

Your guide to

Danazol (Danol[®])

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 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 myelofibrosis (MF).

This drug is given orally.

The drug is known by several names. It also goes under the brand name Danol®. If you need more information about the three types of MPNs you can learn more on our website at www.mpnvoice.org.uk

Danazol comes as a capsule with a grey cap and opaque white body containing a white or almost white powder, with 'D100' printed in black ink. Danazol is currently available in 100mg capsules.

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 different 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 is a hormone, naturally made by the body that can stimulate the production of red cells and make the haemoglobin level rise. Patients are given danazol to prevent the need for blood transfusions and improve symptoms of anaemia. Danazol may also increase platelet production and can therefore help with bleeding due to a low platelet count.

This drug is given orally.

How can Danazol help me?

Danazol can reduce anaemia by increasing red cell production, this in turn will reduce the need for or frequency of blood transfusions and alleviate the side effects associated with anaemia – light headedness, dizziness, tiredness and breathlessness. It may also increase your platelet count, and so reduce the risk of bleeding. In some patients danazol may help with symptoms of disease and can reduce the spleen size.

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.

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 is a 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 or depression
- 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, G.Ps, 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:

- Anisindione
- Atorvastatin
- Bupropion
- Carbamazepine
- Cyclosporine
- Dicumarol
- Fluvastatin
- Lovastatin
- Phenprocoumon
- 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

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 you must 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 mothers' 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.

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 haematology doctor or nurse. We always recommend that you inform your haematology doctor 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.

If you feel anxious about taking danazol

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 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.

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.mprvoice.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 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 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.leukaemialymphomaresearch.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

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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Visit the MPN Voice website to find out more about our

- Buddy system
- 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