



HYDROXYCARBAMIDE (HYDROXYUREA)

WHAT IS HYDROXYCARBAMIDE?

Hydroxycarbamide is a medication used to treat myeloproliferative neoplasms (MPNs). It is one of the first line cytoreductive treatments prescribed to treat MPNs worldwide. The drug is known by several names. **It goes under the brand name Hydrea® in Australia.** It is also called hydroxyurea. It is used to treat all three main types of MPNs: polycythaemia vera (PV), essential thrombocythaemia (ET) and sometimes myelofibrosis (MF). It is available in 500mg (0.5g) oral capsules.

HOW DOES HYDROXYCARBAMIDE WORK IN MPNS?

Blood cells originate from stem cells which are master cells that divide and mature into different types of blood cells: red blood cells, white blood cells and platelets. Our bone marrow acts as a factory for division and maturation of these stem cells into blood cells. Each new blood cell contains DNA that carries instructions the cell needs to grow and function. Once matured, blood cells leave the bone marrow and enter our blood stream.

Hydroxycarbamide works by interfering with the production of DNA (the instructions) inside the blood cells. This prevents the cells from continuing to grow and mature, leading to the death of the blood cell which is then removed by the body. Hydroxycarbamide is classed as a chemotherapy drug because it causes the death of some cells in the body.

Hydroxycarbamide reduces the number of blood cells in patients with MPNs and hence reduces the risk of thrombotic (clotting) and haemorrhagic (bleeding) complications. Treatment may also help to prevent scarring or fibrosis of bone marrow in some but not all cases.

If you have polycythaemia vera (PV) or essential thrombocythaemia (ET)

Hydroxycarbamide can control your blood counts, and this can reduce the risk of both blood clots and bleeding. Evidence suggests that hydroxycarbamide reduces the long-term risk of bone marrow scarring or myelofibrosis. When you take this drug you may notice a reduction in MPN-related symptoms such as headache, visual problems, fatigue, tingling in fingers or toes, night sweats, breathlessness, bleeding, gout and itching.

If you have myelofibrosis (MF)

Hydroxycarbamide can reduce the size of your spleen if it is enlarged. It also reduces the likelihood that you will experience a blood clot. Reducing spleen size can diminish any pain, discomfort, nausea and eating problems that you may have experienced with an enlarged spleen. You may also notice a reduction in other symptoms of MF such as night sweats, fevers and fatigue.

ARE THERE ANY SIDE EFFECTS?

Most people tolerate this drug well and have few side effects. However, it is important you inform your doctor or nurse if you experience any side effects listed below or develop any new symptoms, even if mild.

Common side effects - affect approximately 1-10% of patients taking hydroxycarbamide

- **Reduced red blood cells:** If your red blood cells drop too low (anaemia) you may notice that you are becoming breathless and tire easily.
- **Reduced platelets:** If your platelet count drops too low you may experience nose bleeds, bleeding gums when you clean your teeth, a rash of tiny red spots or increased bruising.
- **Reduced white blood cells:** If your white blood cells drop too low you may have an increased risk of developing infections. You may experience a high temperature, fever, shivers or chills.

If you experience any of the above side effects, you must contact your haematologist immediately. Although uncommon, sudden unexpected changes in blood cell levels may occur. It is important to attend appointments to have blood counts checked and discuss symptoms with your haematologist.

Other common side effects

- Fatigue can be brought on by hydroxycarbamide but is also a known symptom of MPNs
- Diarrhoea or constipation
- Gout (pain and inflammation in the joints), most commonly in the toes



- Non melanoma skin cancers

Less common side effects - affect approximately 0.1-1% of patients taking hydroxycarbamide

- Nausea, vomiting, anorexia, inflammation of the lining of the mouth
- Skin ulcers, itching, skin inflammation
- Changes in kidney function
- Headache, dizziness, disorientation, hallucinations and convulsions
- Fever, chills, malaise
- Skin rash, facial redness, redness of fingers, arms, legs or ears
- Abnormal liver tests

Rare side effects - affect approximately 0.01–0.1% of patients taking hydroxycarbamide

- Hypersensitive or allergic reactions
- Hair loss/thinning
- Lung reactions consisting of abnormal substances in the lungs, fever and breathlessness and inflammation of the air sacs in the lungs
- Difficulty or pain when passing urine

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

- Skin discolouration

The above list is not fully comprehensive and some other side effects can occur. Please consult the product information sheet (available from your pharmacist) if you think you are experiencing any side effects. It is also important that patients inform their doctor if they experience any side effects.

Hydroxycarbamide and cancer

Patients taking hydroxycarbamide may face an increased risk of non-melanoma skin cancer and your skin may be more sensitive to the sun. It is recommended you protect your skin by avoiding sun exposure, using SPF 30+ sunscreen and wearing protective clothing and a hat.

Current evidence suggests that hydroxycarbamide does not increase the risk of transformation of MPNs to leukaemia above any underlying MPN-related risk.

