

Your guide to

Interferon Alpha

Information and advice



MPN  voice



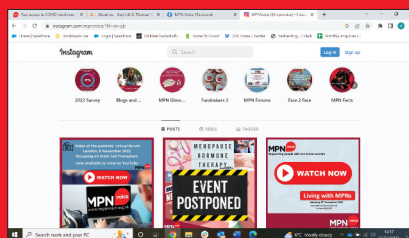
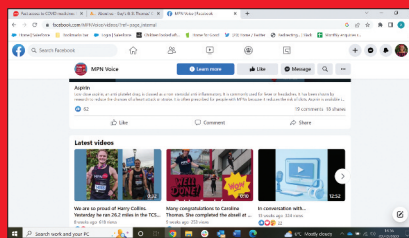
Supporting patients and families affected by MPN

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**

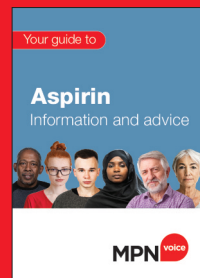
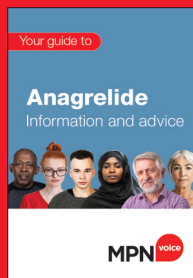


Name: _____

I have the following MPD: _____

Medication: _____

Hospital contact number is: _____



What is this leaflet about?

This leaflet is for people with myeloproliferative neoplasms (MPNs). It offers information about pegylated interferon, specifically both pegylated interferon alpha 2a (Pegasus®) and ropeginterferon alpha 2b, (Besremi®), which are long-acting forms of interferon alpha.

In this leaflet, the term interferon alpha includes peginterferon and ropeginterferon.

In this leaflet you will learn:

- How interferon alpha 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 interferon alpha

This leaflet provides information which can aid your decision about taking interferon and serves as a reference for people already taking the drug. In addition to reading this leaflet it is important that you read the information provided with your medicine.

This leaflet does not explain how to inject interferon alpha as this requires training by a medical professional. You should be taught how to do this by the nurse or doctor who prescribes interferon alpha for you.

If you need more information about MPNs in general please ask your local hospital or visit our website at www.mpnvoice.org.uk

What is interferon?

Interferon alpha is an immunotherapy drug which stimulates the body's immune system and used in the treatment of MPNs. Interferons are substances which occur naturally in our bodies. They belong to a family of proteins also known as cytokines which aid in the body's defence mechanism.

Interferons are used to treat all three main types of myeloproliferative neoplasms (MPNs): polycythaemia vera (PV), essential thrombocythaemia (ET) and myelofibrosis (MF).

Types of interferon

There are a variety of interferons and the class of interferon used to treat MPN is called interferon alpha. This is currently available in so-called pegylated or long acting formulations. The two currently available are Pegasys® and Besremi®. In the UK and several other countries Besremi®, which is a newer drug, is not yet widely available.

Interferon is injected under the skin and comes in a variety of packages and formulations including syringes and multi-dose injection pens. Your health care team will advise you about how to use the interferon you are prescribed.

How interferon works

Our immune system produces interferon to help fight viruses, bacteria and tumours. When given as a medication, interferon suppresses production of blood cells.

Interferon alpha is a man-made copy of naturally occurring interferon. The drug increases interferon levels in your body, thus suppressing over production of blood cells. Pegasys® and Besremi® work as a longer acting form of interferon alpha.

How can interferon treat my MPN?

Interferon alpha is currently recommended as the first choice therapy for younger people with MPNs and women with MPNs who are pregnant or trying to become pregnant. It is recommended as a second choice therapy for individuals who are unable to tolerate other drugs.

Interferon has been shown to:

- Control blood counts of platelets, red blood cells and white blood cells
- Reduce spleen size
- Reduce clotting events
- Reduce symptoms related to MPNs such as itchiness

Are there any drawbacks?

As with all medications, you may experience side effects whilst taking interferon alpha. This is discussed in more detail in the following section.

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

Interferon alpha is only available as subcutaneous injections.

Are there any side effects?

