Hydroxycarbamide

Hydroxycarbamide can be used to treat some people with myeloproliferative neoplasms (MPNs), chronic myeloid leukaemia (CML) or acute myeloid leukaemia (AML).

Summary

- Hydroxycarbamide is a chemotherapy medicine that blocks an enzyme to help stop cancer cells from growing and dividing.
- It is used to treat some people with myeloproliferative neoplasms (MPNs), chronic myeloid leukaemia (CML) and acute myeloid leukaemia (AML).
- Hydroxycarbamide comes as capsules that you take by mouth. Most people take it every day. But some people only take it on certain days of the week.
- You will have regular blood tests to check how well the treatment is working and how your body is coping with it.
- You may get some side effects while you are taking hydroxycarbamide. Some people have very few side effects, whereas other people experience more serious side effects.
- Some side effects can be serious if not treated promptly. Contact your haematology team straight away if you have:
    - A high temperature (higher than 39°C) with tummy, lung, muscle, liver, skin or heart problems within 6 weeks of taking hydroxycarbamide
    - Swelling of your face, lips, tongue or mouth
    - Itching, skin rashes or peeling of your skin and nails
    - Difficulty breathing
    - Unexplained fever, chills or a sore throat

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About hydroxycarbamide

Hydroxycarbamide is a chemotherapy medicine. It blocks an enzyme that cells need to divide and grow. Blocking this enzyme can help stop cancer cells from growing and dividing.

Leukaemia Care Registered Charity Number 1183890. Scotland Registered Charity Number SC049802
Helpline: 08088 010 444

The brand name for hydroxycarbamide is Hydrea. It used to be known as hydroxyurea.

Hydroxycarbamide is used to treat some adults with myeloproliferative neoplasms (MPNs), chronic myeloid leukaemia (CML) or acute myeloid leukaemia (AML). It is also used to treat some other types of cancer and sickle cell anaemia, but we do not cover these on this webpage.

Hydroxycarbamide can be used for either short-term use or long-term use. Sometimes, your doctor might suggest hydroxycarbamide in other circumstances. Your doctor will explain what they recommend for you and why.

Short term use

Your haematology team might recommend a short course of hydroxycarbamide if you have a high white blood cell count that needs to be lowered before you start your main treatment. This might happen if you have AML or CML.

Long term use

Your haematology team might recommend hydroxycarbamide to keep your blood counts under control in the long-term. They might suggest it:

- To reduce your risk of getting blood clots if you have polycythaemia vera (PV) or essential thrombocythaemia (ET)
- To improve your blood counts if you have myelofibrosis (MF)
- To control your white blood cell count if you have AML and intensive treatment is not suitable for you

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Before taking hydroxycarbamide

Before you start treatment, your haematology team will carry out the following tests:

- Blood tests to measure your blood counts
- Blood tests to check your liver and kidney function
- Bone marrow tests

Things to tell your haematology team

Before starting treatment, you should let your haematology team know if you:

- Have any problems with your liver or kidneys
- Are or think you may be pregnant
- Are breastfeeding
- Have ever had gout
- Have leg ulcers
- Have previously had chemotherapy or radiotherapy
- Have folic acid deficiency
- Have recently had or are due to have a vaccine

> **Studies in animals found that hydroxycarbamide may affect sperm. Scientists do not know if this is the same for humans. If you were born male and you may want to have children in the future, ask your haematology team for advice on sperm storage before starting treatment.**

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Taking hydroxycarbamide

Hydroxycarbamide comes as capsules containing 500mg of hydroxycarbamide. Most people take it every day. But some people only take it on certain days of the week.

Your doctor or nurse will tell you what they recommend for you. Your dose should also be printed on the named label on the medicine packaging. If you are not sure, ask your doctor or nurse.

- You should take hydroxycarbamide as prescribed so it can work as well as possible. You can take the capsules at any time of day.
- You can take the capsules before or after food, whichever is best for you.
- Swallow the capsule whole with a full glass of water. To make sure you get the right dose, do not break, crush, dissolve or chew the capsule.