TAKING HYDROXYCARBAMIDE

How to take hydroxycarbamide

- Take either before or after food, in the morning or evening.
- Wash your hands thoroughly before and after taking the capsules.
- Swallow whole with plenty of water.
- If you have difficulty swallowing a capsule, open it carefully, empty the contents into a glass of water and drink all of it immediately.
- Avoid breathing in or touching the contents of the capsules.
- Wipe up any spillage immediately using kitchen roll, then throw the paper away.

Dosage

Your haematologist will give dosage instructions. They may recommend that you take the medication every day, on alternate days or that you vary the amount by day. Please follow the directions precisely.

Non-compliance - It is important that you follow the directions precisely. Failure to do so could result in disease related complications and may increase your risk of vascular and thrombotic complications.

Keeping track

It may be helpful to keep a record or diary to remember when to take your tablets and to record any side effects.



INTERACTIONS WITH OTHER MEDICATIONS OR VITAMINS, HERBAL SUPPLEMENTS OR REMEDIES

Whenever you take hydroxycarbamide (or in fact any medication), always provide the names of other medicines prescribed for you as well as any over-the-counter medications (e.g vitamins, herbal supplements or remedies) to the health care team who are treating you. It can be very helpful to carry a list of the names and dosages of all your medicines to show to your haematologist at appointments.

Some medicines may interact with hydroxycarbamide. These include:

- Clozapine (Clozaril, Denzapine, Zaponex)
- Chemotherapy drugs
- Medicines that are damaging to the bone marrow
- Medicines used to treat HIV
- COVID antivirals

Please note that the above list is not fully comprehensive, and some other medicines may interact or need to be used with caution when taken with hydroxycarbamide. It is important that patients inform their haematologist if they are taking other medications. [The MPN AA has a wallet card which provides for medications to be listed.](#)

Storage and disposal of hydroxycarbamide

- Store in a dry place at room temperature
- Hydroxycarbamide can be dangerous to others. Keep your capsules in a secure location, well out of the reach of children and pets
- Return any unused medication to your local pharmacy or hospital.
- Do not dispose of them in the bin or flush them down the toilet.

WHAT SHOULD I EXPECT?

How fast does it work and how will I feel?

Hydroxycarbamide may take several weeks to begin having an effect on your blood cells. You will probably not feel any benefits until your counts are under control. As your blood counts reduce you may notice a reduction in your MPN-related symptoms. Most people taking this drug tolerate it well and have relatively few side effects.

Will I need follow up?

You will need more frequent blood tests during the first weeks of treatment to determine how your blood count is responding to the medication. Once your blood count has normalised you will need checks less frequently, perhaps every two to three months. Your kidney and liver function may also be verified with blood tests.

WHAT IF I HAVE OTHER MEDICAL CONDITIONS?

Hydroxycarbamide should be used under supervision if you have/have had any of the following:

- Allergies to any ingredients in the drug (listed on the information leaflet that came with your tablets)
- HIV infection or AIDS
- Kidney problems
- Gout
- Previous leg ulcers
- If you are planning pregnancy
- If you have radiation therapy planned

If you think you may have or have had one of these conditions please discuss this with your haematologist.

FREQUENTLY ASKED QUESTIONS

Can I eat and drink normally?

Yes. We recommend that you eat a normal, healthy diet and drink plenty of water.

Can I drink alcohol?

While it is safe to drink alcohol in moderation whilst taking hydroxycarbamide, Australian NHMRC guidelines state that for healthy women and men drinking no more than two standard drinks on any day reduces your risk of harm from alcohol-related disease. Alcohol can cause dehydration, and it is important to avoid becoming



dehydrated if you have an MPN. Please ask your nurse or doctor if you require more information regarding alcohol consumption.

What if I want to have a child?

- It is strongly recommended that you use contraception whilst taking hydroxycarbamide, because this medication can be harmful to a developing foetus.
- When planning to conceive or father a child, you should stop taking hydroxycarbamide for at least three months to allow the drug to clear from your system before trying to conceive.
- It is imperative to discuss your plans together with your haematologist prior to becoming pregnant or fathering a child. Your haematologist can recommend treatment options for you that will not cause harm to your developing foetus and will increase your chance of a successful pregnancy.
- If you or your partner becomes pregnant while taking this drug please contact your haematologist immediately for further advice.

Can I breastfeed while taking hydroxycarbamide?

It is recommended against breastfeeding whilst taking hydroxycarbamide. Hydroxycarbamide is a very strong drug that inhibits blood cell development & can be secreted in breastmilk which can affect your developing baby.

Can I drive?

Hydroxycarbamide does not usually cause drowsiness that impacts upon your ability to drive, however if you are feeling drowsy or fatigued for any reason do not drive.

Do I need to take any special precautions?

