the medicine as usual in the meantime. Do not give extra doses as you may do harm.
- Only give this medicine to *your* child. Never give it 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 for advice.

- 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 medicine you have at home has 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 medicines in a cupboard, away from heat and direct sunlight.



Do not keep the liquid medicine 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 doctor, pharmacist or nurse will be able to give you more information about ciclosporin and about other medicines used to treat nephrotic syndrome.

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

Nephrotic Syndrome in Children Support Group

01823 652 886 - www.nephrotic.co.uk

British Kidney Patient Association

01420 541 424 - www.britishkidney-pa.co.uk

National Kidney Federation

0845 601 02 09 - www.kidney.org.uk

www.medicinesforchildren.org.uk