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# Hydroxycarbamide for Acute Myeloid Leukaemia (AML)

**A Guide for  
Patients**

**Leukaemia Care**  
YOUR Blood Cancer Charity

# Introduction

**Hydroxycarbamide is a licensed medicine, which is standardised for the treatment of patients diagnosed with acute myeloid leukaemia (AML) as well as sickle-cell disease, cancer of the cervix and chronic myeloid leukaemia (CML).**

This patient information booklet is for patients, a family member or a friend of the patient and a carer who like to know more about these drugs. So, we will try and answer some questions like What is Hydroxycarbamide? Who receives it? How is it administered? What are the side effects of Hydroxycarbamide? and What alternative a patient has if Hydroxycarbamide does not work?

Booklet compiled by one of our medical writers Saloua Najjam, PhD. and peer reviewed by one of our medical professionals who is specialised in leukaemia therapy, Nurse Advisor Fiona Heath. We are also grateful to the contribution of our patient reviewer, Stuart Johnson.

If you would like any information on the sources used for this booklet, please email [communications@leukaemiacare.org.uk](mailto:communications@leukaemiacare.org.uk) for a list of references.

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# About Leukaemia Care

**Leukaemia Care is a national charity dedicated to ensuring that people affected by blood cancer have access to the right information, advice and support.**

## Our services

### Helpline

Our helpline is available 9.00am - 10.00pm on weekdays and 9.00am - 12.30pm on Saturdays. If you need someone to talk to, call **08088 010 444**

### Nurse service

We have two trained nurses on hand to answer your questions and offer advice and support, whether it be through emailing **nurse@leukaemicare.org.uk**, over the phone on **08088 010 444** or via LiveChat.

### Patient Information Booklets

We have a number of patient information booklets like this available to anyone who has been affected by a blood cancer. A full list of titles – both disease specific and general information titles – can be found on our

website at **www.leukaemicare.org.uk/resources/filter-by-resource-type/information-booklets**

### Support Groups

Our nationwide support groups are a chance to meet and talk to other people who are going through a similar experience. For more information about a support group local to your area, go to **www.leukaemicare.org.uk/our-support-groups**

### Buddy Support

We offer one-to-one phone support with volunteers who have had blood cancer themselves or been affected by it in some way. You can speak to someone who knows what you are going through. For more information on how to get a buddy call **08088 010 444** or email **care@leukaemicare.org.uk**

## Online Forum

Our online forum, [www.healthunlocked.com/leukaemia-care](http://www.healthunlocked.com/leukaemia-care), is a place for people to ask questions anonymously or to join in the discussion with other people in a similar situation.

## Patient and carer conferences

Our nationwide conferences provide an opportunity to ask questions and listen to patient speakers and medical professionals who can provide valuable information and support.

## Website

You can access up-to-date information on our website, [www.leukaemicare.org.uk](http://www.leukaemicare.org.uk), as well as speak to one of our care advisers on our online support service, LiveChat (9am-5pm weekdays).

## Campaigning and Advocacy

Leukaemia Care is involved in campaigning for patient well-being, NHS funding and drug and treatment availability. If you would like an update on any of the work we are currently doing or want to know how to get involved, email [advocacy@leukaemicare.org.uk](mailto:advocacy@leukaemicare.org.uk)

## Patient magazine

Our free quarterly magazine includes inspirational patient and carer stories as well as informative articles by medical professionals. To subscribe go to [www.leukaemicare.org.uk/resources/subscribe-to-journey-magazine](http://www.leukaemicare.org.uk/resources/subscribe-to-journey-magazine)

# What is Hydroxycarbamide?

**Hydroxycarbamide is supplied in tablet form to be taken orally. You swallow the capsule whole with plenty of water.**

This medicine contains the active substance Hydroxycarbamide and it belongs to two groups of drugs:

- 1.** Group of antineoplastic drugs. Part of this group, Hydroxycarbamide is used to in the treatment of sickle-cell anaemia. Antineoplastic drugs are drugs that inhibit or prevent the growth and spread of tumours or malignant cells.
- 2.** Group of drugs used in hypoplastic (incomplete development), haemolytic (rupture of red blood cells) and renal (kidney) anaemias. Part of this group, Hydroxycarbamide is used in the treatment of sickle-cell anaemia, cancer of cervix and chronic myeloblastic leukaemia.

# Who receives Hydroxycarbamide?

Hydroxycarbamide is mainly indicated for:

- Patients with acute myeloid leukaemia (AML) as a palliative treatment.
- Patients diagnosed with chronic myeloid leukaemia (CML).

Palliative treatment deals with relieving of pain and reducing symptoms rather than dealing with the cause of the condition and curing the disease.

Hydroxycarbamide is also indicated as standard therapy to patients with sickle-cell disease (a hereditary form of anaemia; low number of normal red blood cells) and women with cancer of the cervix.

