

Your guide to

Hydroxycarbamide

Information and advice



MPN  **voice**



Supporting patients and families affected by MPN

Established by a group of MPN patients over 17 years ago, MPN Voice, registered under the auspices of Guy's & St Thomas' Foundation, has a website with a lively online community and up to date information on essential thrombocythaemia (ET), polycythaemia vera (PV), and myelofibrosis (MF).

Backed by leading healthcare professionals, MPN Voice also publishes a newsletter, MPN disease leaflets and drug leaflets, runs regular regional patient forums, funds MPN research and offers a buddy scheme.

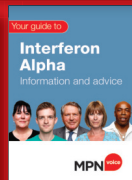
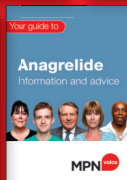
For more information visit the website **www.mpnvoice.org.uk**

Email **info@mpnvoice.org.uk**

MPN Voice previously known as MPD Voice



Name: _____
I have the following MPD: _____
Medication: _____
Hospital contact number is: _____



What is this leaflet about?

This leaflet is for people with myeloproliferative neoplasms (MPNs), also known as myeloproliferative disorders, (MPDs).

It offers information about the medicine hydroxycarbamide.

In this leaflet you will learn:

- How hydroxycarbamide works
- The benefits and drawbacks of taking hydroxycarbamide
- How to take and store hydroxycarbamide
- Answers to frequently asked questions
- How to feel your best while taking hydroxycarbamide

This leaflet provides information that can aid your decision about taking hydroxycarbamide, and is a reference for people who have been prescribed this medication. It is important that in addition to reading this leaflet you also read the information provided with your medicine.

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® and was formerly called “hydroxyurea”. Hydroxycarbamide is used to treat all three main types of MPNs: polycythaemia vera (PV), essential thrombocythaemia (ET) and myelofibrosis (MF). If you need more information about the three types of MPNs you can learn more on our website at www.mpnvoice.org.uk

Hydroxycarbamide comes as a capsule and is taken by mouth. Occasionally it may be supplied as a liquid. Hydroxycarbamide is currently available in 500 mg (0.5g) white, pink or green capsules. The colour of the capsules varies according to the drug company manufacturing it.

How does hydroxycarbamide work?

Blood cells originate from stem cells. Stem cells are master cells which divide and mature into the different types of blood cells: red blood cells, white blood cells and platelets. The marrow in our bones acts as a factory for the division and maturation of these stem cells into blood cells. Each new blood cell contains DNA which carries all the instructions the cell needs to grow and function. Once the blood cells have matured they 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.

When you take hydroxycarbamide the number of blood cells decreases so that 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. The treatment may also help to prevent scarring or fibrosis of your bone marrow in some but not all cases.

Hydroxycarbamide is classed as a chemotherapy drug because it causes the death of some cells in the body. For this reason you may be asked to sign a consent to treatment form before taking this drug for the first time.

If you have polycythaemia vera (PV)

Hydroxycarbamide can control your blood counts, and this can reduce the risk of both blood clots and bleeding. There is evidence to suggest that hydroxycarbamide reduces the long-term risk of bone marrow scarring or myelofibrosis (MF).

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 (MF).

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 the size of your spleen 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 drawbacks?

As with all medications you may experience side effects whilst taking hydroxycarbamide. These are listed in the side effects section below.

You will need frequent blood tests and monitoring whilst taking hydroxycarbamide to ensure that the dose is correct for you.

A small number of people develop a resistance to hydroxycarbamide (so that it no longer works) over a period of years, requiring a switch to another treatment.

If you are sexually active during this course of treatment, you need to use a condom. This is to protect your partner in case there is any chemotherapy in semen or vaginal fluids.

Are there any side effects?

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

Common side effects

Approximately one person in 100 up to one person in 10 (1-10%) of people taking hydroxycarbamide will experience some of these common side effects:

- *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 symptoms above you must contact your hospital immediately.

Sudden and unexpected changes in blood cell levels may occur, although this is uncommon. Therefore it is important to attend appointments to have your blood counts checked and to discuss any symptoms with your haematologist.

Other common side effects

- Fatigue or exhaustion 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

Uncommon side effects affecting approximately one person in 100 to one person in 1000 (0.1–1%) include:

- Nausea, vomiting, anorexia, inflammation of the lining of the mouth
- Abdominal discomfort, heartburn
- Muscle weakness
- 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
- Temporary impairment of the kidneys' ability to filter blood
- Difficulty or pain when passing urine

Rare side effects

Rare side effects affecting approximately one person in 1000 to one person in 10,000 (0.01–0.1%) include:

- 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

Very rare side effects

Very rare side effects affecting less than one person in 10,000 (less than 0.01%) include:

- Skin discolouration
- Wasting of skin and nails

Less common side effects

Uncommon side effects affecting approximately one person in 100 to one person in 1000 (0.1–1%) include:

- 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
- Temporary impairment of the kidneys' ability to filter blood

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. Keep a regular check on your skin and if any changes are noticed, report these to your haematology team.

