

Can hydroxyurea affect my fertility?

Men

- Information is limited about men's fertility and using hydroxyurea.
- Men with untreated severe thalassemia have been found to have lower sperm count. The same has been found in men with thalassemia being treated with hydroxyurea. That said, most men with treated thalassemia can father children.
- Talk to your healthcare team if you are worried about your fertility. You could have your sperm tested or banked before starting hydroxyurea.
- Think carefully about this possible side effect compared to how hydroxyurea can help you feel better and live longer.
- Use birth control if you or your partner is taking hydroxyurea. Talk about birth control options with your partner and health care provider.

Women

- Severe forms of thalassemia may affect a woman's hormones and monthly cycle, making it difficult to become pregnant.
- Hydroxyurea won't affect your fertility.
- Tell your healthcare team if you are planning to get pregnant.
- If you are pregnant and taking hydroxyurea, stop taking the medication and talk to your healthcare team. Hydroxyurea may cause problems with the fetus, but there are many known cases of healthy pregnancies.
- Hydroxyurea may be safe in breastfeeding. Before starting, speak to your healthcare team about if it is the right choice for you.
- Use birth control if you or your partner is taking hydroxyurea. Talk about birth control with your partner and healthcare team.

How do I take hydroxyurea?

- Hydroxyurea comes in a capsule that you can swallow.
- You'll start on a low dose. The dose will slowly go up until your healthcare team knows the drug is working, but not lowering your blood counts too much.
- For hydroxyurea to work, you must take it every day. If you miss a dose, take your regular dose but don't take an extra dose to make up the dose you missed. If you have a fever or other symptoms of infection, call your healthcare team immediately.

How can I take an active part in my care?

- Ask your healthcare team to answer any questions (we know that this sheet won't answer all of your questions or concerns).
- Talk to other people with thalassemia or join a support group.

If you decide to take hydroxyurea:

- Take it every day.
- Take the dose prescribed.
- Get your blood work done.
- Tell your healthcare team about any side effects and changes in your symptoms.

References:

1. Algiragri, 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. Algiragri, A. H., A. Kassam (2017). "Hydroxyurea for hemoglobin E/beta-thalassaemia: a systematic review and meta-analysis." *Int J Hematol.*
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 Adults 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 my 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.
- Avoiding or delaying the need for routine blood transfusions.
- Decreased abnormal bone marrow expansion (extramedullary hematopoiesis).
- Helps to decrease the risk of complications of thalassemia, 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 you 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?

Like all drugs, hydroxyurea can have side effects. You 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 I start taking hydroxyurea?

Tell your healthcare team if:

- You're pregnant or sexually active.
- Have liver disease.

How do I handle the medicine safely?

Hydroxyurea is safe for patients to take if they need it. The following instructions can help with safe handling of hydroxyurea.

- Wash your hands before and after touching the bottle or capsules.
- Wipe spilled medication right away with a damp paper towel, put it in a plastic bag, and throw it away.
- Keep the medicine away from 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.