Lomustine (CeeNU®, CCNU, Gleostine™)

**Pronounced:** LOW-muss-teen

**Classification:** Alkylating Agent

**About Lomustine (CeeNU®, CCNU, Gleostine™)**

Lomustine exerts its anti-cancer affect by a process called alkylation. Alkylation damages the DNA of cells, which prevents them from dividing, and causes them to die. Since cancer cells, in general, divide faster and with less error-correcting than healthy cells, cancer cells are more sensitive to this damage.

**How to Take Lomustine**

Lomustine is taken by mouth in the form of a capsule. You may need several capsules, which may be different colors or sizes, to make up the dose ordered. Lomustine should be taken on an empty stomach – do not eat or drink for 1 hour after and 2 hours before the dose. Swallow the capsules whole with water; do not open, crush or chew them. Because of its side effects, this medication should not be taken more than once every 6 weeks.

It is important to make sure you are taking the correct amount of medication every time. Before every dose, check that what you are taking matches what you have been prescribed.

**Storage and Handling**

Store your medication in the original, labeled container at room temperature and in a dry location (unless otherwise directed by your healthcare provider or pharmacist). This medication should not be stored in a pillbox. Keep containers out of reach of children and pets.

If a caregiver prepares your dose for you, they should consider wearing gloves or pour the pills directly from their container into the cap, a small cup, or directly into your hand. They should avoid touching the pills. They should always wash their hands before and after giving you the medication. Pregnant or nursing women should not prepare the dose for you. Ask your oncology team where to return any unused medication for disposal. Do not flush down the toilet or throw it in the trash.

**Where do I get this medication?**

Depending on your prescription drug coverage, this medication may be available at a retail pharmacy or through a specialty pharmacy. Your oncology team will work with your prescription drug plan to identify an in-network pharmacy for the distribution of this medication via your local pharmacy or through a mail-order specialty pharmacy.

**Insurance information**

This medication may be covered under your prescription drug plan. Patient assistance may be available to qualifying individuals without prescription drug coverage. Co-pay assistance from private third-party foundations may be available. Your care team can help you access these resources if they are available.

**Possible Side Effects of Lomustine**

There are a number of things you can do to manage the side effects of lomustine. Talk to your care team about these recommendations. They can help you decide what will work best for you. These are some of the most common or important
side effects:

**Low White Blood Cell Count (Leukopenia or Neutropenia)**

White blood cells (WBC) are important for fighting infection. While receiving treatment, your WBC count can drop, putting you at a higher risk of getting an infection. You should let your doctor or nurse know right away if you have a fever (temperature greater than 100.4°F or 38°C), sore throat or cold, shortness of breath, cough, burning with urination, or a sore that doesn’t heal.

**Tips to preventing infection:**

- **Washing hands**, both yours and your visitors, is the best way to prevent the spread of infection.
- Avoid large crowds and people who are sick (i.e.: those who have a cold, fever, or cough or live with someone with these symptoms).
- When working in your yard, wear protective clothing including long pants and gloves.
- Do not handle pet waste.
- Keep all cuts or scratches clean.
- Shower or bath daily and perform frequent **mouth care**.
- Do not cut cuticles or ingrown nails. You may wear nail polish, but not fake nails.
- Ask your oncology care team before scheduling dental appointments or procedures.
- Ask your oncology care team before you, or someone you live with has any vaccinations.

**Low Red Blood Cell Count (Anemia)**

Your red blood cells are responsible for carrying oxygen to the tissues in your body. When the red cell count is low, you may feel tired or weak. You should let your oncology care team know if you experience any shortness of breath, difficulty breathing, or pain in your chest. If the count gets too low, you may receive a blood transfusion.

**Low Platelet Count (Thrombocytopenia)**

Platelets help your blood clot, so when the count is low you are at a higher risk of bleeding. Let your oncology care team know if you have any excess bruising or bleeding, including nose bleeds, bleeding gums, or blood in your urine or stool. If the platelet count becomes too low, you may receive a transfusion of platelets.

- Do not use a razor (an electric razor is fine).
- Avoid contact sports and activities that can result in injury or bleeding.
- Do not take aspirin (salicylic acid), non-steroidal, anti-inflammatory medications (NSAIDs) such as Motrin/Advil (ibuprofen), Aleve (naproxen), Celebrex (celecoxib), etc. as these can all increase the risk of bleeding. Please consult with your healthcare team regarding the use of these agents and all over-the-counter medications/supplements while on therapy.
- Do not floss or use toothpicks and use a soft-bristle toothbrush to brush your teeth.

