Your guide to

Busulfan

Information and advice

MPN voice

MPN voice

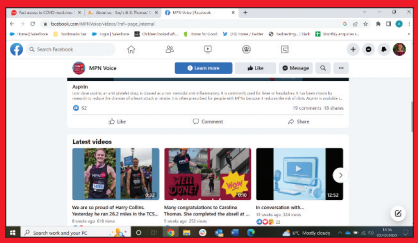
Supporting patients and families affected by MPN

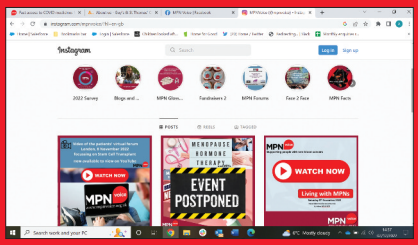
Established by a group of MPN patients in 2003, MPN Voice, registered under the auspices of Guy's & St Thomas' Foundation, has a website with a lively online community and up to date information on essential thrombocythaemia (ET), polycythaemia vera (PV), and myelofibrosis (MF).

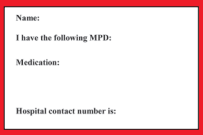
Backed by leading healthcare professionals, MPN Voice also publishes MPN disease and drug leaflets, runs regular in-person regional and online patient forums, has a prominent social media presence, funds MPN research and offers a buddy scheme.

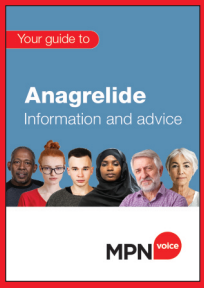
For more information visit the website **www.mpnvoice.org.uk**

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 busulfan.

In this leaflet you will learn:

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

This information can aid you in making the decision to take busulfan and serves as a reference for people already taking this medication.

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

What is busulfan?

Busulfan can be used to control blood counts in patients with polycythaemia vera (PV), essential thrombocythaemia (ET) or 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

How does busulfan 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.

Busulfan works by interfering with the production blood cell DNA. The drug prevents the cells from growing and maturing, which ultimately leads to the death of these cells.

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

How can busulfan treat my MPN?

Busulfan is used to reduce blood cell counts when your body is making too many red blood cells (erythrocytosis), platelets (thrombocytosis) or white blood cells (leucocytosis).

If your haematologist thinks you would benefit from taking busulfan, he or she may suggest you take a 'pulse' dose of this medication. This means that you will be given the drug over a short period of time, for instance over 7–10 days when required or as a single one-time dose.

Haematologists rarely give patients busulfan over long periods of time. However, if you are prescribed busulfan over a long period of time your haematologist and/or MPN specialist nurse will monitor your blood counts very carefully.

If you have polycythaemia vera (PV)

Busulfan can control your blood counts, which helps to reduce the risk of both blood clots and bleeding. When you take this medication 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 busulfan to reduce and control platelet counts reduces the risk of blood clotting, bleeding and developing MF. You may also notice a reduction in 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)

If your spleen is enlarged, taking busulfan can help to reduce its size. Busulfan can also reduce the likelihood that you will experience a blood clot. Reducing the

size of your spleen can reduce pain, discomfort, nausea and eating problems that you may experience with an enlarged spleen. You may notice a reduction in other symptoms of myelofibrosis such as night sweats, fevers and fatigue.

Are there any drawbacks?

As with any medicine you may experience side effects whilst taking busulfan. Possible side effects are listed in the section below.

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

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. In addition, this drug may reduce your fertility, (both men and women, so if you have not completed your family please discuss with your doctor. You should use contraception while taking this medicine if there is a chance of pregnancy.

Are there any side effects?

Most people taking this drug tolerate it well and have few side effects. The side effects listed below are relevant to individuals taking the low doses of busulfan that are given for MPNs. It is important to inform your doctor or nurse if you are experiencing any of the side effects listed on the next pages or any other new symptoms, even if mild.

Very common side effects

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

- *Reduced red blood cells* If your red blood cells drop too low (anaemia) you may notice that you are becoming breathless and that you 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 be at increased risk of developing infections. You may experience high temperature, fever, shivers and chills

If you have any of the symptoms above you must contact your hospital immediately.

