



Cyclophosphamide for nephrotic syndrome

This leaflet is about the use of cyclophosphamide 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

Cyclophosphamide

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. Usually cyclophosphamide is taken for 8–12 weeks. It should help to make the nephrotic syndrome get better (go into or stay in remission).

What is cyclophosphamide available as?

- **Tablets:** 50 mg
- **Liquid medicine** can be ordered specially from your pharmacist

When should I give cyclophosphamide?

Cyclophosphamide is usually given **once** each day. This is usually in the morning.

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

Your child's doctor or nurse will measure how much protein is in their urine (wee), measure how well their kidneys are working and test their blood to make sure the dose is correct.



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

How should I give it?



Tablets should be swallowed with a glass of water, milk or juice. Your child should not chew the tablet.



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?

The medicine should start working straight away although you will not see any difference in your child. The aim is to increase the time that your child's nephrotic syndrome stays in remission, so it will take some time to know if it has helped.

What if my child is sick (vomits)?

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

What if I forget to give it?

Give the missed dose when you remember during the day, as long as this is at least 12 hours before the next dose is due.



Never give a double dose of cyclophosphamide.

What if I give too much?



It may be dangerous to give too much cyclophosphamide.

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

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



Contact your doctor immediately if your child develops any signs of infection such as fever (temperature above 38°C), chills, sore throat, cough or rash.

Other side-effects you need to know about

- Your child may feel sick or be sick (vomit) and they may get diarrhoea. Giving the medicine with some food or a small glass of milk may help. These effects should wear off as your child gets used to the medicine. If they are still a problem after 2 weeks, or you are worried, contact your doctor.
- Your child may notice a strange taste in their mouth while they are taking cyclophosphamide. Eating citrus fruits (e.g. oranges) and taking sips of water may help. This should wear off after a few weeks.
- Cyclophosphamide may affect your child's blood.
 - They may bruise more easily.
 - It may take longer than usual for bleeding to stop.
 - They may get nose bleeds and their gums may bleed when they brush their teeth.
- 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 hair may become thinner and some may fall out. It should grow back when the medicine is stopped. If this happens, discuss it with your doctor at your next visit.
- Your child may get sores in their mouth or on their lips. You can help prevent this by making sure your child brushes their teeth regularly and uses a mouthwash after brushing. If you are worried, or the sores are very painful, contact your doctor for advice.
- Rarely, cyclophosphamide can irritate the bladder and your child may have blood in their urine (wee). Taking the medicine first thing in the morning with plenty of liquid should prevent this.


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


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

- 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 will test your child's blood regularly to check that cyclophosphamide has not affected their liver, kidneys or blood.
- Cyclophosphamide is also used in chemotherapy for cancer. However, this is at a higher dose and for a longer time and can cause serious side-effects. Such side-effects are much less likely at the doses used to treat nephrotic syndrome.

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

 If your child is due to have an immunisation (vaccination), tell your nurse or doctor that they are taking cyclophosphamide. Some vaccines should not be given.

- If cyclophosphamide is taken for a long time, it can affect fertility in both males and females. This is very unlikely when it is used to treat nephrotic syndrome, as it is normally used for a short period. You can discuss this with your doctor.

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 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 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 medicine in a cupboard, away from heat and direct sunlight. It should not be kept in the fridge.
- Make sure that children cannot see or reach the medicine.
- Keep the medicine in the container it came in and avoid touching the tablets as much as possible.

Who to contact for more information

Your doctor or pharmacist will be able to give you more information about cyclophosphamide 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

British Kidney Patient Association

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

National Kidney Federation

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

www.medicinesforchildren.org.uk