**Nausea and/or Vomiting**

Talk to your oncology care team so they can prescribe medications to help you manage nausea and vomiting. In addition, dietary changes may help. Avoid things that may worsen the symptoms, such as heavy or greasy/fatty, spicy or acidic foods (lemons, tomatoes, oranges). Try saltines, or ginger ale to lessen symptoms.

Call your oncology care team if you are unable to keep fluids down for more than 12 hours or if you feel lightheaded or dizzy at any time.

**Mouth Sores (Mucositis)**

Certain cancer treatments can cause sores or soreness in your mouth and/or throat. Notify your oncology care team if your mouth, tongue, inside of your cheek or throat becomes white, ulcerated, or painful. Performing regular mouth care can help prevent or manage mouth sores. If mouth sores become painful, your doctor or nurse can recommend a pain reliever.

- Brush with a soft-bristle toothbrush or cotton swab twice a day.
- Avoid mouthwashes that contain alcohol. A baking soda and/or salt with warm water mouth rinse (2 level teaspoons of
baking soda or 1 level teaspoon of salt in an eight-ounce glass of warm water) is recommended 4 times daily.

- If your mouth becomes dry, eat moist foods, drink plenty of fluids (6-8 glasses), and suck on sugarless hard candy.
- Avoid smoking and chewing tobacco, drinking alcoholic beverages, and citrus juices.

**Loss or Thinning of Scalp and Body Hair (Alopecia)**

Your hair may become thin, brittle, or may fall out. This typically begins two to three weeks after treatment starts. This hair loss can be all body hair, including pubic, underarm, legs/arms, eyelashes, and nose hairs. The use of scarves, wigs, hats, and hairpieces may help. Hair generally starts to regrow soon after treatment is completed. Remember your hair helps keep you warm in cold weather, so a hat is particularly important in cold weather or to protect you from the sun.

**Less common, but important side effects can include:**

- **Lung Changes:** This medication may cause pulmonary infiltrates and fibrosis (a scarring and stiffening of the lung tissue), particularly when high doses have been received. These problems can develop months to years after treatment is completed and may be more common in people with pre-existing lung conditions. You may have breathing tests (pulmonary function tests) performed periodically. Call your physician right away if you have shortness of breath, cough, wheezing, or difficulty breathing.

- **Liver Toxicity:** This medication can cause liver toxicity, which your oncology care team may monitor for using blood tests called liver function tests. Notify your healthcare provider if you notice yellowing of the skin or eyes, your urine appears dark or brown, or you have pain in your abdomen, as these can be signs of liver toxicity.

- **Secondary Cancer:** A secondary cancer is one that develops as a result of cancer treatment for another cancer. This is quite rare, but you should be aware of the risk. In most cases, a secondary cancer related to chemotherapy is a blood cancer (leukemia, lymphoma). This can occur years after treatment. This is most often associated with repeated treatments or high doses. Your provider will monitor your labs closely. Consider having a complete blood count with differential checked annually by your healthcare provider if you received high-risk therapies.

- **Kidney Problems:** Lomustine can impact your kidney functions, especially after receiving large doses of this medication over time. Your healthcare team will monitor your kidney function during and after treatment. If you experience changes in the amount, color, or frequency of your urine, report this to your healthcare team immediately.

- **Eye Concerns:** While receiving lomustine, some patients may develop visual disturbances, changes in their eyesight, or blindness. Notify your healthcare team if you develop any eye pain, swelling, redness, or any vision changes, including blurriness and sensitivity to light.

- **Neurologic Concerns:** This medication can cause disorientation, lethargy, unsteadiness, and confusion. Exercise caution when operating machinery or driving. It may be helpful to take your dose at bedtime.

**Sexual & Reproductive Concerns**

This medication may affect your reproductive system, resulting in the menstrual cycle or sperm production becoming irregular or stopping permanently. Women may experience menopausal effects including hot flashes and vaginal dryness. In addition, the desire for sex may decrease during treatment. You may want to consider sperm banking or egg harvesting if you may wish to have a child in the future. Discuss these options with your oncology team.

Exposure of an unborn child to this medication could cause birth defects, so you should not become pregnant or father a child while on this medication. Effective birth control is necessary during treatment and for 2 weeks after treatment for women and 4 months for men, even if your menstrual cycle stops or you believe you are not producing sperm. You should not breastfeed while receiving this medication and for two weeks after you complete treatment.

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