



Oral lomustine 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 lomustine 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 lomustine?

Lomustine is a chemotherapy medicine commonly used in the treatment of certain types of cancer. It is also sometimes known as CCNU.

What preparations of lomustine are available?

Lomustine is available as 40mg capsules. Some hospitals may be able to obtain 10mg capsules.

Where can I get lomustine from?

You must only get lomustine from your treating hospital. Please remember to bring all medication with you to each hospital visit.

How is lomustine given?

Lomustine is given by mouth, as a single dose. Lomustine can be given on an empty stomach, as this may help to prevent sickness, but it does not have to be given this way. An empty stomach means one hour before, or two hours after, food. You may also give lomustine just before going to bed to help prevent nausea (feeling sick) and vomiting (being sick).

Instructions will be on the label or on the patient dosing information chart. The capsule should be swallowed whole with plenty of water or juice. Do not break, crush or chew the capsules. If nasogastric (NG) feeds are being given, then the administration of lomustine can be timed around the feeds. Your hospital or shared care centre will be able to advise you on this.

The information below is for patients who are unable to swallow the capsules whole.

How to give lomustine if you/your child is unable to swallow whole capsules:

For each dose you will need:

- a pair of non-sterile disposable gloves
- apron and mask
- medicine cup and medicine spoon
- correct dose of lomustine
- kitchen towel
- yoghurt or other cold soft food, such as ice cream or chocolate mousse
- sealable plastic bag
- a cytotoxic sharps bin (available from your hospital or shared care centre)

Follow the instructions below:

1. Put on the gloves, apron and mask.
2. Place some kitchen towel on the work surface.
3. Onto the towel, place a medicine cup containing some yoghurt and a medicine spoon.
4. Check all the information on the medicine bottle is correct for your child and that you understand the dose that is to be given.
5. Lomustine must NOT be mixed with water, squash or fruit juice.
6. Open the packaging and place the correct number of capsules for the dose on the kitchen towel
7. Working over the medicine cup, hold the capsule by each end and gently twist and pull it open, emptying the contents into the medicine cup containing the yoghurt. Take care not to inhale any powder.
8. Repeat this for each capsule.
9. Carefully mix the powder into the yoghurt with the medicine spoon.
10. Use the medicine spoon to give the yoghurt containing the lomustine.
11. Add some more yoghurt to the medicine cup and mix with the spoon.
12. Repeat if necessary to ensure the full dose has been given and all of the yoghurt containing the lomustine has been swallowed.
13. Wrap all the utensils and gloves in the kitchen towel, seal in a plastic bag and place in the cytotoxic sharps bin.
14. Wash hands thoroughly with soap and water.

When not in use, the cytotoxic sharps bin must be closed (but not sealed) and stored out of reach of children.

When each course is finished, or the cytotoxic sharps bin is two thirds full, the sharps bin should be sealed. At the next visit, please **RETURN** the sharps bin to your hospital or shared care centre.

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 lomustine and may be different if more than one chemotherapy drug is given.

What are the common side effects?

Nausea (feeling sick) and vomiting (being sick)

Anti-sickness medicines can be given to reduce or prevent these symptoms. Please contact your treating hospital if sickness is not controlled or continues for more than a few days.

Reduced bone marrow function

Blood counts will be checked regularly to see how the bone marrow is working. A low neutrophil count can increase your/your child's risk of infection. A low haemoglobin count indicates anaemia which may cause unusual tiredness and a low platelet count may cause bruising or bleeding.

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

Loss of appetite

It is possible to 'go off food' and eating while having treatment. Your hospital team will be able to offer advice on how to manage loss of appetite.

What are the less common side effects?

Temporary effect on liver function

Lomustine can cause some changes to liver function. This should return to normal when treatment finishes. If liver function is seriously affected, treatment will be changed. Blood tests may be taken to monitor liver function (called LFTs - liver function tests). If there is pain on the right side of the tummy, yellowing of the skin and eyes, or bruising or bleeding, contact your team for advice.

Hair loss

Lomustine may cause some or all hair to fall out, including eyebrows and eyelashes. This is temporary and the hair will grow back once the treatment is finished.

Mouth ulcers and sores

A sore mouth with or without bleeding gums and ulcers may happen after treatment. Your hospital team will give advice on mouth care but always tell your doctor or nurse if mouth pain is a problem.

Other cancers

If lomustine is given for a long time, there is a very small risk of developing another cancer after many years. If you would like more information, please discuss this with your consultant.

Is there anything else I should know about or do?

Contact your treating hospital if:

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

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

Full blood count

A full blood count will be done regularly at your hospital or by your community team. The dose of lomustine 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 lomustine interact with any other medicines?

Some medicines can affect how well lomustine works. Always tell the medical team about any other medication that is being taken. Check with your doctor or pharmacist before taking any other medicines. This includes supplements and herbal or complementary medicines.

How should the medicine be handled and stored?

- always handle medicines with care
- keep out of reach and sight of children
- store the capsules at room temperature
- keep out of direct sunlight
- handle as little as possible and always wear gloves
- if you are pregnant or think you could be pregnant, discuss handling instructions with your doctor, nurse or pharmacist

Any lomustine that has not been given, or is out of date, must be returned to your treating hospital. **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 to 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 using contraception.

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 lomustine, please contact your treating hospital. This guide only gives general information.

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

i 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



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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.

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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.

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