Your guide to

Danazol (Danol®)

Information and advice

MPN voice

MPN voice

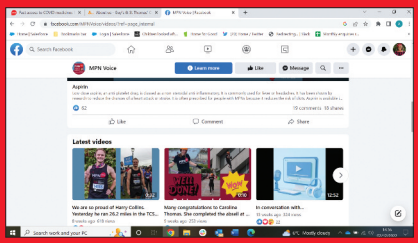
Supporting patients and families affected by MPN

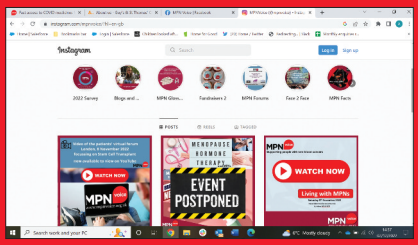
Established by a group of MPN patients in 2003, MPN Voice, registered under the auspices of Guy's & St Thomas' Foundation, has a website with a lively online community and up to date information on essential thrombocythaemia (ET), polycythaemia vera (PV), and myelofibrosis (MF).

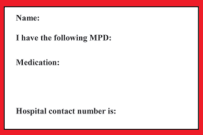
Backed by leading healthcare professionals, MPN Voice also publishes MPN disease and drug leaflets, runs regular in-person regional and online patient forums, has a prominent social media presence, funds MPN research and offers a buddy scheme.

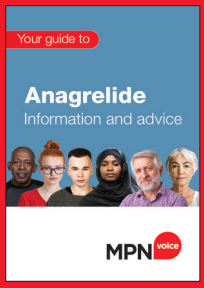
For more information visit the website **www.mpnvoice.org.uk**

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









What is this leaflet about?

This leaflet is for people with myeloproliferative neoplasms (MPNs). It offers information about the medicine danazol.

It contains information on;

- How danazol works
- The benefits and drawbacks of taking danazol
- How to take and store danazol
- Frequently asked questions
- How to feel your best while taking danazol

It is intended to give you the information required to aid your decision about taking danazol or as a reference for people already taking danazol.

It is important that in addition to this leaflet you read the information provided with your medicine.

What is Danazol?

Danazol is a medication used to treat anaemia (low red blood cells) in patients who have myelofibrosis (MF) and sometimes thrombocytopenia (low platelets).This drug is given orally.

Danazol is no longer routinely available in the UK but can sometimes be imported from other countries, this means that there are often supply issues.

If you need more information about the three types of MPNs you can learn more on our website at www.mpnvoice.org.uk

How does Danazol work?

Blood cells originate a type of cell called a “stem cell”. Stem cells are master cells which divide and mature into the distinct types of blood cells: red cells, white cells and platelets. The bone marrow in our bodies acts as a factory, turning stem cells into blood cells. Each new blood cell contains DNA, which carries all the instructions the cell needs to grow and function. Once blood cells mature they leave the bone marrow and enter our blood stream.

Danazol mimics a naturally made hormone that can stimulate the production of red cells and make the haemoglobin level rise.

How can Danazol help me?

Danazol increases red cell production, increasing the haemoglobin and therefore may reduce the need or frequency of blood transfusions. Danazol may also increase platelet production in patients with low platelets or thrombocytopenia.

Are there any drawbacks?

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

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

If you have been diagnosed with prostate issues danazol may not the best medication for you and you will need to discuss this with your haematologist.

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 mild.

Danazol mimics a natural hormone therefore the majority of side effects arise from potential hormonal disturbances in the body.

- feeling sick, stomach pain
- feeling dizzy or tired
- eyesight changes
- skin reactions – rash, changes in skin colour (pigmentation), dermatitis or increased sensitivity to sunlight
- increased growth of hair (particularly on your body or face)
- deepening of voice, hoarseness or sore throat
- muscle cramps, or backache
- headache or migraine
- acne
- oily skin or hair
- increased appetite
- weight gain
- fluid retention/bloating
- sweating or flushing
- reduction in breast size
- high blood pressure
- fast heart beat or palpitations
- nervousness, depression or mood changes
- change in menstrual cycle
- increased risk of liver and prostate cancer

Call your doctor immediately if you experience the following symptoms:

- skin rash
- yellowing of skin and eyes
- constant headache
- constant upset stomach or vomiting or abdominal pain
- visual disturbances
- frequent, prolonged or painful erections

Taking Danazol

How to take danazol

- Take either before or after food, in the morning and/or evening
- Ensure you take it at the same time daily
- Wash your hands thoroughly before and after taking the capsules
- Swallow whole with plenty of water

Dosage

Your doctor, nurse or pharmacist will give dosage instructions. Please be sure to follow the directions precisely.

Storage and disposal of danazol

- Store in the closed container it came in
- Store in a dry place at room temperature away from excess heat and moisture (not in the bathroom)
- Danazol 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

What should I expect when I begin treatment?