- If you struggle to swallow the capsules, you can empty the contents of the capsules into a glass of water and drink straight away. Some of the powder may sit on the top of the water, this is just filler from the capsule, and nothing to worry about.
- Do not breathe in the powder from the capsules.
- If powder from a broken capsule touches your skin, wash it straight away and thoroughly with soap and water.
- If you forget to take your hydroxycarbamide capsule, do not take a double dose to make up for a forgotten capsule. Just take your next dose at the usual day and time.
- If you take too many hydroxycarbamide capsules, tell your haematology team immediately. Signs of overdose include soreness, swelling of your hands and feet and redness of your skin (this may look different on black or brown skin).
- Make sure to drink plenty when you are taking these capsules, as it can help make sure your kidneys stay working well.

Dose

Your haematology team will work out the best dose of hydroxycarbamide for you based on your weight and your blood condition. They will tell you what dose they recommend for you.

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Precautions

There are several precautions to be aware of when you are taking hydroxycarbamide.

- Hydroxycarbamide can increase your uric acid levels, which may lead to gout.
    - Contact your team if get any symptoms of gout. These include sudden joint pain, and hot, swollen red skin around the affected joint (this may look different on black or brown skin).
    - Staying well hydrated by drinking plenty of water can help prevent gout.
- Do not have live vaccines while you are taking hydroxycarbamide. If you are due to have any vaccines, tell your haematology team. It is safe to have non-live vaccines.

- Tell your haematology team if you use a continuous glucose monitor (a type of blood sugar monitor). This is because hydroxycarbamide can affect the readings.
- Hydroxycarbamide can cause drowsiness. Take care if you are driving or using tools or machinery.
- Hydroxycarbamide capsules contain lactose. If you think you may have lactose intolerance, let your haematology team know.
- Some medicines or drugs may interact with hydroxycarbamide. It is important to tell your haematology team about any medicines or supplements you are taking. This includes prescribed medicines and medicines you have bought yourself without a prescription. Examples include:
    - Medicines for cancer treatment
    - Anti-retroviral medicines (used to treat HIV)
    - Medicines that can affect your bone marrow and new blood cell production

If you take hydroxycarbamide in the very long term, it might increase your chance of getting a different leukaemia or skin cancer.

- Your haematology team will monitor your blood counts to check for any signs of leukaemia. If you have any worrying symptoms, tell them. These include fatigue, unexpected bruising or bleeding and frequent or long-lasting infections.
- It is important to protect your skin from the sun to reduce your risk of skin cancer. You can do this by keeping your skin covered, wearing a wide-brimmed hat, and using a high-factor suncream (SPF 30 or higher). Check your skin for symptoms like a growth, an unusual patch (this can vary in size, colour and texture), a new mole or a change in an existing mole. If you notice any, contact your GP.

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Pregnancy, breastfeeding and fertility

Hydroxycarbamide may harm unborn babies.

- If you could get pregnant, it is important to use effective contraception. You need to do this while you are taking hydroxycarbamide and for 6 months after you stop.
- If you could make someone pregnant, it is important to use effective contraception. You need to use effective contraception while you are taking hydroxycarbamide and for 1 year after you stop.
- If you think you might be pregnant, tell your haematology team as soon as possible. They may recommend stopping hydroxycarbamide for a while. They could also recommend switching to a different treatment.
- If you are planning to get pregnant, or make someone pregnant, tell your haematology team. They can discuss your treatment options with you.

Breastfeeding

Hydroxycarbamide passes into breast milk. This could be a risk for breastfed babies or children. You should not breastfeed when taking hydroxycarbamide.

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Monitoring

During your treatment with hydroxycarbamide, you will have regular blood tests.

Your haematology team will use the results of these tests to:

- Check how well hydroxycarbamide is working for you
- Make sure your blood counts have not dropped too low
- Check how well your kidneys are working
- Check the level of uric acid in your blood

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How long to take hydroxycarbamide

If you are taking hydroxycarbamide short-term, you usually carry on taking it until your white blood cell count is low enough to start your main treatment.

