

Hydroxycarbamide treatment plan for haemoglobin disorders

Sickle Cell and Thalassaemia Service

Last reviewed: April 2025

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Information for Patients

Leaflet number: 551 Version: 3

Information for patients who are considering starting treatment

Consultant: Dr A. Webster

Diagnosis: Sickle Cell Disease / Non transfusion Dependent Thalassaemia

Your doctor has recommended that you start taking **hydroxycarbamide**. This booklet tells you why, how and when to take your medication. It will also tell you how much to take.

If you need to see your GP, dentist or another health professional, you should always show them this booklet.

Introduction

This leaflet will answer questions about treatment with hydroxycarbamide (also called hydroxyurea) in sickle cell disease and Thalassaemia.

With advice from your specialist team, they will help you to make a choice about taking hydroxycarbamide or not.

We recommend hydroxycarbamide if:

- you have had 3 or more hospital admissions in the past year for a sickle cell crisis.
- have regular crises at home affecting your work or normal daily life.
- have had 2 or more chest crises.

**Health information and support is available at www.nhs.uk
or call 111 for non-emergency medical advice**

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To give feedback about this information sheet, contact InformationForPatients@uhl-tr.nhs.uk

How does hydroxycarbamide work?

For sickle cell disease:

In **sickle cell disease**, the round red blood cells (RBCs) turn into long rod like cells. This is called a sickle cell. These hard rod like red cells are sticky. They cannot move easily through small blood vessels. The blood vessels can easily become blocked. This will cause pain and damage to different parts of the body.

Hydroxycarbamide can reduce the 'stickiness' of young red blood cells.

All babies are born with foetal haemoglobin (HbF). Babies at 3 months old who do not have sickle cell disease start to make normal adult haemoglobin. Babies with sickle start to make sickle haemoglobin.

HbF helps the RBCs to stay round. This lets them move through the blood vessels. This reduces the blockage which causes sickle cell crisis. High HbF protects the RBCs from becoming sickle cells.

Hydroxycarbamide increases the amount of HbF in the RBCs and reduces sickling.

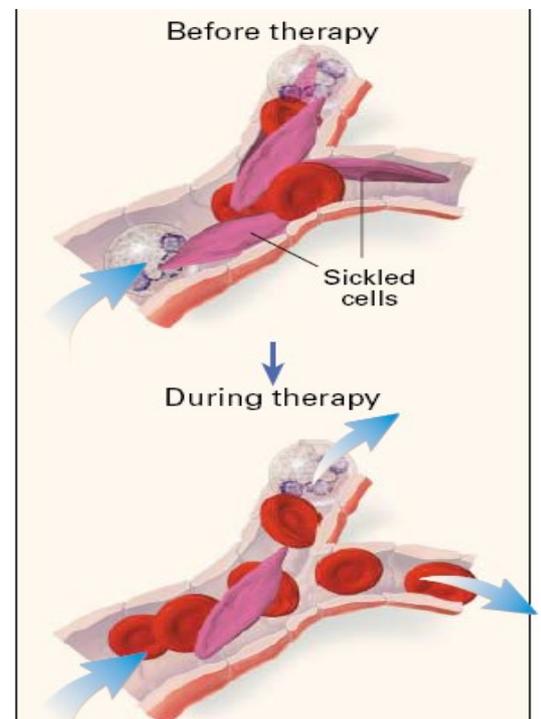
Hydroxycarbamide reduces the number of white blood cells. A high white blood cell count may speed up the 'sickling' of cells.

Hydroxycarbamide does not cure sickle cell disease but can stop many sickle cell related problems.

It helps by reducing the:

- need for blood transfusions
- how bad the sickle cell crisis is
- the number of sickle cell crisis
- number of hospital admissions

It can improve quality of life and increase how long you live for.



For non-transfusion dependent Thalassemia:

Thalassemia is a group of inherited conditions which cause anaemia. How bad the anaemia is different from person to person. Non-transfusion dependent Thalassemia is when you do not need lifelong blood transfusions.

In some people, hydroxycarbamide will cause a rise in HbF. This often found in baby red cells. This will improve the anaemia.

If a trial with the treatment is effective your consultant may recommend doing the treatment on a long term basis.

What tests do I need to do when taking hydroxycarbamide?

Hydroxycarbamide affects the red blood cells, white cell and platelets in the blood. You will need regular blood tests and monitoring while you take this medication.

You will need blood tests 2 weeks after starting the drug. You will also need a blood test after any change of dose. When your blood results are stable you will need blood tests every 8 to 12 weeks. We may reduce your dose if your blood count falls. You must have regular blood tests so we can monitor you to see any changes.

How should I take the medication?