As mentioned earlier, your skin may be more sun-sensitive whilst you are taking hydroxycarbamide. It is recommended that you protect your skin by limiting sun exposure, using SPF 30+ sunscreen and wearing protective clothing and a hat.

Can I have vaccinations such as the flu and COVID-19 jabs while taking hydroxycarbamide?

Yes, you can have most vaccinations including the flu and COVID-19 vaccines whilst taking hydroxycarbamide. Some vaccinations are live vaccines and these should not be taken with hydroxycarbamide. It is important you tell the person giving you the vaccine that you are taking hydroxycarbamide so they can verify it is safe for you to be vaccinated.

COVID-19 - Can I take antivirals while on hydroxycarbamide?

If you test positive for COVID-19, you may be eligible for antiviral treatments. The antiviral most suitable for you will depend on what other medications you are taking and your kidney function. Treatment must be commenced within 5 days of symptom onset, or as soon as possible if you have no symptoms but test positive. Please contact your GP or haematologist to arrange antiviral therapy immediately if required.

WHAT TO DO IF...

You have taken too much medicine/someone else has taken your medicine

If you have taken extra tablets or if another person has taken your medication please contact your haematologist as soon as possible.

You were sick shortly after taking your tablets

If this happens just once, take your next dose as usual. If you are sick over a number of days contact your haematologist.

You forget to take a dose

If you have forgotten to take a dose, do not take any extra but take your next dose as normal. If you have forgotten to take a few doses, start taking them again and contact your haematologist.

You need to have a medical procedure or operation

You may occasionally be required to adjust the dose of hydroxycarbamide if you need an operation. It is important that you inform the doctor or dentist planning the procedure or operation that you are taking hydroxycarbamide and that they co-ordinate your treatment with your haematologist. We always recommend that you inform your haematologist if you have any procedures or operations planned.



You feel anxious about taking hydroxycarbamide?

If you have concerns, please discuss this with your haematologist or GP.

WHAT IF I DO NOT WANT TO TAKE THIS MEDICATION?

Whether or not to take hydroxycarbamide is entirely your decision. If you feel uncertain or prefer not to take this medication, you can choose not to take it, but it is essential that you discuss this decision with your haematologist. If you decide not to take hydroxycarbamide or if you elect to stop after you begin treatment, it is important to inform your haematologist of your decision. He or she can recommend alternatives or other suggestions if necessary to safeguard your health.

WHAT CAN I DO TO HELP MYSELF?

If you have an MPN it's important to take good care of yourself. Many things help you feel better.

- **Don't neglect your general health, particularly your cardiovascular health including stopping smoking and managing your cholesterol.** It is a good idea to have regular physical checkups, including skin checks, eye health examinations and screening tests for mammograms, cervical cancer and prostate cancer.
- **Be blood clot aware.** Having an MPN puts patients at higher risk of having a blood clot. It's good to know the signs and how to prevent blood clots. See STOP THE CLOT website at: https://www.stopthecLOT.org/learn_more/signs-and-symptoms-of-blood-clots/
- **Have regular skin cancer check ups for both melanoma and non melanoma skin cancers,** especially if you are also on treatment regimes such as hydroxycarbamide (hydroxyurea) or ruxolitinib.
- **Good nutrition is important.** Eat a balanced diet including lots of fresh fruit and vegetables, lean protein and whole grains. Drink plenty of water and be careful to prevent dehydration by avoiding excessive alcohol and caffeinated drinks.
- **Maintain a normal weight and maintain your muscle mass** to help keep your cholesterol and blood sugar within normal limits.
- **Exercise is very beneficial** for MPN patients and helps fight fatigue. Be sure to check with your GP and haematologist before launching on any new programme and start slowly and gently if you have not exercised before.
- **Stop smoking.** Ask your GP if you need help.
- **Consider wellness activities** such as yoga, aerobic activity, strength training, meditation, massages, support groups, improved nutrition etc – an international study of hundreds of MPN patients showed wellness activities had a pattern of decreased levels of symptom burden, fatigue, depression, and a higher quality of life for MPN patients. (Survey of integrative medicine in myeloproliferative neoplasms – the SIMM study).

More information on living well with an MPN is available at www.mpnallianceaustralia.org.au

MAKING THE ADJUSTMENT

It can be disconcerting to start a new medication or find you must increase your dosage. You may feel that your MPN is getting worse or that you are at greater risk of serious medical problems. You may also feel concerned about the long and short term risks of taking this medication. It is normal to feel this way and many people with MPNs have had similar experiences. It's worth bearing in mind that many people with MPNs have a long life expectancy, and that the treatments are very effective at controlling blood cell production.

You may want to seek support via one of the sources listed on the MPNAA website under the Australian support section.

GENERAL ADVICE

This leaflet is intended to give you general information about taking hydroxycarbamide, or as a reference for people already taking this medication. It is important that in addition to this leaflet you read the product information available from your pharmacist about hydroxycarbamide and discuss any concerns with your general practitioner or haematologist.