Whilst interferon is an effective treatment for MPNs, this treatment does not suit everyone – some people may not tolerate the side effects they experience. Approximately twenty to thirty per cent of people who begin treatment with interferon eventually stop taking the drug, most often due to side effects. **However many people report that the side effects they initially experience reduce over time, allowing them to tolerate treatment.**

You will find a list of side effects in the table on the following pages. It is important that you inform your doctor or nurse if you are experiencing any of the side effects described, no matter how mild they may be. There are often ways of overcoming side effects or reducing them to a tolerable level.

Some side effects are more common than others. The frequencies shown in the table on the next pages correspond to the following percentages:

- *Very common* Approximately more than one person in ten (10% or more) may experience these side effects
- *Common* Approximately one person in 10 to one person in 100 (1-10%) may experience these side effects
- *Uncommon* Approximately one person in 100 to one person in 1000 (0.1-1%) may experience these side effects
- *Rare* Approximately one person in 1000 to one person in 10,000 (0.01-0.1%) may experience these side effects
- *Very rare* Approximately one person in 10,000 (less than 0.01%) may experience these side effects

Pegasy

Body system	Very common	Common	Uncommon	Rare	Very rare
Frequency	10% or more	1–10%	0.1–1%	0.01–0.1%	Less than 0.1%
General disorders and administration site conditions	Weakness Tiredness Shaking Chills Pain, injection site irritation and irritability	Chest pains Flu like illness Lethargy Hot flushes Thirst Malaise (not feeling well)			
Blood and lymphatic system disorders		Reduced platelets Reduced red blood cells Enlarged lymph glands		Severe reduced red blood cells, white blood cells and platelets	Aplastic anaemia
Immune system			Sarcoidosis Thyroiditis	Autoimmune disorders Severe allergic reactions Systemic lupus erythematosus Rheumatoid arthritis	Idiopathic (or thrombotic) thrombo-cytopenic purpura
Infections		Upper respiratory infection Bronchitis Bacterial, fungal and viral infections Fungal infection of the mouth and herpes	Lung infection Skin infections	Infection of the heart Infections of the internal ear	
Endocrine/hormone disorders		Thyroid dysfunction	Diabetes	Diabetic ketoacidosis	
Metabolism and nutrition disorders	Loss of appetite		Dehydration		

Pegasys (continued)

Body system	Very common	Common	Uncommon	Rare	Very rare
Frequency	10% or more	1–10%	0.1–1%	0.01–0.1%	Less than 0.1%
Psychiatric and nervous system	Feeling depressed/low, anxiety Concentration issues Inability to sleep Headache Dizziness	Mood/emotion change Aggression Nervousness Poor memory Decreased sexual desire Fainting Nightmares Sleepiness Taste changes Migraines Numbness Tingling Tremors Burning sensation Decreased muscle strength	Thoughts of suicide Hallucinations Peripheral neuropathy	Suicidal thoughts/attempts Coma Stroke Convulsions or fitting problems Psychiatric disorders Facial palsy	
Reproductive system		Impotence			
Eye disorders		Blurry vision Eye pain Dry eyes Eye inflammation	Bleeding in retina	Blood clot/bleeding Inflammation/damage in retina of eye Ulceration of the cornea Inflammation and swelling of optic nerve	Loss of vision
Ear and labyrinth disorders		Ear pain	Hearing loss		
Kidney and urine				Kidney impairment/failure	
Cardiac (heart) and blood vessel disorders		Rapid heartbeat/palpitations Swelling in extremities Flushing	High/low blood pressure	Heart failure Heart attack Heart pain Inflammation of blood vessels in the heart Rapid heart rhythm Bleeding in the brain	

Pegasys (continued)

Body system	Very common	Common	Uncommon	Rare	Very rare
Frequency	10% or more	1–10%	0.1–1%	0.01–0.1%	Less than 0.1%
Skin disorders	Loss of hair Skin reactions including itching, dermatitis and dry skin	Rash Increased sweating Psoriasis Hives Eczema Sensitive to sunlight Night sweats			Toxic epidermal necrolysis Stevens Johnson Syndrome Erythema multiforme
Lung/breathing disorders	Cough/shortness of breath	Sinus congestions Shortness of breath Nose bleeds Nose and throat inflammation Nose infections Sore throat Runny nose	Wheeze	Inflammation of the lungs Blood clots in lung Interstitial pneumonia	
Gastro-intestinal disorders	Diarrhoea Nausea Abdominal pain	Vomiting Indigestion Difficulty swallowing Mouth ulcers Gum bleeding Inflammation of mouth and tongue Flatulence Dry mouth Loss of weight	Gastrointestinal bleeding	Stomach ulcer Inflammation of pancreas	
Immune system		A disorder called Sjogren's syndrome where the body's immune system attacks glands that produce fluid (such as the tear and saliva glands) Antibodies which are produced by the body's immune system	Autoimmune disorder of the thyroid gland Sarcoidosis (areas of inflamed tissue in different parts of the body)		

