

Your guide to

Aspirin

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 low-dose aspirin, an over-the-counter medication often recommended for people with MPNs.

In this leaflet you will learn:

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

It is important that in addition to this leaflet you read the information provided with your medicine. If you need more information about myeloproliferative disorders in general please ask your local hospital or visit our website at www.mpnvoice.org.uk

What is aspirin?

Aspirin is an anti-platelet drug often prescribed for people with MPNs. Aspirin is classified as a non-steroidal anti-inflammatory drug. This means that it reduces inflammation but does not contain steroids. Aspirin is available in tablet form and dispersible form (dissolves in water).

How does aspirin work?

Aspirin helps to prevent blood clots from forming. It acts by reducing the 'stickiness' of platelets, in other words, it helps to prevent platelets from sticking together and forming clots.

How can taking aspirin help me?

People with MPNs have what is called “sticky blood”, meaning that the blood of people with MPNs is more likely to form clots than normal.

This “blood stickiness” is caused both by an increase in the number of blood cells and an increase in how likely these cells are to stick both to each other and to the blood vessel wall. Aspirin reduces the stickiness of blood cells, making them less likely to stick to each other and the blood vessel wall. Aspirin does not alter the number of platelets and other blood cells in the body.

Recommended dosage

- The most common recommended doses are 75 mg to 150 mg once only daily or occasionally on alternate days. Regularly missing doses stops the drug’s effect and causes the platelets to become sticky again, so it is important to maintain your regular dose.
- Do not break, crush or chew the tablets. Take them with a full glass of water, after eating.
- Follow the directions on the package or prescription label carefully. Ask your doctor, pharmacist or clinical nurse specialist to explain any part of the instructions that you do not understand.
- Do not take more or less than directed.
- Store in a cool dry place away from direct heat and light.

Are there any side effects?

Common (about one in ten to one in a hundred, 1–10%):

- Tightness in chest/difficulty in breathing
- Dyspepsia/Ulceration
- Gastrointestinal haemorrhage (Gut bleed)
- Other haemorrhage (bleeding)

Rare

(one in 1000 to one in 10,000, 0.01–0.1%):

- Kidney or liver abnormalities
- Allergic reactions
- Nausea and vomiting
- Reye’s Syndrome (children)

Frequently asked questions

What if I have other medical conditions?

Please inform your doctor or clinical nurse specialist if you have any of the following conditions:

- Asthma
- Peptic ulcers
- Previous haemorrhage
- Acquired von Willebrand's disease
- Uncontrollable hypertension
- G6PD deficiency
- Hepatic impairment
- Renal impairment
- Haemophilia
- Platelet count in below $100 \times 10^9/L$

Please also inform your doctor if you are pregnant or currently breastfeeding.

Interactions with other medications

Aspirin can interact with some other drugs, and it can also interact with alcohol. Please inform your doctor or clinical nurse specialist if you consume alcoholic drinks and if you take any of the medications listed below:

- Clopidogel or plavix
- Eptofobatide
- Heparin
- NSAIDS: Ibuprofen or Diclofenac
- Antacids
- Warfarin
- Phenindione
- Phenytoin
- Valproate
- Corticosteroids
- Methotrexate
- Spironolactone
- Metoclopramide

What if I need to have a medical procedure?

It is usually but not always advisable to stop taking aspirin for seven to ten days prior to any invasive procedure such a surgery, angioplasty, dental surgery, bronchoscopy or endoscopy, to prevent bleeding during the procedure. Please inform your doctor or clinical nurse specialist if you are due to undergo any procedures such as, or similar to those above.

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 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. 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 “Support”.

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

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.

I'd like to make a gift of

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Please make your cheque, postal order or CAF voucher payable to **Guy's and St Thomas' Charity - MPN Voice Fund**

Payment enclosed

or please debit my Mastercard Visa Amex Maestro Visa Delta

Please fill in your contact details here and your credit or debit card details on the form below.

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Guy's and St Thomas' Charity will hold your details to process your donation and keep you up to date on fundraising and what's happening at Guy's and St Thomas'. If you would prefer not to hear from us, please let us know now, or at any time by telephone on 0207 848 4701 or email supportgstt@togetherwecan.org.uk

For further information please call 0207 848 4701
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* The last three digits on the signature strip on the back of your debit or credit card. For Amex the four digits on the top right front cover

Make your donation go further

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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.

Yes, I would like Guy's and St Thomas' Charity, to treat this and all donations I have made in the 4 years prior to this year, and all future donations, as Gift Aid donations.

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Please return completed form to Freepost RSUJ-TJCG-YUYU, Guy's and St Thomas' Charity, London, SE1 8WA

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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SE1 9RT

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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 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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