

Ciclosporin

Information for
Parents, Carers & Young People



leeds children's
hospital

caring about children

Introduction

This leaflet contains information about the use of ciclosporin in children, by the paediatric rheumatology team. It is most commonly used to treat macrophage activation syndrome, systemic juvenile idiopathic arthritis or uveitis.

It tells you:

- how the medicine works
- how it should be given
- whether there are any side effects.

Please also read the general information leaflets available at <http://www.medicinesforchildren.org.uk> or available at the hospital pharmacy. This is in addition to any information provided by the manufacturer in the medicine package.

Why have I been given this leaflet?

The leaflet will help you to remember what your doctor has told you about this medicine. It will also help you to decide whether you want to go ahead with this treatment.

For most medicines, information is provided by the manufacturer in the medicine package. This medicine does not have a licence for use for rheumatological conditions in children so the leaflet in the medicine package doesn't tell you everything you need to know. We have written this leaflet to give you some extra information.

What is ciclosporin and how does it work?

In autoimmune conditions the immune system is overactive and attacks normal body tissue. Ciclosporin is an

immunosuppressant, which means that it reduces the effectiveness of the immune system and slows down the disease.

Ciclosporin is not a pain-killing medicine, so your child may need to continue with pain-killers and non-steroidal anti-inflammatories.

When should ciclosporin not be taken?

There are people with certain medical conditions who should not take ciclosporin, or who should take it with extra care. The manufacturer's leaflet will explain this in more detail. Please tell your doctor if you/your child has any of the conditions listed.

Safe reliable contraception is very important when taking immunosuppressive medications. Some medications can cause abnormalities to an unborn child during pregnancy and can affect both the male sperm and the female eggs. Please discuss contraception or planning a pregnancy with your doctor or nurse. They can give you information on what risks the medication may cause to you and your baby. If you think there is a possibility that you are pregnant or your partner may be pregnant please contact your nurse specialist or family doctor immediately.

How should I give ciclosporin?

Ciclosporin is given in capsule or liquid form. The dose depends on your child's weight so the doctor will tell you what dose to give. Give the capsules or liquid at the same time each day with or after meals.

Full instructions will be written on the Pharmacy label on the medicine bottle. Please follow these instructions carefully. The same brand of ciclosporin should be prescribed each time.

You/Your child should avoid significant amounts of grapefruit or grapefruit juice because they may affect how well ciclosporin works. This can result in increased levels in the body which can in turn increase side effects

You/Your child may need to take ciclosporin for months or years. Keep giving the medicine until you/your child's doctor tells you to stop. Do not stop it yourself without talking to the doctor. When you/your child has been free of disease for a prolonged period of time, the dose may be gradually reduced and the medicine eventually stopped.

If you forget to give a dose, give it as soon as you remember. If it is nearly time for the next dose, miss out the one that you forgot.

If your child is sick within 15 minutes of giving a dose, repeat the dose.

Are there any side effects?

Everyone reacts differently to medicines. You/Your child may have some side effects or none at all. All medicines have the possibility of causing side effects. The leaflet provided by the manufacturer contains a comprehensive list of the side effects reported for this medicine.

Ciclosporin may cause shaking or make you/your child feel sick or vomit. During the first week of treatment, some children complain of a burning feeling in their hands and feet. Ciclosporin occasionally leads to an increase in hair growth.

If you/your child develops an infection or sore throat, or looks unwell, contact your doctor urgently.

Ciclosporin may rarely affect the kidneys, so your child's blood tests and blood pressure must be checked regularly. **You/Your**

child must have a blood test to check renal function every two weeks for three months and then every month. Full blood count, liver function tests need to be checked monthly for 3 months then 3 monthly, at the same time as the renal function tests.

Sometimes blood is taken to check the level of ciclosporin in the body. Ciclosporin can suppress the immune system and increase the risk of developing chickenpox or measles, if you/your child is not immune to these infections. Therefore if you or your child is not immune and come into contact with chickenpox or measles while on ciclosporin, contact your doctor.

Please arrange an influenza vaccine every winter, due to the immunosuppressive nature of the medicines. You may also need a pneumococcal vaccine. You/your child should not have live vaccines whilst taking ciclosporin. If you/your child is recommended a vaccination by GP/school nurse and are unsure if it is a live vaccination, please contact the Rheumatology Nurses for advice.

As with all immunosuppressant medication we would recommend safe sun exposure, and in particular avoiding sun burn, due to an increased risk of long term skin damage.

Will ciclosporin affect any other medicines?

Ciclosporin may affect or be affected by some other medicines. You should tell your/your child's doctor or pharmacist about all of the other medicines they take. This includes any medicines prescribed by another doctor as well as medicines bought from a pharmacy or supermarket and any herbal remedies.

If you/your child is prescribed a new medicine (including vaccinations), or you want to buy a medicine (for your child) from a pharmacy, it is important that you tell the doctor or pharmacist about all the medicines that they take, including ciclosporin. You should also tell your/your child's dentist.

Particular concerns occur if the antibiotics in the macrolide family are prescribed- ie erythromycin, clarythromylin and azithromycin. Non-steroidal anti-inflammatory drugs (NSAIDs) can be given with ciclosporin although the normal dose may need to be reduced under the supervision of the Paediatric Rheumatologist. Do not give yourself/your child NSAIDs that have not been recommended by the Rheumatologist.

So this medicine does not have a licence. What does this mean?

The leaflet called **unlicensed medicines** available at <http://www.medicinesforchildren.org.uk/> tells you more about medicine licensing regulations. It also tells you why unlicensed medicines are sometimes used.

Why does ciclosporin not have a licence for use in children?

Sometimes a medicine has been licensed for a certain use in adults and later use shows that it works for a similar illness in children. The manufacturer can choose whether they apply to the Government to have the more recent information added to the licence. This costs a lot of money and sometimes the manufacturer decides it is not worth their while.

Ciclosporin is made by the manufacturer to treat a range of conditions in adults, including to stop transplant rejection, but is also widely used in children.

Remember that your doctor will have thought carefully about which medicine is best for your child's condition.

Where should I store ciclosporin at home?

Store ciclosporin in a cool, dry place, away from direct sunlight. It is important that all medicines are stored out of reach of children.

Where do I get a further supply?

Further supplies are available from your GP. Ask your GP to write a prescription when you have at least a weeks supply left and take the prescription to your local pharmacy in good time. The pharmacy may not have the medicine in stock and may need a few days to arrange a supply.

How can I find out more?

This leaflet has been written to provide general information about the use of ciclosporin in children. If you have any more specific questions or concerns, please speak to one of the following:

Children's Rheumatology Nurse 0113 392 0683

Paediatric Rheumatology Secretary 0113 392 0666



What did you think of your care? Visit bit.ly/nhsleedsfft
Your views matter

© The Leeds Teaching Hospitals NHS Trust • 2nd edition (Ver 2)
Developed by: Paediatric Rheumatology Team
Produced by: Medical Illustration Services • MID code: 20201110_007/RC

LN002497
Publication date
11/2020
Review date
11/2023