

Cyclophosphamide for non-oncology indications

Information for parents / carers / young people

Introduction

This leaflet contains information about the use of Cyclophosphamide in children in the management of rheumatological conditions.

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 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 license for the treatment of 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.

Cyclophosphamide is made by the manufacturer for the treatment of certain cancers and autoimmune conditions in adults. However it is also widely used in children.

Cyclophosphamide is used to treat several different types of rheumatic disease, including: systemic lupus erythematosus (SLE), vasculitis, juvenile dermatomyositis (JDM).

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

What is cyclophosphamide and how does it work?

In some conditions where the immune system is overactive, cyclophosphamide is used to suppress the immune system (by damaging rapidly multiplying cells) to bring the disease under control. This means that it dampens down the immune system and slows down/controls the disease. Cyclophosphamide doesn't work straight away and it may take six weeks or more before you notice an improvement.



Why does cyclophosphamide not have a license for use in rheumatological conditions 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 license. This costs a lot of money and sometimes the manufacturer decides it is not worth their while.

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

When should cyclophosphamide not be taken?

There are people with certain medical conditions who should not take cyclophosphamide, 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 have any of the conditions listed in the leaflet.

Safe, reliable contraception is very important when taking immuno-suppressive 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 is cyclophosphamide given?

Cyclophosphamide is given as an infusion over 15 minutes, with intravenous hydration of four hours. Normal practice in the UK is to give Cyclophosphamide as a first dose followed by an increased dose two weeks later and then monthly for a total five doses. Further doses can be recommended depending on your child's/your response to the treatment. Methylprednisolone is sometimes given in the hour before the hydration if necessary for disease management.

If the cannula stops working before the end of the hydration, you/your child will be advised to drink the same amount of fluid as would be given intravenously over the next few hours.

Are there any side effects?

All medicines can cause side effects.

- Cyclophosphamide may cause feelings of nausea or vomiting. Anti-sickness medication will be prescribed to help prevent this.
- There may be some hair thinning or hair coming out a little more easily when brushing. This is generally reversible once treatment with cyclophosphamide stops.
- There is increased potential for infection due to reduced immunity (more especially with concurrent steroids). All possible infections should be reviewed by a doctor. We will arrange for open access to your local hospital for early review if this is a potential problem.
- Cyclophosphamide can suppress the immune system and increase the risk of developing a severe case of chicken pox or measles. If you/your child are/is in contact with chicken pox or measles while on cyclophosphamide, contact the Rheumatology Team, or your GP.
- Mouth ulcers, and rarely mood disturbance can sometimes occur. Please discuss any concerns with the Paediatric Rheumatology Team.

- Very rarely cyclophosphamide can cause inflammation and bleeding of the bladder wall. If you notice any blood in your/your child's urine you should seek medical advice immediately. A urine specimen will be taken before cyclophosphamide infusions to check for blood. Drink 6-8 glasses of clear fluid on the day after infusion to reduce the risk of this happening.
- There is a risk of fertility impairment although the effects are usually dependant on the cumulative (collective) dose of the drug taken over years. If you feel you would like more information, please discuss this with your doctor.
- Reliable contraceptive precautions are recommended for male and female patients for at least six months after finishing treatment, as well as before and during treatment.
- There is a slightly increased risk of certain types of cancer.

You/your child will have a blood test at each infusion and we will arrange for a blood test in the week before an infusion to ensure blood cell levels are within safe levels to continue with a planned cyclophosphamide infusion. Checks are required to detect any problems that might occur with the bone marrow, kidney or liver.

Please report easy bruising or easy bleeding. If a worry, this may prompt a repeat blood test.

Vaccines

Due to the immunosuppressive nature of the medicine, please have an influenza (flu) vaccine every winter at your GP Practice. We recommend a dose of PPV-23 for all patients aged two years old and over and on immunosuppression (providing at least 8 weeks after PCV-13 vaccination).

Future vaccines including travel vaccines should be discussed with the Team as live vaccines should be avoided.

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

Everyone reacts differently to medicines. It is very unlikely that you/your child will have all the listed effects.

Will cyclophosphamide affect any other medicines?

Cyclophosphamide may affect or be affected by some other medicines. There are certain drugs which, when used in combination with cyclophosphamide can increase blood levels and cause problems. You should tell your/your child's doctor or pharmacist about all 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 you/your child) from a pharmacy, it is important that you tell the doctor or pharmacist about all the medicines that they take, including cyclophosphamide. You should also tell your/your child's dentist.

How can I find out more?

This leaflet has been written to provide general information about the use of cyclophosphamide in children with a non-oncology condition. If you have any more specific questions or concerns, please speak to one of the following:

Children's Rheumatology Nursing Team
0113 392 0683
 Paediatric Rheumatology secretary
0113 392 0666

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