



Hydroxycarbamide

Information for teenagers

- As part of your treatment for sickle cell disease (SCD), you have been prescribed a drug called Hydroxycarbamide.
- **It is very important that you are closely monitored when taking this medication.**
- This is to make sure that you are on the correct dose.
- **You must** take the prescribed medication correctly, whether it is in tablet or liquid form, so that you can have the full benefit.

What is Hydroxycarbamide?

- Hydroxycarbamide is regularly used in the treatment of different blood disorders.
- Hydroxycarbamide is given to all children and young people with sickle cell disease (HbSS and HbSBeta0) from 9 months old.

How does Hydroxycarbamide work?

- Hydroxycarbamide increases the production of foetal (baby) haemoglobin in your blood. This can reduce the sickling episodes that you experience, by stopping the sickle haemoglobin from sticking together. **This can take some weeks/months to take effect.**
- It reduces the white blood cell count (neutrophil), which is often raised in people who have severe sickle cell disease. This is important because the white cells produce chemicals, which can cause inflammation (swelling) and might speed up sickling. Having fewer of them makes this less likely.
- By taking this medication you should have fewer, less severe, and less painful episodes.
- This will mean that you will feel better and might experience less visits to the hospital, for long periods of time. You will be able to spend more time doing the things that you enjoy.

How do you take it?

- Hydroxycarbamide comes in a liquid or a capsule and is taken by mouth. Treatment begins on a low dose, daily, usually at:

20mg/kg in a child

0.5g (one capsule) or 15mg/kg (rounded up to the nearest capsule) in an adult.



- The dose will be gradually increased every two to three months, until the right dose is achieved.
- This will be the dose that gives the most benefits without side effects.
- The decision will be based on symptoms and blood test results.
- The blood tests are done 2 weeks after starting the medication. Then, depending on the result, blood tests will be done more or less frequently.
- This process may take several weeks to complete. After this you will need blood tests every three months.
- If you experience any unwanted side effects or something shows up in the blood tests, the Hydroxycarbamide may be stopped or given at a lower dose.

Patients who are unwilling to be monitored regularly will not be allowed to take Hydroxycarbamide.

Sexual behaviour

- Patients who are **sexually active must use contraception while taking hydroxycarbamide** as its effects have not been formally tested in pregnancy.
- Patients who are trying to get pregnant must stop taking Hydroxycarbamide three months before trying.
- Once the couple are pregnant, the man can restart his Hydroxycarbamide. A woman taking Hydroxycarbamide must stay off it until the baby has been born, and she has finished breastfeeding.

Giving my consent (permission)

- If you agree to take Hydroxycarbamide, you will need to sign a consent form. If you are under 18 years of age, a parent or guardian may be required to sign the consent form, though you can sign it too.

What to expect

- Most patients are well and have very little or no side effects.
- **It is important that you do not stop taking Hydroxycarbamide.** It may take a couple of months before you reach the right treatment dose and can benefit from the effects of the medication.
- Hydroxycarbamide can occasionally make patients feel sick or be sick, cause skin rashes, hair loss, diarrhoea, liver damage, weight gain, and if the blood count drops significantly, infection or bleeding. It may also cause darkening of the nails.



Risks

- If your temperature is over 38°C you should contact the team (details below) to arrange an urgent blood test at the hospital.
- Many people ask if Hydroxycarbamide increases the risk of cancer. We all have a risk of developing cancer during our lifetime.
- Some medications increase this risk a little, and this is true of a few medications which work in a similar way to hydroxycarbamide.
- There is **no evidence** that the risk of cancer is increased in patients with sickle cell disease who take Hydroxycarbamide, and we now have 20 years of evidence to support this.
- **Fertility** - There is evidence that suggests that Hydroxycarbamide can lower the sperm count of young men. However, it does increase again when they stop taking the medication. It is currently unclear about the effect on pre-pubertal boys.
- Males on Hydroxycarbamide can be offered sperm cryopreservation above the age of 14 years, usually completed when they are 17-18 years of age.

Please note that if you experience a sickle cell crisis with pain, even severe pain, you must continue to take the hydroxycarbamide.

Contact details

Children's clinical nurse specialist: 020 7288 3017 / 07799 347 161

Patient advice and liaison service (PALS)

If you have a compliment, complaint or concern please contact our PALS team on 020 7288 5551 or whh-tr.PALS@nhs.net

If you need a large print, audio or translated copy of this leaflet please email whh-tr.patient-information@nhs.net. We will try our best to meet your needs.

Twitter.com/WhitHealth

Facebook.com/WhittingtonHealth

Whittington Health NHS Trust

Magdala Avenue

London

N19 5NF

Phone: 020 7272 3070

www.whittington.nhs.uk

Date published: 28/08/2024

Review date: 28/08/2026

Ref: CYP/PaedHaem/HIT/04

© Whittington Health

Please recycle

