

Your guide to

Anagrelide

Information and advice



MPN  voice



Supporting patients and families affected by MPN

Established by a group of MPN patients over 10 years ago, MPN Voice, registered under the auspices of Guy's and St Thomas' Charity, has a website with a lively online community and up to date information on essential thrombocythaemia (ET), polycythemia 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.

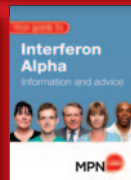
For more information visit the website www.mpnvoice.org.uk

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 gives information about the medicine anagrelide.

In this leaflet you will learn:

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

The leaflet is intended to give you the information required to aid your decision about taking anagrelide, or as a reference for people already taking this medication. It is important that in addition to this leaflet you read the information provided with your medicine.

What is anagrelide?

Anagrelide is a medication used to treat myeloproliferative neoplasms/ disorders (MPN/MPDs).

The drug is known by several names. It also goes under the brand name Xagrid® or Agrylin®. Anagrelide can be used to treat all three main types of MPNs: polycythaemia vera (PV), essential thrombocythaemia (ET) and myelofbrosis (MF). It is most frequently used to treat ET. If you need more information about the three types of MPNs you can learn more on our website at www.mpnvoice.org.uk

Anagrelide is currently available in 0.5mg (500mcg) white capsules. It is taken by mouth.

How does anagrelide work?

Anagrelide acts to reduce the production of platelets in our bodies. Platelets are produced in the bone marrow by stem cells, which are “master” cells. They act in response to stimulus from hormones in our bodies and can develop into any type of blood cell: red cell, white cell or platelet. Stem cells pass through several development stages as they mature into fully functional blood cells. Once mature, they exit the bone marrow and enter the blood stream.

Scientists believe that anagrelide works by reducing the production of new platelets from cells called megakaryocytes, the bone marrow cells responsible for producing platelets. We believe that anagrelide interferes with proteins at the surface of the megakaryocytes cell and this prevents development of new platelets.

When you take anagrelide the number of platelet cells in your body decreases. This in turn allows your blood to flow more freely and you will be less likely to suffer a blood clot or thrombosis.

Anagrelide is not a chemotherapy drug; however, some hospitals classify anagrelide as a form of chemotherapy because it interferes with cell development, and the prescribing regulations are similar to those governing a chemotherapy drug. For this reason you may be asked to sign a consent to treatment form before you start taking this drug for the first time.

How can anagrelide treat my MPN?

Anagrelide is currently recommended for use in individuals who are unable to tolerate other drugs used to treat MPNs. It is mainly used to treat high platelet counts in ET but can also be used in combination with other drugs (such as hydroxycarbamide) or in combination with venesection for PV.

Anagrelide has the advantage over other therapies in that it will only reduce the platelet count. This means that red and white blood cells counts will not be affected.

Reducing the platelet count can reduce the risk of experiencing a blood clot or a bleed. It may also help to reduce any symptoms experienced as a result of having too many platelets such as headache, visual problems, fatigue, tingling in fingers and toes, bleeding or itching.

Are there any drawbacks?

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

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

Anagrelide only reduces platelets. If you have elevated red cells or white cells you may either require another drug or venesection therapy to control this.

A small number of people will not respond to anagrelide or may develop a resistance to anagrelide (so that it no longer works) over a period of years, requiring a switch to another treatment.

Anagrelide may not be as good as some other therapies at slowing the development of myelofibrosis in patients with ET or PT (primary thrombocythaemia).

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 any other new symptoms, even if they are mild.

Anagrelide can cause episodes of fast heart rate, so your haematologist or nurse will check your heart rate before you start treatment.

Very common side effects

Approximately more than one person in 10 (more than 10%) of people taking anagrelide will experience some of these side effects:

- Headache

Less common side effects

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

- Anaemia
- Fluid retention (swollen hands and feet)
- Dizziness
- Palpitations
- Fast heart beat (tachycardia)
- Nausea
- Diarrhoea
- Stomach pains
- Excessive wind
- Vomiting
- Rash
- Fatigue
- Weight gain
- Sleepiness
- Reduced coordination
- Difficulty speaking or forming words
- Migraine
- Angina/chest pain
- Heart attack
- Enlargement or inflammation of the heart
- Drop in blood pressure when standing
- Ringing in ears (tinnitus)
- Double vision
- Increased pressure in arteries of lungs
- Abnormal substances and inflammation in the lungs
- Inflammation of the intestine
- Bleeding gums
- Dry skin
- Increased need to pass urine at night
- Reduced kidney function

If you experience any of the symptoms above please inform your doctor or nurse.

Uncommon side effects

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

- Weight loss
- Numbness
- Sleep disturbances
- Depression
- Confusion
- Heart failure
- Pain
- Flu like symptoms
- Loss of strength/weakness
- Cardiac or heart side effects including heart failure and abnormalities of the heart muscle

Taking anagrelide

How to take anagrelide

- Take either before or after food, in the morning, lunchtime or evening
- Swallow whole with plenty of water
- Do not split the capsule
- Take at the same time every day

Dosage

Your doctor, nurse or pharmacist will give dosage instructions. You will be started on a low dose. Your dose may be increased based on how your body responds. He or she may recommend you split your dose to take throughout the 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.

