

Hydroxycarbamide treatment for haemoglobin disorders (children)

East Midlands Sickle Cell and Thalassaemia Service

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Next review: October 2025

Leaflet number: 610 Version: 2.1

Information for Patients and parents

Hydroxycarbamide record

Consultant: Dr K Bhuller

Diagnosis: Sickle Cell Disease (SCD) _____

Allergies:

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Name of GP:

.....

Surgery address:

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.....

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Contact number:

.....

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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

Hydroxycarbamide record

Your doctor has recommended the following treatment for your child: **Hydroxycarbamide**

Syrup

Capsules

Who is hydroxycarbamide recommended for?

Following the BABY HUG trial (published in The Lancet, 2011) it was recommended that all children with sickle cell anaemia (HbSS, and S β^0 thalassaemia) are considered for treatment with hydroxycarbamide from 9 months of age. This is due to its affect in reducing the severity of sickle cell disease.

The aim of giving hydroxycarbamide is to improve both quality and quantity of life by

- lowering number of pain and chest crisis
- lowering risk of stroke

(Qureshi et al., *Guidelines for the use of hydroxycarbamide in children and adults with sickle cell disease* 2018).

Hydroxycarbamide may be recommended for your child if they:

- are over 9 months of age and have HbSS or S β^0 thalassaemia
- have had sudden and severe (acute) hospital admissions for sickle cell crisis in the last 12 months
- have had sudden and severe (acute) sickle chest syndrome and needed a blood transfusion or admission to the high dependency unit
- are at risk of a stroke
- have any other serious complications related to SCD

How does hydroxycarbamide work?

In sickle cell disease, hydroxycarbamide may reduce the number and severity of painful sickle cell crises. It is thought to work in 3 ways:

- by increasing production of haemoglobin F (baby haemoglobin)
- by reducing the 'stickiness' of young red blood cells
- by reducing the number of white blood cells. A high white blood cell count may speed up the 'sickling' of cells.

If you would like any more information about hydroxycarbamide please read the separate information leaflet you will have been given or use the contact details shown at the back of this booklet.

What are the benefits?

Hydroxycarbamide is not a cure for sickle cell but can help prevent or delay many of the complications of the disease.

It helps to reduce the:

- number and severity of pain crises
- number of hospital admissions
- number of sudden and severe (acute) chest syndrome events (chest crisis)
- need for blood transfusions

It can also:

- improve long-lasting (chronic) anaemia
- increase life expectancy
- improve quality of life

It usually takes at least 3 months before we can tell if the hydroxycarbamide is working. Sometimes it takes longer if we need to increase the dose to get the best result.

Hydroxycarbamide **must be given as directed**. It will **not work** if it is taken now and again or only if your child is ill or in pain. You should speak with the haemoglobinopathy team if you are not able to take the medication as directed.

Answers to common questions

Does taking hydroxycarbamide increase the a risk of developing cancer?

Hydroxycarbamide is a mild form of chemotherapy. When used by patients with an abnormal bone marrow who already have an increased risk of cancer it has been linked with higher rates of cancer.

But this side effect has not yet been seen in patients with sickle cell disease.

Treatment of sickle cell conditions with hydroxycarbamide has been in use since 1995. It has been given to many 1000s of patients. The rate of cancer in this group of patients is no more than we see in the normal population.

Does hydroxycarbamide affect fertility?

There is not enough evidence now to know if the ability to become pregnant or father a child may be affected by taking this drug. It is important to discuss this with your consultant haematologist.

It is also important to use contraception, if your child is sexually active, as the medication could potentially damage the developing baby. It is generally advised to speak to your haematologist if trying for a baby as hydroxycarbamide is advised to be stopped 3 to 6 months before becoming pregnant, if possible.

What are the possible side effects?

Your child may have side effects whilst taking hydroxycarbamide. Please let the doctor or nurse know if you notice any side effects so that these can be closely checked by the haematologist or nurse specialist.

Common side effects - affects between 1 and 10 out of every 100 people (1 to 10%)

- anaemia: a fall in haemoglobin level. This may result in your child becoming breathless and easily tired.
- a low white blood cell count: this can raise the chance of your child getting an infection.
- a low platelet count: this may raise the chance of your child bleeding and bruising.

As your child will be having regular blood tests, we will be able to find any problems at an early stage.

Less common side effects - which affect between 1 and 10 out of every 1,000 people (0.1 to 1%)

- Feeling and being sick (nausea and vomiting), loss of appetite
- sore mouth, mouth ulcers
- itching and skin inflammation / rash

Rare side effects - these affect between 1 and 10 out of every 10,000 people (0.01 to 0.1%)

- gout (pain and inflammation in the joints)
- hypersensitive or allergic reactions
- hair loss or hair thinning

Very rare side effects - these affect less than one person in 10,000 (less than 0.01)

- skin discolouration
- wasting of skin and nails

Xromi has methyl parahydroxybenzoate (E218). This may cause allergic reactions. Xromi is the brand of hydroxycarbamide liquid solution.

What is hydroxycarbamide not used to treat?

Hydroxycarbamide is not likely to reduce frequency of, or stop sickle cell disease complications related to:

- leg ulcers
- bone damage (avascular necrosis)
- Infections

How will my child's health be checked?

