

CCNU (Lomustine)

The possible benefits of treatment vary; for some people this chemotherapy may reduce the risk of the cancer coming back, for others it may control the cancer and its symptoms. Your doctor will explain to you whether you will receive chemotherapy or another type of treatment, or a combination of both. Your doctor or nurse will be happy to answer any questions you have about your treatment. You will find it useful to refer to the booklet 'Chemotherapy, a guide' which gives general information on chemotherapy and side effects.

Your treatment

Your doctor has prescribed a course of treatment with CCNU (cis-chlorethyl-nitrosurea) chemotherapy, also known as Lomustine.

The treatment consists of CCNU capsules taken orally as a single dose, once every 6 weeks.

This treatment is repeated every 6 weeks, usually for a total of 6 cycles, or as long as your doctor advises.

Lomustine is taken as a single dose of capsules taken together.

They should be swallowed whole with a glass of water on an empty stomach. If you have swallowing difficulties, please let your clinical team know, as they can advise on how best to manage taking the oral chemotherapy.

You will have a routine blood test before the start of each cycle of treatment.

Occasionally, we may not be able to go ahead with your treatment until your blood counts are back to a safe level. If this happens, your chemotherapy may be delayed a week.

This treatment can have serious or possibly life-threatening side effects. It is very important that you report side effects straight away. Don't delay, if you feel unwell, please ring The Christie Hotline on **0161 446 3658**. The lines are open 24 hours a day.

Increased risk of serious infection

You are vulnerable to infection while you are having chemotherapy. Minor infections can become life-threatening in a matter of hours if left untreated. Symptoms of infection include fever, shivering, sweats, sore throat, diarrhoea, discomfort when you pass urine, cough or breathlessness. We recommend that you use a digital thermometer so you can check your temperature. You can buy one from your local chemist.

If you feel unwell, you have symptoms of an infection or your temperature is 37.5°C or above, or below 36°C contact The Christie Hotline straight away.



Instructions for taking Lomustine:

- Lomustine should be swallowed whole, with a glass of water. They can be taken any time of the day, in the evening if preferred.
- Your total daily Lomustine dose may be made up of several Lomustine capsules of different strengths. If you are unsure about how to take your capsules, please ask a member of your clinical team.
- The capsules should never be opened or crushed. If they become damaged, avoid getting the powder on your skin or in your eyes. If you accidentally get some on your skin or in your eyes you should wash immediately.
- Take your anti-sickness medication (Ondansetron) 30 minutes to 1 hour before taking the Lomustine capsules.
- If you vomit after you take the Lomustine capsules, contact The Christie Hotline for advice.
- Continue taking Ondansetron regularly every 12 hours for 2 days.
- You will also be provided with an alternate anti-sickness medicine (Metoclopramide), which may be used after your Ondansetron is finished or used in combination with ondansetron if required.
- If you continue to feel sick or vomit, please contact The Christie Hotline or your GP as you may need a review of your anti-sickness tablets.
- Your doctor may have prescribed other medications such as steroids (dexamethasone), anti-epileptics, stomach-protecting drugs or painkillers – these should be taken as prescribed in the usual way. It is usually fine to continue to take any other medications you have been prescribed that are not related to your brain tumour, such as blood pressure tablets. Please check these with your doctor.
- If you are ever unsure about when you should take your Lomustine, please check with your clinical team or The Christie Hotline.

Flu vaccinations

Is it alright for me to have a flu jab during the time I'm having chemotherapy?

It's safe to have a flu jab, but depending on the sort of chemotherapy you have had, it may not give quite as much protection against infection as usual. Some patients may need two vaccinations. However, if you're thinking of having any other vaccinations, do check with your Christie doctor first, because some vaccines should be avoided.

Possible side effects

This treatment can cause many different side effects. Some are more likely to occur than others. Everyone is different and not everyone gets all the side effects. Most side effects are usually temporary, but in some rare cases they can be life-threatening. It is important to tell your hospital doctor or nurse about any side effects so they can be monitored and, where possible, treated.

Common side effects (more than 1 in 10)

• Bruising or bleeding (Warning!)

This treatment can reduce the production of platelets which help the blood clot. Let your doctor know if you have any unexplained bruising or bleeding, such as nosebleeds, blood spots or rashes on the skin, and bleeding gums. You may need a platelet transfusion.

• Nausea and vomiting (sickness)

The severity of this varies from person to person, and tends to be worst for the few days after your chemotherapy. Take your anti-sickness medication (Ondansetron) 30 - 60 minutes prior to taking your chemotherapy capsules. Continue taking the anti-sickness medication regularly every 12 hours for 2 days. You will also be provided with additional sickness medication (Metoclopramide) should you require this. If you continue to feel or be sick, contact your GP or this hospital, because your anti-sickness medication may need to be changed or increased.

• Lethargy

Lomustine chemotherapy may make you feel tired and lacking in energy. It can be frustrating when you feel unable to cope with routine tasks. If you do feel tired, take rest and get help with household chores. If necessary, take time off work. Gentle exercise such as walking can be beneficial.