Storage and disposal of anagrelide

- Store in a dry place at room temperature.
- Anagrelide can be dangerous to others. Keep your capsules in a secure location well out of the reach of children and pets.
- Return any unused capsules to your local pharmacy or hospital. Do not dispose of them in the bin or flush them down the toilet.
- Do not use tablets after the expiry date which is stated on the packaging.

Can I take other medicines or vitamins, herbal supplements or remedies if I am taking anagrelide?

Whenever you take anagrelide (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 or need to be used with caution when taking with anagrelide. These include:

- Omeprazole
- Theophylline
- Atazanavir
- Cilostazol
- Cimetidine
- Clozapine
- Cyclobenzaprine
- Ciprofloxacin
- Gatifloxacin
- Levofloxacin
- Norfloxacin
- Ofloxacin
- Fluvoxamine
- Imipramine
- Inamrinone
- Mexiletine
- Milrinone
- Naproxen
- Riluzole
- Sucralfate
- Tacrine
- Ticlopidine

What should I expect when I begin treatment?

How fast does it work?

Anagrelide can take several weeks to start 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 that you experience fewer symptoms. Most people taking this drug tolerate it well and have relatively few side effects, and side effects usually become less noticeable over time.

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 begins to adjust to the treatment you will need less frequent checks, perhaps every two to three months. Your nurse or haematologist may check your kidney and liver and heart function with blood tests or scans.

What if I have other medical conditions?

Anagrelide should be used under supervision if you have now or have had any of the following conditions:

- Heart problems
- Kidney problems
- Liver problems
- Intolerance to some sugars

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 anagrelide, we recommend you do not exceed the recommended weekly limits of 21 units of alcohol per week for a man and 14 units for a woman. 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 that you use contraception whilst taking anagrelide, because this medication can be harmful to a developing foetus.
- When planning to conceive or to father a child, you should stop taking anagrelide 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.

Can I breastfeed while taking anagrelide?

We strongly recommend against breastfeeding your child whilst taking anagrelide. Anagrelide is a very strong drug that inhibits blood cell development. It can be secreted in breast milk and this may affect your baby's development.

Who will prescribe anagrelide for me?

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

Can I drive?

Anagrelide can cause dizziness and drowsiness; if you experience these side effects your ability to drive may be affected. 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 anagrelide. You may need to protect your skin by avoiding exposure to the sun, using sunscreen and wearing protective clothing and a hat.

Can I have vaccinations such as the flu jab while taking anagrelide?

You can have most vaccinations including the flu vaccine whilst taking anagrelide. However, some vaccinations are live vaccines and should not be taken with anagrelide. It is important you tell the person giving you the vaccine that you are taking anagrelide so they can check that it will be safe for you.

What to do if...

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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 you are sick just once, take your next dose as usual. If you are sick over a number of days please 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.

If you need to have a medical procedure or operation

You may occasionally be required to adjust or stop taking anagrelide if you need an operation. It is important that the doctor or dentist planning the procedure or operation be informed that you are taking anagrelide and that he or she plans your procedure together with your haematology doctor or nurse. We always recommend that you inform your haematology doctor or nurse when planning any procedures or operations.

If you feel anxious about taking anagrelide

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

What if I do not want to take this medication?

Whether or not to take anagrelide is your decision. If after discussing everything 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 anagrelide 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 medication options please visit our website at www.mpnvoice.org.uk and click on “Treatments”.

Consent

Your doctor will probably ask you to sign a consent form if you decide to begin treatment. This confirms that you know why anagrelide 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 is 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. Keep your cholesterol and blood sugar within normal limits.
- Exercise is very beneficial for people with MPNs and helps to 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.

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. MPN Voice offers a “buddy” programme for interested patients. Please contact us at buddies@mpnvoice.org.uk for more information.

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 and St Thomas' charity, 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

It's 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 almost ½ million 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 or lymphatic cancer.

Tel: 08088 010 444

www.leukaemiacare.org.uk

Leukaemia and Lymphoma Research

The charity focuses on improving the lives of patients with all types of blood cancer, 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.

www.leukaemia-lymphoma-research.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 information about MPNs, chemotherapy drugs, side effects and how best to manage side effects.

Tel: 0808 808 0000

www.macmillan.org.uk

Spotlight on MPN

An international website on myeloproliferative neoplasms, intended for patients and caregivers. Produced by Novartis Oncology.

www.spotlightonmpn.com

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



MPN Voice is registered under the auspices of Guy's and St Thomas' Charity. Registered Charity No 251983 - 30

If you can help, please complete the donation form on the next page

Donations

MPN Voice is funded by donations made by generous supporters. All money raised goes towards providing better information for patients and their families e.g booklets such as this, as well as investing in research to investigate why some people develop MPNs. Any donation will make a difference so thank you for your kind support.

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For further information please call 0207 848 4701
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If you are a UK taxpayer, Guy's and St Thomas' Charity, on behalf of MPN Voice, can reclaim the tax on your donation and receive an extra 25p for every £1 donated.

You need to have paid at least as much UK Income and/or Capital Gains Tax as the amount to be reclaimed on all your charitable donations in the appropriate tax year. Please inform us if you no longer pay UK tax at any time after the date of this declaration.

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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 and St Thomas' Charity at info@gsttcharity.org.uk or visit their website for more information at www.gsttcharity.org.uk



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- Medical Alert Cards
- 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