



## HYDROXYCARBAMIDE (HYDROXYUREA)

### WHAT IS HYDROXYCARBAMIDE?

Hydroxycarbamide is a medication used to treat myeloproliferative neoplasms (MPNs). It is currently the drug most frequently 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 myelofibrosis (MF). It comes as a capsule, taken by mouth. Hydroxycarbamide is available in Australia in 500mg (0.5 g) pink and aqua 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.

When you take hydroxycarbamide the number of blood cells decreases so your bloodstream will be less crowded, your blood will flow more freely, and you will be less likely to suffer a blood clot or thrombosis. Treatment may also help to prevent scarring or fibrosis of bone marrow in some but not all cases.

#### If you have polycythaemia vera (PV)

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 PV-related symptoms such as headache, visual problems, fatigue, tingling in fingers or toes, night sweats, breathlessness, bleeding, gout and itching.

#### If you have essential thrombocythaemia (ET)

Two studies suggest that using hydroxycarbamide to reduce and control platelet counts reduces risks of blood clotting, bleeding and developing myelofibrosis. When you take this drug you may notice a reduction in your ET-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.

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If you experience any of the side effects listed on the previous page you must contact your hospital 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

**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

## Hydroxycarbamide and cancer

Although very rare, there is a possibility that hydroxycarbamide may increase the risk of skin cancer. There is also a possibility that hydroxycarbamide may increase the tendency of MPNs to change to a form of leukaemia. This is very uncommon and it has not been proven that this is a result of treatment with hydroxycarbamide.

## 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 doctor 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.

### 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.

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## 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 body is responding to the medication. Once your body has adjusted you will need checks less frequently, perhaps every two to three months. Your kidney and liver function may also be verified with blood tests.

## CAN I TAKE OTHER MEDICINES?

Whenever you take hydroxycarbamide (or in fact any medication), it is important to inform your medical advisors about all other medications you are taking: this includes medicines prescribed for you as well as any vitamins, herbal supplements or remedies bought in chemists. Always provide names of these medications and remedies to hospital doctors, GPs, nurses and pharmacists treating you, prescribing additional medications or giving you advice. It can be useful to carry a list of names and dosages of all your medicines to show your doctor at appointments.

Some medicines may interact with hydroxycarbamide. These include:

- Clozapine (Clozaril, Denzapine, Zaponex)
- Didanosine (Videx)
- Stavudine (Zerit)
- Chemotherapy drugs
- Medicines that are damaging to the bone marrow
- Medicines used to treat HIV

## 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 doctor.

## 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?**

- We strongly recommend 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 doctor 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 doctor immediately for further advice.

### **Can I breastfeed while taking hydroxycarbamide?**

We recommend against breastfeeding your child whilst taking hydroxycarbamide. Hydroxycarbamide is a very strong drug that inhibits blood cell development. It can be secreted in breast milk 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?**

Your skin may be more sensitive to sun whilst you are taking hydroxycarbamide. You may need to protect your skin by avoiding sun exposure, using sunscreen and wearing protective clothing and a hat.

### **Can I have vaccinations such as the flu jab while taking hydroxycarbamide?**

Yes, you can have most vaccinations including the flu vaccine 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.

## **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 doctor 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 doctor.

### **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 doctor.

### **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 doctor.

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## 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.

### Keep your doctor in the loop

If you decide not to take hydroxycarbamide or if you elect to stop after you begin treatment, it is important to inform your doctor of your decision. He or she can recommend alternatives or other suggestions if necessary to safeguard your health.

### Is there an alternative?

Other treatment alternatives are available and you can discuss options with your haematologist.

## 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.

- 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.

More information on living well with an MPN is available at [www.mpnallianceaustralia.org.au](http://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 cell production.

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

