



Oral cyclophosphamide for children and young people

An information guide for patients, parents and carers

The purpose of this guide is to give information on the use of oral cyclophosphamide in children and young people with cancer.

Please read this guide carefully alongside any patient information provided by the manufacturer. We have written this guide to give you more information about the use of this medicine in children and young people. Keep it somewhere safe so you can read it again.

What is cyclophosphamide?

Cyclophosphamide is a chemotherapy medicine commonly used in the treatment of certain types of cancer and leukaemia.

What preparations of cyclophosphamide are available?

Cyclophosphamide is available as 50mg tablets. A liquid may be available at some hospitals.

should be swallowed whole. Do not break or chew the tablet. Instructions will be on the label or on the patient dosing information chart.

Liquid medicine should be measured in an oral syringe through a bung/stopper in the neck of the bottle (supplied by the pharmacy). Your hospital or shared care centre will explain how to measure liquid medicine using a syringe and how to dispose of the syringe after use.

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Where can I get cyclophosphamide from?

Cyclophosphamide must only be obtained from the hospital at which you/your child is being treated or from your community pharmacy. Please remember to bring all medication with you at each hospital visit.

How is cyclophosphamide given?

Cyclophosphamide is given by mouth and should be taken in the morning with plenty of water. The tablet

Are there any possible side effects?

It is important to remember that everyone reacts differently to chemotherapy. Some will have very few side effects whilst others will have more.

The side effects listed below will not affect everyone who is given cyclophosphamide and may be different if more than one chemotherapy drug is given. If you experience any of the following side effects, contact your team for advice.

What are the common side effects?

Hair loss

Some or all of your/your child's hair may fall out, including eyebrows and eyelashes. This is temporary and hair will grow back when treatment has finished.

Reduced bone marrow function

Blood counts will be checked regularly to see how the bone marrow is working. A low neutrophil count can make you/your child more at risk of infection. A low haemoglobin count indicates anaemia which may make you/your child unusually tired, and a low platelet count may cause bruising or bleeding.

Please contact your hospital team if there are signs of any infection, especially a high temperature or signs of unusual tiredness, bruising or bleeding.

Nausea (feeling sick) and vomiting (being sick)

If this occurs it is usually mild. Anti-sickness medicines can be given to reduce or prevent these symptoms. Please contact your team if sickness is not controlled.

Taste changes

Food may taste different. Normal taste will usually come back after the treatment finishes.

What are the less common side effects?

Irritation of the bladder wall

Cyclophosphamide may cause irritation of the bladder wall. This may appear as blood in the urine, dark urine or pain when passing urine. If this happens contact your team for advice.

Mouth ulcers

If your/your child's mouth becomes sore or small ulcers develop, contact your team for advice. Always follow the

advice from your hospital on how to take good care of your/your child's mouth before and during treatment.

Changes to nails

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

Second cancers

There is a very small risk of a second cancer developing after many years. If you would like more information about this, please discuss with your consultant.

Is there anything else I should know about or do?

Contact the hospital at which you/your child is being treated if:

- a dose of cyclophosphamide is forgotten
- vomiting occurs after taking the dose
- too much cyclophosphamide is given

Which tests/investigations may take place before, during or after treatment with cyclophosphamide?

Full blood count

A full blood count will be done regularly at your hospital or by your community team. The dose of cyclophosphamide may need to be adjusted according to the result. The new dose will be recorded on the label or on the patient dosing information chart.

Does cyclophosphamide interact with any other medicines?

Some medicines can affect how well cyclophosphamide works. Always tell the prescriber about any other medication that is being taken. Make sure and check with the doctor or pharmacist before taking any other medicines. This includes supplements, herbal and complementary medicines.

How should the medicine be handled and stored?

- keep out of reach and sight of children
- store the tablets at room temperature
- store liquid in a fridge
- keep out of direct sunlight
- cyclophosphamide liquid has a short expiry once opened so make sure you write the date opened on the bottle

- handle as little as possible and always wear gloves
- if you are pregnant or think you could be pregnant, please discuss handling instructions with your doctor, nurse or pharmacist
- always handle medicines with care

Any cyclophosphamide that has not been given, or is out of date, must be returned to the hospital at which you/your child is being treated. **Do not throw away at home.**

Please read the CCLG factsheet – safe handling of chemotherapy medicines

Pregnancy

If you are sexually active while taking anti-cancer medicines or drugs, it is important that you use contraception such as condoms, the pill or coil to avoid pregnancy. You may need to take a pregnancy test to confirm you are not pregnant before taking this medicine. Contraception should continue for a while after treatment finishes. Your team will advise how long you should continue contraception for.

Fertility

Depending on the type, dose and combination of medicines given during your treatment, it is possible that fertility may be affected. For girls, this means that it may be harder for them to become pregnant in the future. For boys, this may mean that their sperm is less fertile which can affect their chance of having children in the future.

If you would like more information about this please discuss with your medical team.

If you have any questions about mercaptopurine, please contact the hospital at which you/your child is being treated. This guide only gives general information.

Always discuss individual treatment with your/your child's medical team. Do not rely on this guide alone for information about treatment.



USEFUL ORGANISATIONS

Children's Cancer and Leukaemia Group (CCLG)

publishes a variety of free resources to order or download
www.cclg.org.uk

Young Lives vs Cancer offers practical support to children and young people with cancer and to their families
www.younglivesvscancer.org.uk

Macmillan Cancer Support offers support and advice to those affected by cancer.
www.macmillan.org.uk

EMC (Electronic Medicines Compendium) offers up to date, approved and regulated information for licensed medicines.
www.medicines.org.uk



Children's
Cancer and
Leukaemia
Group

the EXPERTS
in CHILDHOOD
CANCER

Children's Cancer and Leukaemia Group
Century House, 24 De Montfort Street
Leicester LE1 7GB

0333 050 7654
info@cclg.org.uk | www.cclg.org.uk

ChildrensCLG CCLG_UK

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Patient Information Forum

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Children's Cancer and Leukaemia Group (CCLG) is a leading national charity and expert voice for all childhood cancers.

Each week in the UK and Ireland, more than 30 children are diagnosed with cancer. Our network of dedicated professional members work together in treatment, care and research to help shape a future where all children with cancer survive and live happy, healthy and independent lives.

We fund and support innovative world-class research and collaborate, both nationally and internationally, to drive forward improvements in childhood cancer. Our award-winning information resources help lessen the anxiety, stress and loneliness commonly felt by families, giving support throughout the cancer journey.

Our work is funded by donations. If you would like to help, text 'CCLG' to 70085 to donate £3. You may be charged for one text message at your network's standard or charity rate. CCLG (registered charity numbers 1182637 and SC049948) will receive 100% of your donation.

We are grateful to all those who have contributed to this publication. We make every effort to ensure that this information is accurate and up to date at the time of printing. CCLG does not accept any responsibility for information provided by third parties including those referred to or signposted to in this publication. Information in this publication should be used to supplement appropriate professional or other advice specific to your circumstances.

If you have any comments on this factsheet, please contact us at publications@cclg.org.uk. CCLG publications on a variety of topics related to children's cancer are available to order or download free of charge from our website.