If you wish to have further information on AML or CML, please view our collection of patient information booklets that are available on our website at [www.leukaemiacare.org.uk](http://www.leukaemiacare.org.uk)

# How is Hydroxycarbamide administered?

You will normally take Hydroxycarbamide as an outpatient. Your nurse or pharmacist will give you tablets to take at home. They are taken orally.

The length of treatment for Hydroxycarbamide is dependent on your diagnosis and dosage.

The aim of treatment is for the white cell count to be lowered by the hydroxycarbamide. Blood tests will be regularly taken to monitor this.

## Dosage

The dose of Hydroxycarbamide is adjusted depending on your white blood count.

Depending on the white blood count and overall wellbeing of the patient, Hydroxycarbamide is recommended at high dose, which may be lowered during consolidation stage depending on how the patient's disease is progressing.

## Kidney function

Your treating doctor may prescribe some supportive medication while you are having Hydroxycarbamide to decrease uric acid level, because the built up of this leads to gout and kidney stones while receiving cancer treatment. Therefore your clinical nurse will be recording your renal kidney function during the treatment.

## AML patients

As an AML patient, you may also have another supportive medication to help clear uric acid from the blood. Uric acid is a chemical waste produced in your body when breaking down food and it is normally cleaned out of the blood by the kidneys. This second supportive medication is given to AML patient depending on their white blood counts.

## Blood tests

Your consultant will determine the frequency of blood test you will be requiring including full blood count. During your treatment with Hydroxycarbamide, the dose of the given drug may be changed at any time depending on haematological toxicity caused by the treatment. By haematological toxicity we mean toxicity of the blood due to the drug that has been taken rather the disease itself.

The given dose of Hydroxycarbamide could be reduced by your treating doctor due to reduction in red blood count (anaemia), in neutrophils (type of white blood cells) blood count (neutropenia) or in platelets (thrombocytopenia).

## GCSF Support

Your doctor may also be giving you some granulocyte-colony stimulating factor (GCSF)

support (also known as colony-stimulating factor 3). GCSF is a glycoprotein important for stimulating the bone marrow to produce granulocytes from myeloid progenitor cells. Granulocytes like neutrophils, eosinophils, basophils and monocytes are white blood cells (leukocytes) with different forms of nucleus.

## Pregnancy and Contraception

Hydroxycarbamide should not be given to women if they are breast feeding and it should be avoided during pregnancy as various studies on animals showed that this drug is teratogenic, meaning it interferes with the normal development of foetus. If you have sex while having chemotherapy, you need to use a condom. This is to protect your partner in case there is any chemotherapy in your semen or vaginal fluid.

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# How is Hydroxycarbamide administered? (cont.)

## Fertility

Your fertility may be affected. If you are worried about this talk to your doctor before starting treatment.

## Treatment length

The length of treatment you will receive will be explained by your healthcare team. It will vary according to disease type and response to treatment.

# What are the side effects of Hydroxycarbamide?

This treatment can have serious or possibly life-threatening side effects. Therefore, it is very important that you report side effects straight away.

Chemotherapy is the most commonly prescribed anti-cancer treatment but while you are having it, you are vulnerable to infections. Symptoms of infection like fever, shivering, discomfort when you pass urine, sweats, sore throat, diarrhoea, cough or breathless should be reported to your doctor or nurse to prevent them becoming life threatening if they are untreated.

Everyone will experience different side effects from this induction chemotherapy. It is important to report side effects to your nurse so that they can be managed and treated effectively. You will have routine blood tests to monitor the effects of the chemotherapy.

## Common side effects

- **Risk of infection** - Hydroxycarbamide reduces the

number of white cells in your blood which makes you more likely to get an infection.

- **Bruising and bleeding** - Hydroxycarbamide can reduce the number of platelets in your blood. Platelets are cells that help your blood to clot. Tell your doctor if you experience any unexplained bruising or bleeding.
- **Anaemia** - Your red blood cells may be reduced. These cells carry oxygen around the body. If your red blood cell count is low you may feel tired and breathless. If you feel like this, contact your doctor, you may need a blood transfusion.
- **Tiredness** - Tiredness is often worse towards the end of your treatment and for some time after it has finished. Try to pace yourself and get as much rest as you need. Regular gentle exercise can help.
- **Diarrhoea** - Make sure you drink at least 2 litres of fluid a day.

Your doctor can prescribe drugs to control diarrhoea.

- **Constipation** - Try to drink at least 2 litres of fluid a day. Try to eat more foods that contain high levels of fibre such as fruit, vegetables and wholemeal bread.
- **Sore mouth** - Your mouth may become sore and you may develop mouth ulcers. Frequent mouth care is very important.
- **Hair loss** - Your hair may thin, but you are unlikely to lose all the hair from your head. It is almost always temporary and your hair will grow back after the treatment ends.
- **Increased Uric acid** - As the hydroxycarbomide breaks down the cancer cells, uric acid is released. Too much uric acid can cause swelling and pains in the joints, which is called gout. You may be given allopurinol tablets to help prevent this. You will have regular blood tests to check the uric acid levels.