A sudden and unexpected change in blood cell levels is not common but may occur. It is therefore important to attend appointments to have your blood counts checked and to discuss any symptoms with your haematologist.

Less common side effects

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

- Diarrhoea
- Nausea or vomiting
- Mouth ulcers
- Heart problems
- Inflammation of lungs which can cause breathlessness, cough or raised temperature. Such inflammation may have a gradual onset after long-term use of busulfan
- Dark patches on skin
- Liver disease
- Infertility

Uncommon side effects

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

- Early menopause/periods stopping

Rare side effects

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

- Severe drop in all blood cells (aplastic anaemia or pancytopenia)
- Liver abnormalities
- Yellowing of the eyes/jaundice
- Hair loss

- Dry mouth and lips
- Skin reactions/rash and itching/very dry skin
- Inability to sweat or lack of sweating
- Mouth ulcers
- Diarrhoea

Very rare side effects

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

- Muscle weakness in arms and legs/difficulty in speaking
- Drooping eyelids (myasthenia gravis)
- Breast enlargement in men
- Weight loss
- Weakness

Busulfan and cancer

There is a possibility that the use of busulfan over the course of several years may increase the risk of developing cancers including leukaemia. This risk is particularly increased when more than one chemotherapy agent has been used, for instance if busulfan is used in combination with, or following drugs such as hydroxycarbamide.

Taking busulfan

Busulfan comes as a 2 mg white round tablet and is taken by mouth.

How to take busulfan

- Take either before or after food, in the morning or evening, but at the same time each day
- Wash your hands thoroughly before and after taking the tablets
- Swallow whole with plenty of water
- Do not crush, break or chew tablets

Dosage

Your doctor, nurse or pharmacist will give dosage instructions. He or she may recommend that you take the medication every day over a short period of time, for instance over a limited period of 7 to 14 days, as a single dose, or very rarely on a continuous basis (every day for an indefinite period of time). 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 busulfan

- Store in a dry place at room temperature
- Keep your medication in its original packaging
- Busulfan can be dangerous to others. Keep your tablets in a secure location, well out of the reach of children and pets
- Return any unused tablets to your local pharmacy or hospital. Do not dispose of them in the bin or flush them down the toilet
- If you use a pill box or dossett box the busulfan must be kept separate from other medications

What should I expect when I begin treatment?

How fast does it work?

Busulfan can take a couple of weeks to begin having an effect on your cells. You will probably not feel any benefits until your counts are under control. It may take a few courses before your blood counts reach the desired level.

How will I feel?

As your blood counts come down you may notice a reduction in your 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 once every two to three months. Your kidney and liver function may also be verified with blood tests.

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

Whenever you take busulfan (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 for you 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.

Medications that may interact with busulfan include:

- Cyclophosphamide
- Itraconazole
- Metronidazole
- Oxygen
- Phenytoin
- Chemotherapy drugs
- Medicines that damage the lungs

What if I have other medical conditions?

Busulfan 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)

- If you have ever experienced seizures, fits or epilepsy (even if in the past)
- If you are planning pregnancy
- If you have radiation therapy planned
- If you have lung disease

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 healthy diet and drink plenty of water.

Can I drink alcohol?

While it is safe to drink alcohol in moderation whilst taking busulfan, 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?

- We strongly recommend that you use contraception whilst taking busulfan, because this medication can be harmful to a developing baby
- When planning to conceive or to father a child, you should stop taking busulfan 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 busulfan?

We strongly recommend against breastfeeding your child whilst taking busulfan. Busulfan 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 busulfan for me?

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

Can I drive?

Busulfan 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 whilst you are taking busulfan. 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 busulfan?

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

What to do if...

You have taken too much medicine or someone else has taken your medicine

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 a medical procedure or operation

You may occasionally be required to adjust or stop taking your busulfan treatment if you need an operation. It is important that the doctor or dentist planning the procedure or operation be informed that you are taking busulfan 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 planned.

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 busulfan

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 busulfan 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 busulfan 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 you 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 busulfan 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
- Ensure your GP checks your blood pressure and cholesterol annually

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

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
- Treatment and drug leaflets
- Regional in-person forums and online forums
- Online community of MPN patients
- Funding of some of the latest MPN research
- Backing by leading health professionals
- Active social media community

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

MPN voice

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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 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.

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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

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- 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