

Hydroxycarbamide treatment plan for haemoglobin disorders

Sickle Cell and Thalassaemia Service

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Information for patients who are considering starting treatment

Consultant

Dr A. Webster

Diagnosis

Sickle Cell Disease / Thalassaemia Intermedia

Allergies:

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Name of GP:

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Surgery address:

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Contact number:

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

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

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

Visit www.leicestershospitals.nhs.uk for maps and information about visiting Leicester's Hospitals
To give feedback about this information sheet, contact InformationForPatients@uhl-tr.nhs.uk



How does hydroxycarbamide work?

In **sickle cell disease**, the round red blood cells turn into long rod-like cells called sickle cells. These rod-like red cells are sticky and cannot move easily through small blood vessels. The blood vessels can easily become blocked causing 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. When they are three months old babies who do not have sickle cell disease start to make normal adult haemoglobin. However, babies with sickle start to produce sickle haemoglobin.

Foetal haemoglobin helps the red blood cells to stay round and therefore able to move through the blood vessels. This reduces the blockage which causes sickle cell crises. High foetal haemoglobin protects the red cells from becoming sickle cells.

Hydroxycarbamide increases the amount of foetal haemoglobin in the red blood cells and reduces sickling.

As well as the benefits above, 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 prevent many sickle cell related complications.

It helps by reducing the:

- need for blood transfusions
- severity and number of sickle cell crises
- number of hospital admissions

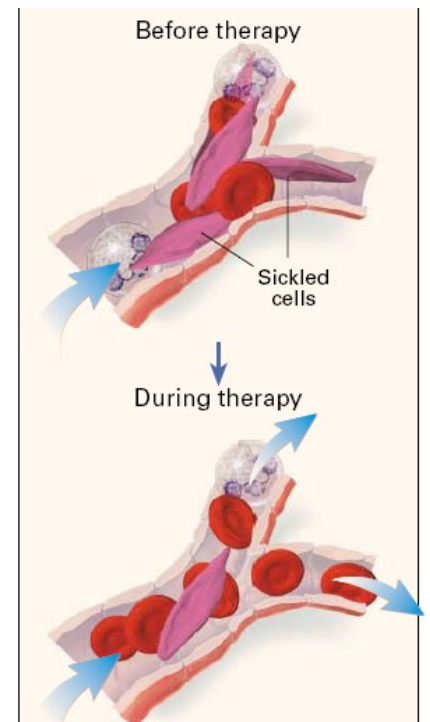
It can also improve quality of life and increase life expectancy.

Thalassaemia Intermedia is a group of inherited conditions which result in anaemia. The severity of the anaemia can vary between people affected. In some individuals hydroxycarbamide will cause a rise in Haemoglobin F (usually found in baby red cells), which will in turn improve the anaemia associated with this condition. If a trial of treatment with hydroxycarbamide is effective, your consultant may recommend continuing the treatment on a long term basis.

Important information

You must telephone the hospital for medical advice if you have 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
- Soreness or ulcers in your mouth
- Skin rash or skin ulcers



Useful information

You should not be given any live vaccines while you are taking hydroxycarbamide.

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

You should always read the instructions that come with your medication carefully. If you have any questions please ask your doctor, nurse or pharmacist. While you are taking hydroxycarbamide, discuss any new medication with your doctor or pharmacist before taking. This includes herbal medicines and over-the-counter remedies, such as paracetamol and cold remedies.

How will I be monitored whilst I am taking hydroxycarbamide?

Hydroxycarbamide affects the red blood cells, white cell and platelets in the blood so you will need regular blood tests and monitoring while you take this medication. You will need blood tests two weeks after starting the drug or after any change of dose. Once your blood results are stable you will need blood tests every eight to twelve weeks. Your dose may be reduced if your blood count falls. It is very important that you have regular blood tests so we can monitor you to identify any changes.

Safe handling instructions

You need to take special precautions when taking hydroxycarbamide:

- Please ensure that your capsules are stored in a safe place, out of the reach of children
- 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 should I do if I am sick after taking my medication?

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

What should I do if I forget to take my medication?

If you forget to take your medication do not take a double dose. Let us know, and keep to your regular dose schedule.

Avoiding pregnancy

It is not advisable to become pregnant, or father a child, while taking hydroxycarbamide as the developing baby may be harmed. You should use an effective form of contraceptive while taking this medication, and for at least three months after stopping the drug.

Fertility

Your ability to become pregnant or father a child may be affected by taking this drug. It is important to discuss fertility with your doctor before starting treatment. For men: hydroxycarbamide does not prevent you from making a woman pregnant or fathering a child. A man's sperm count may be reduced and there is a possibility of abnormal sperm being produced. This will usually return to normal after the medication has been stopped for two to three months.

Contact details

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

Telephone number: 0808 178 2212

Clinical Nurse Specialist

Mobile telephone: 07950 891490

Office telephone: 0116 258 6081

Sickle cell & Thalassaemia Support Officer

Telephone: 0116 258 6081

Lead Nurse Specialist - Haemoglobinopathies

Telephone: 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

Telephone : 0116 258 6491

Monday to Friday, 8.30 am to 5.30 pm

UK Thalassaemia Society

Telephone: 020 8882 0011

Email: info@ukts.org

Website: www.ukts.org

Sickle Cell Society

Telephone: 020 8961 7795

Email: info@sicklecellsociety.org

Web: www.sicklecellsociety.org

Macmillan Information and Support Centre (Leicester Royal Infirmary)

Telephone: 0116 258 6189

Website: www.leicestershospitals.nhs.uk/cancerinfo

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اگر آپ کو یہ معلومات کسی اور زبان میں درکار ہیں، تو براہ کرم مندرجہ ذیل نمبر پر ٹیلی فون کریں۔
على هذه المعلومات بلغة أخرى، الرجاء الاتصال على رقم الهاتف الذي يظهر في الأسفل

જો તમને અન્ય ભાષામાં આ માહિતી જોઈતી હોય, તો નીચે આપેલ નંબર પર કૃપા કરી ટેલિફોન કરો

ਜੇ ਤੁਸੀਂ ਇਹ ਜਾਣਕਾਰੀ ਕਸਿ ਹੋਰ ਭਾਸ਼ਾ ਵਿਚ ਚਾਹੁੰਦੇ ਹੋ, ਤਾਂ ਕਰਿਪਾ ਕਰਕੇ ਹੇਠਾਂ ਦਿੱਤੇ ਗਏ ਨੰਬਰ 'ਤੇ ਟੈਲੀਫੋਨ ਕਰੋ।

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

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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