## Uncommon

- **Nervous system disorders** - Dizziness.
- **Skin and subcutaneous tissue disorders** - Rash, discoloured nails (melanonychia) and partial or complete hair loss (alopecia).
- **Effects on the lungs** - Hydroxycarbomide can cause changes to the lungs. Always tell your doctor if you develop a cough, fever, wheezing or breathlessness.

# What happens if Hydroxycarbamide doesn't work?

For patients with acute myeloid leukaemia (AML), your consultant may suggest other chemotherapy drugs like:

- Fludarabine (Fludara)
- Cyclophosphamide
- Chlorambucil (Leukeran)
- Bendamustine (Levact)

or some targeted therapies using monoclonal antibodies.

The most commonly used which are on the market are:

- Alemtuzumab (Campath)
- Rituximab (Mabthera)

Overall, following the outcome of your treatment with Hydroxycarbamide, your consultant is the best person to discuss with and to decide on the next step to take.

It is important to note that, with the advent of TKI medications, the use of hydroxycarbamide is rarely used. Instead, patients may go straight on to a TKI (imatinib or other targeted kinase inhibitor).

Leukaemia Care offers nationwide support groups for people affected by a diagnosis of a blood or lymphatic cancer. Visit [www.leukaemiacare.org.uk](http://www.leukaemiacare.org.uk), or call **08088 010 444**, to find out more and to find a group near you.

# Glossary

## Antineoplastic

It is a drug that inhibits or prevents the growth and spread of tumours or malignant cells.

## Chemotherapy

It is a type of cancer treatment that uses one or more drugs with powerful chemical to kill growing cancer cells.

## Acute Myeloid Leukaemia

Acute myeloid leukaemia (AML) is a blood cancer which affects the white blood cells known as myeloid cells.

## Leukaemia

A cancer of the blood with many different subtypes. Some forms are acute (develop quickly) and others are chronic (develop slowly). Leukaemia is an excess number of abnormal cells in the blood, usually white blood cells, which stop the bone marrow working properly.

## Thrombocytopenia

Deficiency of platelets in the blood. White blood cell are the cells the body makes to help fight infections. There are several types of white blood cells. The two most common types are the lymphocytes and neutrophils.

# Useful contacts and further support

There are a number of helpful sources to support you during your diagnosis, treatment and beyond, including:

- Your haematologist and healthcare team
- Your family and friends
- Your psychologist (ask your haematologist or CNS for a referral)
- Reliable online sources, such as Leukaemia Care
- Charitable organisations

There are a number of organisations, including ourselves, who provide expert advice and information.

## Leukaemia Care

We are a charity dedicated to supporting anyone affected by the diagnosis of any blood cancer.

We provide emotional support through a range of support services including a helpline, patient and carer conferences, support group, informative website, one-to-one buddy service and high-quality patient information. We also have a nurse on our help line for any medical queries relating to your diagnosis.

Helpline: **08088 010 444**  
**[www.leukaemiacare.org.uk](http://www.leukaemiacare.org.uk)**  
**[care@leukaemiacare.org.uk](mailto:care@leukaemiacare.org.uk)**

## Bloodwise

Bloodwise is the leading charity into the research of blood cancers. They offer support to patients, their family and friends through patient services.

**020 7504 2200**  
**[www.bloodwise.org.uk](http://www.bloodwise.org.uk)**

## Cancer Research UK

Cancer Research UK is a leading charity dedicated to cancer research.

**0808 800 4040**  
**[www.cancerresearchuk.org](http://www.cancerresearchuk.org)**

## Macmillan

Macmillan provides free practical, medical and financial support for people facing cancer.

**0808 808 0000**  
**[www.macmillan.org.uk](http://www.macmillan.org.uk)**

## Maggie's Centres

Maggie's offers free practical, emotional and social support to people with cancer and their families and friends.

**0300 123 1801**  
**[www.maggiescentres.org](http://www.maggiescentres.org)**

## Citizens Advice Bureau (CAB)

Offers advice on benefits and financial assistance.

**08444 111 444**  
**[www.adviceguide.org.uk](http://www.adviceguide.org.uk)**

Leukaemia Care is a national charity dedicated to providing information, advice and support to anyone affected by a blood cancer.

Around 34,000 new cases of blood cancer are diagnosed in the UK each year. We are here to support you, whether you're a patient, carer or family member.

## Want to talk?

Helpline: **08088 010 444**

(free from landlines and all major mobile networks)

Office Line: **01905 755977**

**[www.leukaemicare.org.uk](http://www.leukaemicare.org.uk)**

**[care@leukaemicare.org.uk](mailto:care@leukaemicare.org.uk)**

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**Leukaemia Care**  
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