If you are taking hydroxycarbamide long-term, you usually carry on taking it unless:

- It has not worked well enough
- It stops working well
- You are having side effects that are difficult to cope with

If this happens, your haematology team might stop hydroxycarbamide, adjust your dose or recommend a different treatment.

> **Do not stop taking hydroxycarbamide without talking to your haematology team.**

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Side effects

You may get some side effects while you are taking hydroxycarbamide. Some people have very few side effects, whereas other people experience more serious side effects.

Tell your haematology team if you get any side effects. They may be able to suggest things to help.

If you are getting side effects that are difficult to cope with, your haematology team might suggest:

- Lowering your dose of hydroxycarbamide
- Changing how often you have hydroxycarbamide
- Stopping hydroxycarbamide treatment

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Serious side effects

> **The following side effects may be serious and require urgent treatment. Contact your doctor or nurse straight away if you have any of these side effects.**

The most common serious side effects for people having hydroxycarbamide:

- A high temperature (higher than 39°C) with tummy, lung, muscle, liver, skin or heart problems within 6 weeks of taking hydroxycarbamide.
- An allergic reaction. You may get symptoms like:
    - Swelling of your face, lips, tongue or mouth
    - Itching, skin rashes or peeling of your skin and nails
    - Difficulty breathing
    - Unexplained fever, chills or sore throat

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Very common side effects

Very common side effects affect more than 10 in every 100 people who are taking hydroxycarbamide.

Very common side effects include:

- Frequent or long-lasting infections due to a low white blood cell count
- Unexpected bruising or bleeding, like nosebleeds, bleeding gums, blood spots or rashes, due to a low platelet count
- Feeling tired, dizzy or short of breath, due to a low red blood cell count (anaemia)
- Loss of appetite
- Feeling sick or being sick
- Diarrhoea or constipation
- Sore, painful or inflamed mouth or lips, mouth ulcers
- Indigestion, tummy pain or discomfort
- Blood in your poo or black, tarry poo
- Sore, itchy or peeling skin, rashes, bumps or changes in your skin colour (this may look different on black or brown skin)
- Muscle weakness
- Hair loss
- Changes to the way your fingernails and toenails look
- Pain or discomfort when peeing
- A high uric acid level, which can lead to gout or kidney stones
- Changes in how well your kidneys work (found on a blood test)
- Fever or chills

- Weakness, lack of energy or feeling generally unwell

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Common side effects

Common side effects affect more than 1 but less than 10 out of every 100 people who are taking hydroxycarbamide.

Common side effects include:

- Skin cancer
- Seeing, hearing or feeling things that are not there
- Dizziness, disorientation, feeling confused
- Fits (seizures)
- Pain, burning, numbness or tingling in your feet and hands due to nerve damage
- Feeling very tired or sleepy
- Headache
- Shortness of breath, difficulty breathing, cough, chest pain
- Liver or gallbladder problems which can cause tummy pain, loss of appetite, a rash, fever, feeling or being sick, dark-coloured pee, light-coloured poo, itching, and yellowing of your skin and the whites of your eyes (this may look different on black or brown skin)

> **If you are worried about any side effects or symptoms you have, contact your haematology team.**

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If hydroxycarbamide does not work

If hydroxycarbamide is not working well, your haematology team might suggest altering your dose, how often you have treatment, or stopping treatment if your blood counts drop.

If this is not suitable for you, or does not work, they will talk to you about your treatment options. These options vary depending on the type of leukaemia or MPN you have and whether you are taking hydroxycarbamide in the short-term or long-term.

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Sources we used to develop this information

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Need support?

You are not alone. We're here for you whether you have a diagnosis yourself or know someone who has. If you'd like advice, support, or a listening ear, call our freephone helpline on 08088 010 444 or send a WhatsApp message to 07500 068 065.

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