- Do not open the capsules or crush the tablets.
- Take with a full glass of water.
- You can take it with food or on an empty stomach.
- Take it at the same time each day.
- Make sure you do not run out of medication. Contact the Clinical Nurse Specialist (CNS) team if you are running out.
- Think of ways that will help you remember when to take your medication. This can be setting a reminder on your phone or taking your medication before you brush your teeth.
- **Do not use** if you are breast feeding.
- If you take too much of the medication by mistake, contact your CNS team or the haematology helpline.
- You should always read the instructions that come with your medication carefully. If you have any questions please ask your doctor, nurse or pharmacist.
- Talk to your doctor or pharmacist before taking any new medication when taking hydroxycarbamide. This includes herbal medicines and over the counter remedies, such as paracetamol and cold remedies.
- Do not stop your treatment before the course is finished. If your doctor tells you to stop then you must stop. You should return any unused capsules to your pharmacist.
- **Do not take** any live vaccines while you are taking hydroxycarbamide. This includes yellow fever vaccines.

Safe handling instructions

Here are some rules to follow when handling hydroxycarbamide:

- You must make sure that your capsules are stored securely in a safe place. They should be out of reach of children.
- Store it in a dry place at room temperature.
- Only the patient should handle the capsules. If a relative or carer has to do this, they should wash their hands well after touching with the medication.
- You should wash your hands after handling the medication. Return any unused medication to your hospital or local pharmacy. Do not throw the capsules in the bin or flush them down the toilet.

What should I do if I am sick after taking my medication?

Nausea and vomiting are unusual with hydroxycarbamide. If you do get nauseous or vomit, your doctor can prescribe anti-sickness (anti-emetic) drugs. This will prevent or reduce these symptoms. If you are sick just after taking your capsules please let your specialist team know. Take the next dose as scheduled. Do not take an extra dose.

Can I get pregnant?

We do not recommend becoming pregnant or conceiving a child while taking hydroxycarbamide. This is because it cause harm to the growing baby.

You should use an effective form of contraceptive while taking this medication. You should keep doing this for at least 3 months after stopping the drug.

For women: there is no evidence that hydroxycarbamide effects fertility.

For men: sperm count may be reduced. There is a risk of abnormal sperm being produced. This usually returns to normal after the medication has been stopped for 3 months.

Side effects of hydroxycarbamide

Most people tolerate hydroxycarbamide treatment well. But like all medicines there are some potential side effects. The risk of side effects is reduced by checking your blood counts and seeing you regularly in the clinic. Most side effects return to normal after stopping the medication or reducing the medication.

Low blood counts are a side effect you should look out for. If this happens you may notice:

- you are more tired or short of breath. This is because of the fall in haemoglobin.
- you bruise or bleed more easily. This is because of low platelets (a type of blood cell important in blood clotting).
- you get mouth ulcers or pick up infections more easily because of low white blood cells.

You may not know if your blood counts are low to start with. You must attend your clinic appointments for these to be checked. You can talk about any other symptoms that you are worried about with your doctor or CNS at these appointments.

Other uncommon side effects:

- an upset stomach (diarrhoea, constipation or sickness)
- poor appetite
- headaches or dizziness
- allergic reaction such as skin rash
- skin and nail becoming darkened (pigmentation)
- hair thinning
- skin ulcers
- abnormal liver or kidney function tests

There is no evidence of hydroxycarbamide for sickle cell disease increasing the risk of leukemia or other cancers.

Getting medical help:

You must call the hospital for medical help if you have any symptoms that worry you, or any of the following:

- Shivers and / or a temperature of 38° C or higher
- Bad nausea, vomiting or diarrhoea
- Any bruising or bleeding
- Soreness or ulcers in your mouth
- Skin rash or skin ulcers

Haematology Helpline (24 hours a day, 7 days a week)

Phone number: 0808 178 2212

Clinical Nurse Specialist (CNS)

Mobile phone: 07950 891490

Office phone: 0116 258 6081

Contact details

Haematology Helpline (24 hours a day, 7 days a week)

Phone number: 0808 178 2212

Clinical Nurse Specialist

Mobile phone: 07950 891490

Office phone: 0116 258 6081

Lead Nurse Specialist - Haemoglobinopathies

Phone: 0116 258 6081

Phlebotomy room (for blood tests) Ground floor, Osborne Building

Monday to Thursday 8.30 am to 4.45pm, Friday: 8.30am to 3.00pm

UHL Medicines Information: Monday to Friday, 8.30 am to 5.30 pm

Phone : 0116 258 6491

UK Thalassaemia Society

Phone: 020 8882 0011

Email: info@ukts.org

Website: www.ukts.org

Sickle Cell Society

Phone: 020 8961 7795

Email: info@sicklecellsociety.org

Web: www.sicklecellsociety.org

Macmillan Information and Support Centre (Leicester Royal Infirmary)

Phone: 0116 258 6189

Website: www.leicestershospitals.nhs.uk/cancerinfo

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