



Cyclophosphamide for haematology/oncology conditions: information for families

This information sheet explains what cyclophosphamide is, how it is given and some of the possible side effects. Each person reacts differently to medicines, so your child will not necessarily suffer from every side effect mentioned. If you have any questions or concerns, please speak to your doctor, nurse or pharmacist.

Please read this in conjunction with any patient information leaflet provided by the manufacturer. However, please note that this information sheet explains about the use of cyclophosphamide in children and young people so may differ from the manufacturer's information.

What is cyclophosphamide?

Cyclophosphamide is a chemotherapy medicine used to treat certain types of cancer and leukaemia. It is also given to children before and after transplants and to treat some inflammatory conditions.

How is it given?

It is given as an injection or an infusion into a vein (intravenously or IV) through a cannula, central venous access device, implantable port or PICC line.

It may be given by mouth in tablet or liquid form. Oral cyclophosphamide is best taken in the morning at the same time every day with plenty of water as directed by your doctor, nurse or pharmacist.

What are the side effects?

Nausea and vomiting

Anti-sickness drugs can be given to reduce or prevent these symptoms. Please tell your doctor or nurse if your child's sickness is very bad or continues for more than a few days.

Hair loss

Your child may lose some or all of their hair or it may become thinner. This is temporary and the hair will grow back once the treatment is finished.

Bone marrow suppression

There will be a temporary reduction in how well your child's bone marrow works. This means they may become anaemic (low red blood cells), bruise or bleed more easily than usual, and have a higher risk of infection.

Your child's blood counts will be checked regularly to see how the bone marrow is working. Please tell your doctor if your child seems unusually

tired, has bruising or bleeding, or any signs of infection, especially a high temperature.

Strange taste

Your child may experience a strange taste in their mouth while receiving cyclophosphamide. This is temporary. They may prefer stronger flavoured foods.

Fertility

Depending on the combination of medicines and the dose that your child is given, his or her fertility may be affected. If you feel you would like more information, please discuss this with your doctor.

Irritation of the bladder wall

Cyclophosphamide can cause irritation of the bladder wall. This may lead to a condition called haemorrhagic cystitis which causes blood to appear in the urine. Your child will be given a medicine called mesna and intravenous fluids to reduce or stop this irritation.

Mesna is used to protect the bladder wall from harmful effects of cyclophosphamide. He or she will also be encouraged to drink lots of fluids. Your child's urine may be tested for blood while they are receiving cyclophosphamide.

Hot flushes and dizziness

Cyclophosphamide can sometimes cause your child to feel hot and dizzy. This is most likely to happen when cyclophosphamide is given as a slow intravenous injection in a vein.

Secondary cancers

There is a very small chance that some children on long-term cyclophosphamide might develop a secondary cancer. If you feel you need more information about this, please talk to your child's doctor.

Changes in nails

Your child's nails may become darker. Your child's nail growth will return to normal in the future.

Changes in heart function

In some cases when high doses of cyclophosphamide are administered, the drug may alter the muscle of your child's heart and how well it works. Before having high dose cyclophosphamide, your child will have a test called an echocardiogram (Echo). This test will also be used to monitor the heart during the course of treatment and at long-term follow-up clinic.

Interactions with other medicines

Some medicines can react with cyclophosphamide, altering how well it works. Always check with your doctor or pharmacist before giving your child any other medicine, including medicines on prescription from your family doctor (GP), medicines bought from a pharmacy (chemist) or any herbal or complementary medicines.

Important

- Keep all medicines in a safe place where children cannot reach them.
- Cyclophosphamide should be kept in a cool, dry place away from direct sunlight or heat.
- If your child is taking cyclophosphamide liquid, it can only be used for two months once opened. Write the date you opened the bottle on the label to remind you.
- You should handle this medicine with care, avoiding touching it where possible. If you are pregnant or think you could be pregnant, please discuss handling instructions with your doctor, nurse or pharmacist. Please see our *Special handling requirements* information sheet for further details.
- If your child vomits straight after taking the dose, inform your local doctor or nurse, as your child may need to take another one. Do not give them another dose without informing the doctor or nurse.
- If you forget to give your child a dose, do not give a double dose. Inform your doctor or

nurse and keep to your child's regular schedule.

- If your doctor decides to stop treatment with cyclophosphamide or the medicine passes its expiry date, return any remaining medicine to the pharmacist. Do not flush them down the toilet or throw them away.

Useful numbers

- GOSH switchboard 020 7405 9200
- Pharmacy medicines information 020 7829 8608 (Monday to Friday from 9am to 5pm)

Disclaimer

Please read this information sheet from GOSH alongside the patient information leaflet (PIL) provided by the manufacturer. If you do not have a copy of the manufacturer's patient information leaflet please talk to your pharmacist. A few products do not have a marketing authorisation (licence) as a medicine and therefore there is no PIL.

For children in particular, there may be conflicts of information between the manufacturer's patient information leaflet (PIL) and guidance provided by GOSH and other healthcare providers. For example, some manufacturers may recommend, in the patient information leaflet, that a medicine is not given to children aged under 12 years. In most cases, this is because the manufacturer will recruit adults to clinical trials in the first instance and therefore the initial marketing authorisation (licence) only covers adults and older children.

For new medicines, the manufacturer then has to recruit children and newborns into trials (unless the medicine is not going to be used in children and newborns) and subsequently amend the PIL with the approved information. Older medicines may have been used effectively for many years in children without problems but the manufacturer has not been required to collect data and amend the licence. This does not mean that it is unsafe for children and young people to be prescribed such a medicine 'off-licence/off-label'. However, if you are concerned about any conflicts of information, please discuss with your doctor, nurse or pharmacist.