

## Hydroxyurea for Sickle Cell Disease

Your child needs to take a medicine called hydroxyurea (say: hye-DROX-ee-yoor-EE-a). This information sheet explains what hydroxyurea does and how it is given to your child. It also explains what side effects, or problems, your child may have when he or she takes this medicine.

### What is hydroxyurea?

Hydroxyurea is a chemotherapy medicine that has been used to treat many disorders, including sickle cell disease. Research has shown that patients with sickle cell disease who take hydroxyurea:

- are admitted to hospital because of painful events only half as often as patients who do not take hydroxyurea
- have fewer acute chest crises
- have less need for blood transfusions if they are admitted to hospital

You may hear hydroxyurea called by its brand name, Hydrea. Hydroxyurea comes in a capsule form.

### Your child may be offered hydroxyurea if

- he or she has had 3 or more admissions to the hospital for significant painful crises in the last 12 months
- he or she has needed 1 or more exchange transfusions for 1 or more acute chest crises
- he or she has taken significant time away from school or work due to painful crises managed at home

### Before hydroxyurea is given to your child

Tell your child's doctor if your child has had an unusual or allergic reaction to hydroxyurea or any other medicine.

Talk with your child's doctor or pharmacist if your child has any of the following conditions. Precautions may need to be taken with these medicines if your child:

- may be pregnant
- has liver disease

### How is hydroxyurea given to your child?

- Give your child hydroxyurea exactly as your doctor or your pharmacist tells you to. Talk to your child's doctor before you stop giving this medicine for any reason.
- Give your child hydroxyurea once a day, around the same time every day. Many patients prefer to take it at bedtime.
- You may give hydroxyurea with or without food. Giving it with food may help to prevent stomach upset.
- Your child should drink lots of fluids (liquids) each day.
- If your child throws up (vomits) less than half an hour after taking hydroxyurea, give another dose of the medicine. If your child vomits more than half an hour after taking hydroxyurea, do not give another dose. Give the next dose the next day at the usual time.
- Hydroxyurea is supplied as a 500 mg capsule in Canada. Your child should swallow the capsule whole with a glass of water or other liquid.

- If your child is not able to swallow capsules or is taking a dose that is less than a whole capsule, review the best way to give hydroxyurea with the pharmacist. The capsule can be opened and dissolved in a medication syringe to give the prescribed dose. Throw away the left-over medicine.
- The pharmacist will teach you how to handle hydroxyurea safely, including using gloves when mixing powder from the capsule. The pharmacist will also teach you how to throw away the medicine safely.
- Anyone handling hydroxyurea should wash their hands before and after touching the bottle or capsules.

### **What should you do if your child misses a dose of hydroxyurea?**

- If a dose is missed, do not give a make-up dose.

### **What are the possible side effects of hydroxyurea and how are they monitored?**

Your child may have some of these side effects while he or she takes hydroxyurea. Check with your child's doctor if your child continues to have any of these side effects and they do not go away, or they bother your child:

- Nausea and vomiting: Avoid taking hydroxyurea on an empty stomach.
- Skin rash: This may be a non-specific rash that goes away even when the medication is continued. If a rash develops, see the doctor who prescribed hydroxyurea to your child.
- Hair loss: There can be thinning of the hair. The hair loss does not usually result in bald spots. If this happens, the risk and benefit of taking hydroxyurea (improved health and fewer crises) must be discussed with your child's doctor to decide about continued use of the drug.
- Lowering of some blood counts: Your child needs to have a blood test to check blood counts every 2 weeks for the first year of treatment. These tests can be done at a local laboratory and the results are faxed to the your child's doctor. If the white cell count is below a predetermined acceptable level, you will be called to hold the drug, and repeat the blood test in 4 to 5 days. The counts usually recover and the drug can be continued as prescribed. If the white cell count falls again, then the dose will be reduced to the dose your child was on before the counts started to fall. Your child will keep taking this lower dose.
- Skin and nail darkening: After taking hydroxyurea for some time, some patients develop darkening of the nails and skin over creases such as knuckles. This effect goes away once the drug is no longer in use.
- Liver dysfunction (problems): This is unusual, but blood tests are taken every 3 months to assess for this complication.
- Long-term effects: Hydroxyurea is a chemotherapy drug, and some of these types of drugs have been associated with patients developing cancer over many years. But in over 20 years of hydroxyurea use in sickle cell disease patients, there have been no reported cases this medicine causing cancer.

**What safety measures should you take when your child is using hydroxyurea?**

Hydroxyurea can lower the number of white blood cells in the blood temporarily, which increases your child's chances of getting an infection. Your child can take the following precautions to prevent infections, especially when the blood count is low:

- Avoid people with infections, such as a cold or the flu.
- Avoid places that are very crowded with large groups of people.
- Be careful when brushing or flossing your child's teeth. Your doctor, nurse, or dentist may suggest different ways to clean your child's mouth and teeth.
- You and your child should not touch your child's eyes or inside their nose without washing hands first.

There is a chance that hydroxyurea may cause birth defects if it is taken at the time of conception or if it is taken during pregnancy. If your daughter is sexually active, she should use some kind of birth control while receiving hydroxyurea. If your daughter gets pregnant while she is taking hydroxyurea, she should stop taking it right away and let her doctor know.

Your daughter should stop taking hydroxyurea for at least 3 months before trying to get pregnant. Hydroxyurea may also lower sperm counts.

Check with your child's doctor or pharmacist before giving your child any other medicines

(prescription, non-prescription, herbal, or natural products).

**What other important information should you know about hydroxyurea?**

- The drug has to be taken every day, not just when a painful crisis starts. It will not take away the pain in an active crisis. It works by making changes to the blood cells which prevent crises. It reduces sickling, decreases red cell breakdown, and increases protective fetal hemoglobin.
- At the 1-month visit, the red blood cells are larger. This is seen on testing and looking under the microscope. These red cells are able to move through the tiny blood vessels more easily and break less easily. Parents often report that their child's appetite has increased.
- By 3 months on the drug, there is also an increase in the fetal hemoglobin and overall hemoglobin level. We know that patients with higher fetal hemoglobin levels have fewer crises.
- By 6 months, your child should have had fewer painful crises than in the 6 months before starting treatment.
- How long a patient continues to take the drug will be a decision between him/her and the treating physician.

Hydroxyurea is covered by all private insurance plans and Ontario Drug Benefit plan.

Make sure you always have enough hydroxyurea to last through weekends, holidays, and vacations. Call your pharmacy at least 2



days before your child runs out of medicine to order refills.

Keep hydroxyurea at room temperature in a cool, dry place away from sunlight. Do NOT store it in the bathroom or kitchen.

Do not keep any medicines that are out of date. Check with your pharmacist about the best way to throw away outdated or leftover medicines.

Keep hydroxyurea out of your child's sight and reach and locked up in a safe place. If your child takes too much hydroxyurea, call the Ontario Poison Centre at one of these numbers. These calls are free.

- Call 416-813-5900 if you live in Toronto.
- Call 1-800-268-9017 if you live somewhere else in Ontario.
- If you live outside of Ontario, call your local Poison Information Centre.

Disclaimer: The information in this Family Med-aid is accurate at the time of printing. It provides a summary of information about hydroxyurea and does not contain all possible information about these medicines. Not all side effects are listed. If you have any questions or want more information about hydroxyurea, speak to your healthcare provider.

