

Hydroxycarbamide treatment for haemoglobin disorders (children)

Sickle Cell and Thalassaemia Service

Leaflet number: 610

Version: 2

Information for Patients and parents

Produced: Oct 2022

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Hydroxycarbamide record

Consultant

Dr K. Kotecha / Dr K Bhuller

Diagnosis

Sickle Cell Disease (SCD)

Allergies:

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Name of GP:

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Surgery address:

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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**

Who is hydroxycarbamide recommended for?

Hydroxycarbamide may be recommended for your child if they:

- have moderately severe or severe sickle cell disease (SCD)
- have had three or more acute hospital admissions for sickle cell crisis in the last 12 months
- have experienced 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 complications related to sickle cell disease.

Following the BABY HUG trial (published in The Lancet, 2011) it was recommended that that all children with SCD are considered for treatment with hydroxycarbamide from a young age due to its impact in reducing the severity of sickle cell disease.

How does hydroxycarbamide work?

In sickle cell disease, hydroxycarbamide may reduce the frequency and severity of painful sickle cell crises. It is thought to work in three 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 further 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.

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

It helps to reduce the following:

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

It can also:

- Increase life expectancy
- Improve quality of life

It usually takes at least three 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.

Treatment will not work if it is taken now and again or only when your child is ill or in pain.

What are the possible side effects?

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

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

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

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

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

- 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– 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

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 associated with higher rates of cancer.

However, this side effect effect has not been seen in patients with sickle cell disease.

Treatment with hydroxycarbamide has been in use since 1995 and has been given to many thousands of patients. The rate of cancer in these treated patients is no more than we see in the normal population.

What is hydroxycarbamide not used to treat?

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

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

How will my child's health be monitored?

As the medication affects the red cells, white cells and platelets in the blood your child will need regular blood tests and monitoring whilst undergoing treatment:

- after starting hydroxycarbamide or after a dose change a blood test will be required two weeks later and then (providing the results are satisfactory) every eight to 12 weeks
- if the blood counts are too low two weeks of starting Hydroxycarbamide or a dose change, follow up blood tests will be more frequent until the blood counts are stable
- once the blood count is stable you will have blood tests and be seen every 8 to 12 weeks.

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

What is the dose of hydroxycarbamide?

The consultant will calculate the correct dose according to your child's weight. This 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 and this will be dispensed by the hospital.

Please telephone the hospital to seek 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 inform your hospital nurse or specialist if your child has:

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

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

Your child should not be given any live vaccines while taking hydroxycarbamide.

If they are admitted to hospital for any reason please show this booklet to the doctor, nurse or pharmacist.

Do not stop treatment before the course is finished, unless the doctor tells you to do so. Please return any unused capsules of hydroxycarbamide to the pharmacist. You must not flush unwanted medication down the toilet or throw them away.

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 paracetamol and cold remedies.

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.

What if my child is sick after taking hydroxycarbamide?

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

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.

Fertility

There is not enough evidence currently 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.

[illegible]

[illegible]

Contact details**Clinical Nurse Specialist**

Mobile telephone: 07958 010060

Office telephone: 0116 258 6081

UHL Medicines Information

Monday to Friday 8.30 am to 5.30 pm

Telephone : 0116 258 6491

Sickle Cell Society54 Station Road
London
NW10 4UA

Telephone: 020 8961 7795

Email: info@sicklecellsociety.org

Web: www.sicklecellsociety.org

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Telephone: 111

NHS Choices

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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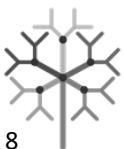
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Aby uzyskać informacje w innym języku, proszę zadzwonić pod podany niżej numer telefonu

Previous reference:

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