Can hydroxyurea affect my fertility?

Men

- Not much is known about men's fertility and using hydroxyurea.
- Men with severe sickle cell disease often have lower sperm counts and some abnormal sperm. Taking hydroxyurea can lower the sperm count even more. This may not reverse after you stop taking it. But it doesn't mean you can't father a child.
- Talk to your doctor if you're worried about your fertility. You could have your sperm tested and bank sperm samples 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 providers.

Women

- Hydroxyurea won't affect your fertility.
- Tell your doctor if you're planning to get pregnant.
- If you're pregnant and taking hydroxyurea, stop taking it right away and talk to your doctor. Taking hydroxyurea during pregnancy may cause problems with the fetus.
- Hydroxyurea may be safe in breastfeeding. Before starting, speak to your doctor about whether it is the right choice for you.
- Use birth control if you or your partner is taking hydroxyurea. Talk about birth control options with your partner and health care providers.

How do I take hydroxyurea?

- Hydroxyurea comes in a capsule that you 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, not just when you have pain. If you miss a day, take your regular dose the next day. Don't take an extra dose to make it up.
- If you have a fever or other symptoms of infection, call your care team immediately.

How can I take an active part in my care?

- Ask your healthcare team to answer any more questions (we know that this information sheet won't answer all of your questions or concerns).
- Talk to other people with sickle cell disease 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

CanHaem
The Canadian Haemoglobinopathy Association

References:

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CanHaem
The Canadian Haemoglobinopathy Association

Hydroxyurea for Adults with Sickle Cell Disease

Basic Information for patients & families

Created by the Education Committee of the Canadian Haemoglobinopathy Association 2017

www.canhaem.org

What is sickle cell disease?

Sickle cell disease is a red blood cell disorder that is inherited (passed down from parents to children). It happens when a person has 2 hemoglobin S genes (hemoglobin SS) or 1 hemoglobin S gene plus another abnormal hemoglobin gene (hemoglobin S-ß thalassemia, hemoglobin SC, and others). People with this disease have it for life.

Normal red blood cells are soft with a round shape. They flow easily through blood vessels. Sickle cell disease causes red blood cells to change to a hard sickle shape (e.g., the shape of a banana). This shape sticks to blood vessels and other blood cells and blocks blood flow through your organs.

What are some symptoms of sickle cell disease?

- Very bad pain
- Organ damage
- Higher risk of stroke
- Feeling tired all the time from anemia (low levels of red blood cells)
- Lower quality of life
- Shorter life than people without sickle cell disease
- People with sickle cell disease may spend a lot of time in the hospital.

How can hydroxyurea help my sickle cell disease?

Hydroxyurea is the only medicine approved to treat sickle cell disease that can reduce symptoms and complications from the disease over time.
Taking hydroxyurea can have many benefits. They include:

- Having less pain
- Spending less time in hospital
- Improving anemia
- Needing fewer blood transfusions
- Having a lower risk of stroke
- Helping with chest problems (fewer acute chest syndrome events)
- Enjoying a better quality of life

Who should think about taking hydroxyurea?

Talk to your doctor about hydroxyurea if you:

- Have sickle cell disease (especially hemoglobin SS or Sß thalassemia)
- Have had serious or repeated acute chest syndrome
- Often have pain that stops you from living your life or going to work or school
- Are on blood transfusion therapy to prevent a stroke
- Have severe anemia

How does hydroxyurea work?

Hydroxyurea helps the body to make fetal hemoglobin (hemoglobin F). This helps to stop red blood cells from becoming sickle shaped and blocking blood flow, so organs get enough blood. It also reduces the number of white blood cells so they are less likely to cause a blockage.

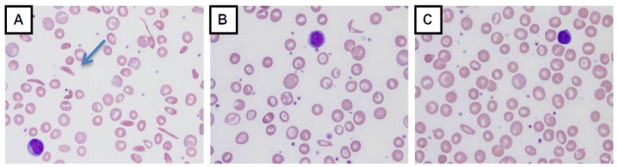

Figure used with permission from Ware, RE Blood 2010; 115(26):5300-11

A. Sickle cells without Hydroxyurea (Blue arrow)
B. Fewer sickle cells in a patient taking Hydroxyurea
C. Even fewer sickle cells after Hydroxyurea was adjusted to the patient's best dose

Is hydroxyurea safe to use?

Hydroxyurea has been safely helping people with sickle cell disease for more than 20 years. It can be helpful in babies as young as 9 months, as well as for children and adults of all ages. Because this medication was first used to treat forms of blood cancers, some people are afraid to try hydroxyurea because they think it might cause cancer. This is not true. Large studies of people with sickle cell disease taking hydroxyurea for many years show no higher risk of cancer.

What are common side effects of hydroxyurea?

The benefits of hydroxyurea in keeping you healthier with sickle cell disease outweigh the risk of serious side effects. 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 your dose
- Stopping the hydroxyurea temporarily
- Making other changes in your care

Low white blood cell counts
Your white blood cells fight infections. Hydroxyurea is supposed to lower your white blood cell count. But sometimes it goes too low. If this happens, it is harder for your body to fight infection.

Low platelet counts
Your platelet cells help prevent bleeding. If your platelet counts are too low you may have more bleeding and bruise easily.

Nausea
Hydroxyurea can cause nausea, but it's not common with the doses used for sickle cell disease. Most people have no problems. Nausea can be decreased by taking your medicine with food or by taking it right before bed.

Nail darkening
Hydroxyurea may cause darkening of your nails.

Less commonly, hydroxyurea may cause abnormal liver enzyme tests, or skin rashes.

How will I know that hydroxyurea is working?

Your health care team will check how well the medicine is working by doing blood tests. They will also ask you questions about your symptoms and any side effects of the drug. It can take 3 to 6 months to start feeling better after starting hydroxyurea. If it's working and you don't have serious side effects, you'll be asked to keep taking it.