• Constipation

Try to drink plenty of fluids and eat foods high in fibre. You can also try simple laxatives which you can buy from a pharmacy, but make sure you tell your Christie doctor about this. Your Christie doctor or GP can provide stronger laxatives if necessary.

• Anaemia (Low number of red blood cells)

While having this treatment you may become anaemic. This may make you feel tired and breathless. Let your doctor or nurse know if these symptoms are a problem. You may need a blood transfusion.

• Headache

Let your doctor know if you get headaches while you are on treatment.

• Hair loss

Some hair loss may occur during treatment, including body and facial hair. It is advisable to avoid perms, colours, use of hot brushes and vigorous frequent washing that could increase hair loss. Please remember that this is a temporary side effect and your hair will grow back when your treatment is completed. Very rarely, hair loss may be permanent.

The cancer information centre offers a coping with hair loss service to all patients where support, information and advice will be given. Drop in, contact **0161 446 8100** or email informationcentre@christie.nhs.uk. Information about the wig service can also be found here and vouchers for wigs can also be obtained for eligible patients. The wig room provides a drop in service, please see The Christie leaflet 'The wig fitting service' for further information.

The Maggie's Centre runs a Talking Heads hair loss support workshop for anyone who is anticipating or experiencing hair loss (both men and women). These sessions cover the practicalities of hair loss as well as offering support with its emotional impact. Contact Maggie's on **0161 641 4848** or email manchester@maggiescentres.org.

Uncommon side effects (less than 1 in 10)

• Diarrhoea

If this becomes a problem during or after your treatment. anti-diarrhoea tablets can be prescribed by your doctor. Ask the staff for a copy of 'Eating - help yourself' which has some useful ideas about diet when you are having treatment.

Rare side effects (less than 1 in 10)

- **Effects on vision**

Very rarely, Lomustine may affect your eyesight. Contact your Christie doctor if you experience any changes in your vision.

- **Changes to the lungs (Warning!)**

There have been rare reports of changes to lung tissue (interstitial pneumonia or lung fibrosis). If you develop unexplained breathlessness or coughing, seek medical attention, or contact The Christie Hotline on **0161 446 3658**.

- **Liver problems**

This treatment can occasionally cause abnormal liver blood tests and jaundice. This is rarely very severe, but your liver function will be monitored every time you come to the clinic for your treatment.

Occasionally, we may need to delay or suspend your chemotherapy until your liver blood tests have improved. If this happens, your clinical team will discuss it with you.

- **Kidney function**

Lomustine rarely affects your kidney function. Your kidney function will be monitored regularly while you are having treatment. It is important to drink plenty of fluids (at least 8 cups) the day before and for a few days after chemotherapy.

Serious and potentially life threatening side effects

In a small proportion of patients chemotherapy can result in very severe side effects which may rarely result in death. The team caring for you will discuss the risk of these side effects with you.

Sex, contraception and fertility

Protecting your partner and contraception: We recommend that you or your partner use a condom during sexual intercourse while you are having the course of chemotherapy. Chemotherapy is dangerous to unborn babies and this will also protect you and your partner from any chemotherapy drugs that may be present in semen and in the vagina. If you suspect that you may be pregnant please tell your doctor immediately.

Fertility: This chemotherapy may affect your ability to have children. Your doctor or nurse should have discussed this with you. If not, please ask them before you start treatment.

Late side effects

Some side effects may become evident only after a number of years. In reaching any decision with you about treatment, the potential benefit you receive from treatment will be weighed against the risks of serious long term side effects to the heart, lungs, kidneys and bone marrow. With some drugs there is also a small but definite risk of developing another cancer. If any of these problems specifically applies to you, the doctor will discuss these with you and note this on your consent form.

Contacts

If you have any general questions or concerns about your treatment, please ring the area where you are having treatment:

Neuro-oncology clinical nurse specialist - **0161 446 8441**

Your consultant's secretary:

Dr McBain - **0161 918 7008**

Dr Borst /Dr Milanovic - **0161 446 3362**

Dr Colaco/Dr Whitfield/Dr Kennedy - **0161 918 7197**

For urgent advice ring The Christie Hotline on **0161 446 3658** (24 hours)

Your consultant is:

Your hospital number is:

Your key worker is:

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If you need information in a different format, such as easy read, large print, BSL, braille, email, SMS text or other communication support, please tell your ward or clinic nurse.

The Christie is committed to producing high quality, evidence based information for patients. Our patient information adheres to the principles and quality statements of the Information Standard. If you would like to have details about the sources used please contact **the-christie.patient.information@nhs.net**

For information and advice visit the cancer information centres at Withington, Oldham or Salford. Opening times can vary, please check before making a special journey.



Contact The Christie Hotline for
urgent support and specialist advice
The Christie Hotline: 0161 446 3658
Open 24 hours a day, 7 days a week