Taking hydroxycarbamide

How to take hydroxycarbamide

- Take either before or after food, in the morning or evening. Ensure that you take it at the same time every day
- You may wish to take it in the evenings if you are experiencing side effects so you sleep through them. You can discuss this with your nurse or doctor
- Wash your hands thoroughly before and after taking the capsules
- If you do not wish to touch the capsule you could push the capsule out of its wrapper into an egg cup
- Swallow whole with plenty of water
- If you have difficulty swallowing a capsule, discuss with your nurse or doctor
- Avoid opening, breathing in or touching the contents of the capsules
- If the capsule does break wipe up any spillage immediately using kitchen roll, then throw the paper away

Dosage

Your doctor, nurse or pharmacist will give dosage instructions. He or she may recommend that you take the medication every day, on alternate days of the week or that you vary the amount by day. Please be sure to follow the directions precisely.

Keeping track

It may be helpful to keep a record to remember when to take your tablets and to record any side effects. You may be given a diary or booklet for this purpose. There are also apps available for mobile phones that can remind you to take your medication.

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?

Hydroxycarbamide may take several weeks to begin having an effect on your cells. You will probably not feel any benefits until your counts are under control.

How will I feel?

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 to the medication you will need checks less frequently, perhaps every two to three months. Your kidney and liver function may also be checked 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 the names of these medications and remedies to the hospital doctors, GPs, nurses and pharmacists who are treating you, prescribing additional medications or giving you advice. It can be very helpful to carry a list of the names and dosages of all your medicines to show to your doctor or nurse 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 now or have had any of the following conditions:

- Allergies to any of the ingredients in the medicine (these will be 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 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, we recommend you do not exceed the recommended weekly limits of 14 units for men and women. 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?

Taking hydroxycarbamide does not mean you cannot have children, however:

- We strongly recommend that you use contraception whilst taking hydroxycarbamide, because this medication can be harmful to a developing foetus

- When planning to conceive or to father a child, you should stop taking hydroxycarbamide for a period of 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.

Who will prescribe hydroxycarbamide for me?

Your doctor, specially-trained nurse, hospital pharmacist or sometimes your GP will prescribe your medication.

Can I drive?

Hydroxycarbamide is not known to cause drowsiness that could affect your driving, 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 and you may find you burn more easily whilst you are taking hydroxycarbamide. You may need to protect your skin by avoiding exposure to the sun, using sunscreen with UV filters 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 nurse or 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.

I need to have a medical procedure or operation

You may occasionally be required to adjust or stop your 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 haematology doctor or nurse. We always recommend that you inform your haematology doctor or nurse if you have any procedures or operations planned.

You feel anxious about taking hydroxycarbamide?

If you have concerns, please discuss this with your doctor or nurse. You can also visit the Treatment decisions section of our website www.mpnvoice.org.uk

What if I do not want to take this medication?

Whether or not to take hydroxycarbamide is entirely your decision. If after talking things over with your haematologist you still feel uncertain or prefer not to take this medication, you can choose not to take it.

Keep your doctor or nurse 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 or nurse of your decision. He or she can recommend alternatives or other suggestions if necessary to safeguard your health.

Is there an alternative?

There are other treatment alternatives available and you can discuss additional options with your haematologist. If you wish to read up about them please visit our website at www.mpnvoice.org.uk and click on "Treatment Decisions".

Consent

Your doctor will generally ask you to sign a consent form when you begin treatment. This confirms that you know why hydroxycarbamide has been recommended for you, and that you understand the risks and benefits of this treatment.

What can I do to help myself?

If you have an MPN it's important to take good care of yourself. There are many things you can do to 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
- Ensure you have your cholesterol and blood pressure checked annually at your GP surgery

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. You may want to discuss your concerns with a family member or friend.

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 can read more about the psychological aspects of MPN treatment on our website at www.mpnvoice.org.uk under "Living with MPNs".

Medical exemptions for treatment

MPN patients in England are entitled to an exemption certificate and should obtain a FP92A form from their GP or haematologist. Further details can be found on our website at www.mpnvoice.org.uk in the living with MPNs, everyday challenges/cost of medication section.