As the medication affects the red cells, white cells and platelets in the blood, your child will need regular blood tests whilst having treatment, this will need checking when:

- starting hydroxycarbamide
- while the blood count is stable you will have blood tests every 8 to 12 weeks.
- you will need a blood test 2 weeks after a change of dose or when you have started taking the medication again after a pause
- if the blood counts are too low, follow up blood tests will be more frequent until the blood counts are stable (Your child will be asked to pause the medication if this happens)

We will not be able to prescribe treatment if regular blood tests are not carried out.

What if my child is unwell while taking hydroxycarbamide?

Please phone the hospital to get medical advice if your child has any symptoms that worry you, or any of the following:

- shivers and / or a temperature of 38° C or higher
- severe nausea, vomiting or diarrhoea
- any bruising or bleeding

You should tell your hospital nurse or specialist if your child has:

- soreness or ulcers in their mouth
- skin rash
- skin ulcers

What is the dose of hydroxycarbamide?

The medical team will work out the correct dose according to your child's weight.

The dose may increase if it becomes less effective and as your child grows.

Your child will be prescribed the hydroxycarbamide in the clinic by the haematologist. It can be dispensed by the hospital pharmacy only.

The nursing team will let you know if the haematologist would like you to increase the dose or if you need to attend for any more blood tests.

Important drug information:

If your child needs to see their GP, dentist or another health professional, you should always tell them that your child is taking hydroxycarbamide medication or show them this booklet.

If your child is admitted to hospital for any reason please show this booklet to the doctor, nurse or pharmacist, if possible. Do not stop treatment before the course is finished, unless the haemoglobinopathy team tells you to do so.

Always read the instructions that come with the medication carefully. If you have any questions please ask the doctor, nurse or pharmacist. Discuss any new medication with your doctor or pharmacist before taking them. This includes herbal medicines and over-the-counter remedies, such as cough and cold remedies.

Please **return any unused capsules of hydroxycarbamide to the pharmacist**. You must not flush unwanted medication down the toilet or throw them away.

Please ensure that the medication is **stored in a safe place, out of the reach of children**.

Hydroxycarbamide can be taken with food or on an empty stomach.

You need to take special precautions when taking hydroxycarbamide.

- Ideally, only the patient should handle the capsules. If a relative or carer has to do this, they should wash their hands well after contact with the medication.
- You should wash your hands after handling the medication.

Please let the haemoglobinopathy team know when you have almost run out of hydroxycarbamide, we can arrange a prescription for a further 12 week supply as long as your child has kept up to date with their blood tests.

The pharmacy will not dispense any more medication if your child has not had a blood test in the past 12 weeks.

Hydroxycarbamide medication can only be prescribed by your consultant haematologist or registrar at the hospital, not by the GP. The medication can only be dispensed by the hospital pharmacy and this is where it must be collected from.

What should I do if a dose is missed?

If your child misses a dose do **not** let them take a double dose. Let us know, and keep to the regular dose schedule.

What if my child is sick after taking hydroxycarbamide?

Feeling or being sick are unusual with hydroxycarbamide. If they do occur, the doctor can prescribe anti-sickness (anti-emetic) drugs to stop or reduce these symptoms. If your child is sick just after taking your capsules please let your hospital nurse or specialist know.

Patient own record: Medication doses and change of dose

Hydroxycarbamide 500mg capsules 500mg / 5ml suspension (please delete as appropriate)

Date of dose instruction	Number of capsules/5ml spoonfuls per day						
	Mon	Tues	Wed	Thurs	Fri	Sat	Sun

Patient own record - blood tests and results

No. per week	Hb	HCRT	Retics	Platelets	Neuts	Dose Changed Yes/No	Name/ Signature

Patient agreement

By consenting to yourself or your child starting on hydroxycarbamide medication, you are agreeing that you have understood the benefits and possible side effects that have been explained to you in this leaflet.

The haemoglobinopathy team will work with you to closely check your child whilst taking hydroxycarbamide. Please contact us if you have any concerns or for advice.

Please make sure you tell us if your child is not able to take the medication as directed or if you have stopped or paused the medication without being told to do so.

Please make sure you can bring your child for blood tests every 10 to 12 weeks as requested and organised by the haemoglobinopathy team. If this advice is not followed, you may be asked to stop your child's medication.

Leaflet given and explained by _____

Sign _____

Parent/carer sign _____

(Please scan onto CITO once completed)

Contact details

Clinical Nurse Specialist

Mobile telephone: 07958 010060

Office telephone: 0116 258 6081

Leicester Hospitals Medicines Information

Monday to Friday 8.30 am to 5.30 pm

Telephone : 0116 258 6491

Sickle Cell Society

54 Station Road

London

NW10 4UA

Telephone: 020 8961 7795

Email: info@sicklecellsociety.org

Web: www.sicklecellsociety.org

NHS 111

Offers medical help and advice from fully trained advisers supported by experienced nurses and paramedics. Available 24 hours Telephone: 111 **NHS Direct** provides online information and guidance on all aspects of health and healthcare, to help you make choices about your health

Web: www.nhs.uk

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على هذه المعلومات بلغةٍ أخرى، الرجاء الاتصال على رقم الهاتف الذي يظهر في الأسفل
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Aby uzyskać informacje w innym języku, proszę zadzwonić pod podany niżej numer telefonu

Previous reference:

If you would like this information in another language or format such as EasyRead or Braille, please telephone 0116 250 2959 or email equality@uhl-tr.nhs.uk



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