How fast does it work?

Danazol can take many weeks to start having an effect on your cells, therefore you will probably not feel any benefits until your counts have become controlled.

How will I feel?

As your red blood cells increase you may notice your symptoms improving. Most people taking this drug tolerate it well and have relatively few side effects.

What follow-up will I need?

You will need more frequent blood tests during the first weeks of treatment to determine how your body is responding to the medication, and to check for safety in liver and kidney function. Once this has settled you will need less frequent checks, perhaps every two to three months. Your kidney and liver function may be checked with blood tests.

Can I take other medicines if I am taking Danazol?

It is important that you tell the person who is giving you either advice about medicines or a new prescription (i.e. hospital doctors, GPs, nurses and pharmacists) the names of all the medicines you are taking, including vitamins, and herbal supplements or remedies bought in chemists. It is always helpful if you carry a list of your medicines to show your doctor or nurse at appointments.

Some medicines may interact or increase the risk of certain side effects so caution should be used whilst taking the medications listed below:

- Atorvastatin and other 'statin' drugs
- Bupropion
- Carbamazepine
- Ciclosporin
- Tacrolimus
- Warfarin

What if I have other medical conditions?

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

- Liver disease
- Kidney disease
- Heart disease
- Porphyria
- Blood clots
- Diabetes
- Epilepsy
- Migraines
- Raised cholesterol
- Pancreatitis

Frequently asked questions

Can I eat and drink normally?

- Yes. We recommend a normal healthy diet and drinking plenty of water.
- Do not drink alcohol while you are taking danazol. This is because drinking alcohol while taking danazol can make you feel sick or short of breath.

What if I want to have a child?

- If you are planning a pregnancy or to father a child, please discuss this with your doctor.

Pregnancy

- Do not take danazol if you are pregnant, might become pregnant or think you may be pregnant. If you or your partner becomes pregnant while taking this drug contact your doctor immediately for further advice.

Can I breastfeed while taking danazol?

- Do not breastfeed if you are taking danazol. This is because small amounts may pass into the mother's milk. If you are planning to breastfeed, talk to your doctor, nurse or pharmacist.

Can I drive?

Danazol has no or negligible influence on the ability to drive and use machines however if you are feeling drowsy or fatigued for any reason do not drive.

Who will prescribe danazol for me?

- Either your doctor or specially trained nurse or pharmacist at the hospital or sometimes your GP will prescribe your medication.

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

Yes, you can have most vaccinations including the flu vaccine whilst taking danazol. Some vaccines are live, e.g the shingles vaccine, so please ensure the person giving the vaccine uses the non-live version Shingrix.

If you need to have a medical procedure or operation

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

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.

Stopping your medication

It is important to take your medication as instructed because sudden cessation or changes to your prescribed dosage without clinical advice is dangerous to patients and can lead to harm.

If you feel anxious about taking danazol

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

What if I do not want to take this medication?

Whether or not to take danazol is entirely 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 danazol or if you elect to stop after you begin treatment, it is important to inform your doctor or nurse of your decision preferably before you stop taking the tablet. He or she can recommend alternatives or other suggestions if necessary to safeguard your health.

Consent

Your doctor may ask you to sign a consent form if you decide to begin treatment. This confirms that you know why danazol 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 MPN patients 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 also offers a “buddy” programme for interested patients. Please email 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 & St Thomas' Foundation, MPN Voice provides patients and families affected by MPNs with a comprehensive range of disease and medication publications, a buddy scheme and runs regional in-person forums and online 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.

Tel: 07934 689354
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 60 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.

Tel 0300 3303322
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

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 2080 888
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

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 like to receive news and updates by email

☐ I do not want to be contacted by email or post

Please fill in your details below:

Quantity	Title of booklet
	Essential Thrombocythaemia and Polycythaemia Vera
	Myelofibrosis
	Anagrelide
	Aspirin
	Busulfan
	Danazol
	Fedratinib
	Hydroxycarbamide
	Interferon Alpha
	Momelotinib
	Ruxolitinib
	A4 MPN Voice Poster
	Travel and Insurance

Title	First name
Last name	
Organisation	
Job title	
Address	
	Postcode
Email	
Phone	

Please return completed form to
MPN Voice, c/o Guy's & St Thomas' Foundation, The Grain House, 46 Loman Street, London SE1 0EH

please cut here

About this publication and MPN Voice

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

You may contact MPN Voice by post:

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or

Email: info@mpnvoice.org.uk

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

MPN voice

MPN Voice is registered under the auspices of Guy's & St Thomas' Foundation.
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Visit the MPN Voice website to find out more about our

- Buddy system
- Medical alert cards
- Regional in-person and online patient forums
- Social media
- Online community of MPN patients
- Funding of some of the latest MPN research

www.mpnvoice.org.uk

MPN voice

Supporting people and families affected by MPN