Resources for patients and families

MPN Voice

Registered under the auspices of Guy's & St Thomas' Foundation, MPN Voice provides patients and families affected by MPNs with a comprehensive range of disease and medication publications, regular newsletters, a buddy scheme and runs regional patient forums as well as funding research into MPNs and drugs trials. The website also offers access to an online community of MPN patients as well as the latest news and reports from leading healthcare professionals.

www.mpnvoice.org.uk

Anthony Nolan

Its vision is to save the lives of everyone who needs a bone marrow or stem cell transplant. Established in 1974, the Anthony Nolan Bone Marrow Register was the founding member of Bone Marrows Worldwide in 1988. Today the register has over 600,000 potential donors on it.

Tel: 0303 303 0303

www.anthonynolan.org

British Heart Foundation

Founded over 50 years ago by a group of medical professionals who wanted to fund extra research into the causes, diagnosis, treatment and prevention of heart and circulatory disease. The website offers health advice to prevent heart disease and practical tips for healthy living.

www.bhf.org.uk

Leukaemia Care

Offers a helpline and website which provides support to anyone affected by a blood cancer.

Tel: 08088 010 444

www.leukaemiacare.org.uk

Blood Cancer UK

Formerly known as Leukaemia and Lymphoma Research, the charity is dedicated to finding the causes of blood cancers including leukaemia, lymphoma and myeloma. It does this through dedicated research focused on finding the causes, improving diagnosis and treatments as well as investment in groundbreaking clinical trials for all blood cancer patients.

Tel: 0808 169 5155
www.bloodcancer.org.uk

Medicines.org

A website run in collaboration with the NHS providing up to date, reliable and understandable information about medicines. A great resource for all medicines.

www.medicines.org.uk

Macmillan Cancer Support

Offers a comprehensive website with cancer support and information about MPNs, chemotherapy drugs, side effects and how best to manage side effects.

Tel: 0808 808 0000
www.macmillan.org.uk

Stroke Association

Offering help and advice for people and families affected by stroke. The website offers tips on recognising the signs of a stroke as well as the preventative lifestyle measures everyone should consider if at high risk of a stroke.

Tel: 0303 3033 100
www.stroke.org.uk

Could you help us?

Your support will enable us to help many more MPN patients and their families



If you have an MPN or know someone with this condition **MPN Voice** aims to offer support and advice.

Visit **www.mpnvoice.org.uk** to find out more about our

- Buddy System
- Medical Alert Cards
- Newsletters
- Treatment and drug leaflets
- Regional patient forums
- Online community of MPN patients
- Funding of some of the latest MPN research
- Backing by leading health professionals

www.mpnvoice.org.uk
email info@mpnvoice.org.uk



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Order more information

Our **information booklets** can be downloaded from www.mpnvoice.org.uk
Or you can request copies by completing this form. Booklets are free of charge but any donations will be gratefully received, particularly if you are ordering bulk quantities.

We would love to keep you up to date on how we help MPN patients and their families deal with this rare blood disorder. Please tick the boxes below to state your contact preferences

- ☐ I would prefer NOT to be contacted by post
- ☐ I would prefer NOT to be contacted by telephone
- ☐ I am happy to receive email updates

Quantity	Title of booklet
	Anagrelide
	Aspirin
	Busulfan
	Danazol
	Hydroxycarbamide
	Interferon Alpha
	Ruxolitinib
	Newsletter
	A4 MPN Voice Poster
	Travel and Insurance

Please fill in your details below:

Title
First name
Last name
Organisation
Job title
Address
Postcode
Please indicate your age range (tick applicable box) <input type="checkbox"/> 20-30 <input type="checkbox"/> 31-50 <input type="checkbox"/> 51-64 <input type="checkbox"/> 65+
Email
Phone

Please return completed form to
MPN Voice (leaflets)
c/o Department of Haematology, Guy's and St Thomas' Hospital, London SE1 9RT

About this publication and MPN Voice

This document was written by Yvonne Francis, an NHS MPN specialist nurse, with input from consultant haematologists, specialist nurses, psychologists and volunteers of MPN Voice.

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We welcome your feedback. Please write with your suggestions to our postal address or email us at info@mpnvoice.org.uk

You can also contact the Guy's & St Thomas' Foundation at info@gsttfoundation.org.uk or visit their website for more information at www.gsttfoundation.org.uk



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Visit the MPN Voice website to find out more about our

- Buddy system
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- Newsletters
- Regional patient forums
- Online community of MPN patients
- Funding of some of the latest MPN research

www.mpnvoice.org.uk



Supporting people
and families affected
by MPN