



# Lomustine: information for families

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This information sheet explains what lomustine 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 lomustine in children and young people so may differ from the manufacturer's information.

## What is lomustine?

Lomustine is a chemotherapy medicine used to treat certain types of cancer. It is also sometimes known as CCNU.

## How is it given?

Lomustine is given by mouth in the form of a capsule.

## What are the side effects?

### Nausea and vomiting

Anti-sickness medicines 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.

### Loss of appetite

It is possible that your child may 'go off' food and their appetite may reduce while having treatment. The dietitians may be able to suggest ways of making food more attractive to your child.

### Bone marrow suppression

There will be a temporary reduction in how well your child's bone marrow works. This means your

child may become anaemic (reduced 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.

### Hair loss

Your child may lose some or all of their hair, including eyebrows and eyelashes. This is temporary and the hair will grow back once the treatment is finished.

### Mouth sores and ulcers

Your child may get painful or bleeding gums, ulcers or a sore mouth. You will be given advice about appropriate mouth care including a copy of our leaflet. If your child complains of having a sore mouth, please tell your doctor or nurse.

### Temporary effect on liver function

Lomustine can cause some mild changes to your child's liver function. This should return to normal when the treatment is finished. Blood tests (LFTs) may be taken to monitor your child's liver

function. Please contact your doctor immediately if your child complains of pain in their right side or the whites of their eyes or their skin develops a yellow tinge.

## Interactions with other medicines

Some medicines can react with lomustine, 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.

## Giving lomustine in a mixture at home

You can mix the medication with ice cream, yoghurt or similar food like chocolate mousse, as below. You should do this away from bright sunlight.

1. Assemble all the equipment you will need:
  - gloves (disposable or household)
  - a small pair of sharp, clean scissors (to be used only for this purpose)
  - a dessert spoon
  - a teaspoon
  - a small tray (this can be plastic or disposable cardboard)
  - small portion of ice cream, yoghurt or chocolate mousse
  - kitchen roll - kept just for this purpose
  - a sharps bin
  - a plastic medicine pot
2. Put the on gloves.

Note: If the capsules are too hard to cut, try putting them (still in their foil packaging) in the plastic medicine pot with some warm water for a minute or two.

3. Remove the capsule from the blister pack and put the required number of capsules for each dose into the plastic medicine pot.
4. Place the dessert spoon on a clean surface.

5. Take a capsule between finger and thumb and hold upright firmly
6. Working over the tray use the scissors to cut the tip off the capsule and then carefully squeeze the contents on to the dessert spoon.
7. Discard the empty capsule in the sharps bin.
8. Use the kitchen roll to wipe any drug from the gloves and then dispose of the used kitchen roll immediately in the sharps bin.
9. Repeat for each capsule needed.
10. After all the required capsules have been snipped, use the teaspoon to place some soft ice cream, yoghurt or mousse onto the deserts spoon.
11. Using the teaspoon mix the ice cream, yoghurt or mousse with the medicine.
12. Give the medicine to your child.
13. Clean all equipment, including scissors and gloves (if using house-hold gloves) in warm soapy water.
14. Put the disposable gloves in the sharps bin. Wash your hands thoroughly.
15. Return the sharps bin to hospital when full.

Note: This medicine is very thick and sticks to the sides of nasogastric tubes. Even if you usually give medicines to your child through a nasogastric tube you should try to give this medicine by mouth. If you have difficulties please ask your nurse or doctor.

## Accidental spillages

- If you accidentally spill the tablets or mixture medicines on the work surface or floor, wearing gloves, cover the spillage with kitchen paper. Wipe the area with water then clean with household cleaner and water.
- If the mixture gets onto your skin, you must wash the area immediately, using plenty of water. If the skin is sore you should contact your GP (family doctor) for advice.
- If the mixture accidentally gets into your eyes, wash with plenty of running water for at least

10 minutes. If your eyes are sore after this, you should go to your nearest Accident and Emergency (A&E) department.

- If the mixture is spilt on clothing, the spill should be blotted dry with kitchen paper. Clothing should be removed immediately and washed separately from other items. Used kitchen paper should be disposed of as above.
- Used paper towels, masks, vomit and dirty disposable nappies should be placed inside two rubbish bags and disposed of along with your normal rubbish.

If any type of spillage occurs you should contact GOSH for advice immediately.

### **Important**

- Keep all medicines in a safe place where children cannot reach them.
- Lomustine should be kept in a cool, dry place away from direct sunlight or heat.

- You should handle these medicines with care, avoiding touching them 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 lomustine or the medicine passes its expiry date, return any remaining tablets 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.