

Hydroxyurea safe handling instructions

- Wash your hands before and after touching the bottle or capsules.
- Your child can take their own pills without any special precautions.
- For parents and caregivers, consider wearing disposable gloves when touching the capsules or bottle of hydroxyurea, especially if you or someone in your home is pregnant.
- If the medication (liquid or powder from the capsule) is spilled, wipe it up right away with a damp paper towel, put it in a plastic bag, and throw it away.
- Keep the medicine away from other children and pets.
- Keep hydroxyurea in a cool, dry place away from sunlight, so it doesn't get ruined.
- Ask your pharmacist how to get rid of any extra medicine safely.

How should I give hydroxyurea to my child?

Give it as prescribed by your child's doctor, nurse practitioner (NP). It may be given as a capsule or liquid. The hydroxyurea dose may be changed over time as your child grows.

For hydroxyurea to work, you must take it every day. Please remember to call your pharmacist for a refill before you run out of your child's medicine.

- If your child misses a dose, give the missed dose as soon as you remember. But if it's almost time for their next dose, skip the missed dose and give the next one. Do not double the dose.
- Your child can take it with or without food.
- If your child throws up soon after taking this medicine, call your child's hematology team.

What if my child is also taking other medicine?

Hydroxyurea may interact with other medicines. Check with your child's hematology team or pharmacist before giving your child any other medicines. This includes over-the-counter medicines, herbals, and vitamins.

If your child is also taking other medicine, make sure they take each one at the right time and don't mix them. Ask your child's hematology team or pharmacist to help you plan a way to give your child's medications at the right time.

How will the healthcare team monitor the effects of hydroxyurea?

Your child will get regular blood tests to see how well the medicine is working and to check for side effects. Your child needs to have these tests to stay on hydroxyurea.

Please avoid missing any hematology team or lab appointments as these are to monitor for possible side effects and to keep your child healthy.

1. Algiragiri, A. H., et al. (2014). Hydroxyurea for nontransfusion-dependent β -thalassaemia: A systematic review and meta-analysis. *Hematol Oncol Stem Cell Ther.*,10(3), 116-125.
2. Algiragiri, A. H. and A. Kassam (2017). "Hydroxyurea for hemoglobin E/beta-thalassaemia: a systematic review and meta-analysis." *Int J Hematol.*
3. Bohara V V., Ray S, Chakrabarti P, Ray SS, Nath UK, Chaudhuri U. Optimizing the dose of hydroxyurea therapy for patients with β -thalassaemia intermedia (Hb E- β -thalassaemia): A single center study from eastern India. *Hemoglobin.* 2014.
4. Ezzat, H., et al. (2018). CONSENSUS STATEMENT ON THE CARE OF PATIENTS WITH THALASSEMIA IN CANADA, 2ND EDITION. Available from URL: <https://www.canhaem.org/wp-content/uploads/2018/10/consensus-statement-Thalassaemia-Final.pdf>
5. Foong, W. C., et al. (2016). "Hydroxyurea for reducing blood transfusion in non-transfusion dependent beta thalassaemias." *Cochrane Database Syst Rev* 10: CD011579.
6. Karimi, M., et al. (2012). "Comparative study of hypogonadism in beta-thalassaemia intermedia patients with and without hydroxyurea." *Hematology* 17(2): 122-124.
7. Kosaryan, M., et al. (2014). "The effect and side effect of hydroxyurea therapy on patients with beta-thalassaemia: a systematic review to December 2012." *Hemoglobin* 38(4): 262-271.



Hydroxyurea for Children with Thalassemia

Information for patients & families



Created by the Education Committee of the
Canadian Haemoglobinopathy Association 2020

www.canhaem.org

What is hydroxyurea?

Hydroxyurea is a medicine used to treat some children and adults with thalassemia. It helps the body make fetal hemoglobin (hemoglobin F), which is the type of hemoglobin newborn babies make. The fetal hemoglobin can help increase the total amount of both hemoglobin and red blood cells, so a person is less anemic. Hydroxyurea will only work in people who have the ability to make hemoglobin, so not all thalassemia patients will benefit from it.

How can hydroxyurea help thalassemia?

While hydroxyurea is not a cure, it can make thalassemia milder over time. It works better in certain types of thalassemia and each person will respond to hydroxyurea differently. Some of the benefits of taking hydroxyurea can include:

- Increased sense of well-being.
- Having more energy.
- Improving anemia.
- Reduced risk of leg ulcers.
- Avoiding or delaying the need for routine blood transfusions.
- Decreased abnormal bone marrow expansion (extramedullary hematopoiesis).
- Helps to prevent the complications of thalassemia that present later in life, such as:
 - Pulmonary hypertension.
 - Leg ulcers.
 - Low bone density (osteoporosis).

Not all people with thalassemia will need to take hydroxyurea. Your hematology team believes the benefits of hydroxyurea in keeping your child healthier outweigh the risk of serious side effects. The decision to take hydroxyurea is your decision. Your hydroxyurea should only be changed/stopped by your hematology team.

Is hydroxyurea safe?

Hydroxyurea has been safely helping people with another type of red blood cell disorder, called sickle cell disease, for more than 20 years. It is routinely used in all ages, from babies to older adults. Recent research looking at a total of 17 studies did not find any significant, long-term side-effects with taking hydroxyurea.

Many people are afraid to try hydroxyurea because they think it might cause cancer. This is not true. Large studies of people taking hydroxyurea for many years showed no higher risk of cancer.

What are possible side effects from taking hydroxyurea?

The benefits of hydroxyurea in keeping your child healthier outweigh the risk of serious side effects. Having a higher hemoglobin level so your child can do well in school, be active, and feel healthy are most important. Your child's hydroxyurea should only be changed/stopped by your child's hematology team.

Like all drugs, hydroxyurea can have side effects. Your child will be asked to have regular blood tests to watch for most of these. Most side effects go away by:

- Lowering the dose.
- Stopping the hydroxyurea temporarily.

Possible side effects:

- Nausea, vomiting, and diarrhea.
- Abnormal liver tests.
- Skin rash.
- Darkening of nails and skin.
- Loss of appetite.
- Non-permanent hair loss.

Hydroxyurea can lower your white blood cell and platelets counts so regular blood work is important:

• *Low platelet counts:*

Your platelets help stop any bleeding. If your platelet counts are too low, you may have more bleeding and bruise easily.

• *Low white blood cell counts:*

Your white blood cells fight infections. Hydroxyurea can lower your white blood cell count. But sometimes it goes too low especially if blood work is not being monitored. This makes it harder for your body to fight infection. Handwashing is the best way to prevent infections from developing.

What should the doctor know before my child starts taking hydroxyurea?

Tell your child's doctor if your child:

- Is pregnant or is sexually active.
- Has liver disease.

How do I handle the medicine safely?

Hydroxyurea is safe for patients to take if they need it. But it may cause side effects as listed previously. So, the following instructions can help with safe handling of hydroxyurea.