Besremi

Body system	Very common	Common	Uncommon	Rare	Very rare
Frequency	10% or more	1–10%	0.1–1%	0.01–0.1%	Less than 0.1%
General disorders and administration site conditions	Flu-like symptoms Feeling tired	Fever, weakness, chills, general health problems Irritation or redness at the site of injection Decreasing body weight Decreased appetite Headache Feeling dizzy Reduced sense of touch or sensation Feeling sleepy Sensation of tingling and 'pins and needles' Arthritis pain in arm and legs Bone pain	Inflammation of the bladder Painful urination Increased need to urinate Inability to urinate Pain or itching at the site of injection Sensitivity to weather change		
Blood and lymphatic system disorders	Decrease in the number of a type of white blood cells (called leucocytes) and in blood clotting cells (called platelets)	Increase of triglycerides (a type of lipid) in the blood Damage of the capillaries (very small blood vessels) in the body Decrease in the number or size of red blood cells Increase of lactate dehydrogenase enzyme	Increase in the number of platelets High blood pressure Reduced blood supply to certain parts of the body Haematoma (collection of blood under the skin) Flushing Antibodies produced by the body's immune system against red blood cells		Idiopathic or thrombotic thrombocytopenic purpura (increased bruising, bleeding) Decreased platelets, Anaemia and extreme weakness)
Liver			Poor functioning of the liver	Liver failure Fatty liver Bile duct inflammation	
Muscle and bone disorders	Pain in joints and muscles	Back pain Muscle weakness Joint inflammation		Inflammation of muscles	

Besremi (continued)

Body system	Very common	Common	Uncommon	Rare	Very rare
Frequency	10% or more	1–10%	0.1–1%	0.01–0.1%	Less than 0.1%
Infections		Infection of the respiratory tract Runny or stuffy nose Fungal infections Flu	Infection and re-infection with herpes Bacterial infections		
Endocrine/hormone disorders		Increase or decrease in the thyroid gland activity Increase of thyroid stimulating hormone Inflammation of the thyroid gland	Diabetes		
Psychiatric and nervous system		Aggressive behaviour Feeling depressed Feeling anxious Problems with falling asleep or staying asleep Mood changes Lacking bodily energy or motivation	Attempted suicide, thoughts about killing yourself Panic attack Hallucination (seeing, hearing or feeling things that are not there) Feeling stressed Feeling nervous Lack of interest in activities Nightmare Irritability Confusion Damage to the nervous system Migraine Mental disorder (health condition involving changes in thinking emotion or behaviour) Visual or sensory disturbances Shaky hands	Bipolar disorders (mood disorders with episodes of sadness and excitement), mania (extreme excitement or unreasonable enthusiasm)	
Reproductive system			Impotence/sexual problems		

Besremi (continued)

Body system	Very common	Common	Uncommon	Rare	Very rare
Frequency	10% or more	1–10%	0.1–1%	0.01–0.1%	Less than 0.1%
Eye disorders		Dry eyes	Loss of vision which may be caused by bleeding in the retina (the light-sensitive layer in the eye), or by build-up of fat in or under the retina Eye discomfort Eyelid eczema	Loss of vision which may be caused by damage to the retina (such as obstruction of the blood vessels in the eye) or the optic nerve	
Ear and labyrinth disorders		Hearing loss Ringing in ears (tinnitus) Spinning feeling (vertigo)			
Kidney and urine			Increase of uric acid		
Cardiac (heart) and blood vessel disorders	Changes in your heartbeat (when the heart beats very fast and uneven)		Heart disorders such as heart block (a disorder in the heart's electrical activity) Blood clots in the blood vessels of the heart Leakage of the aortic valve	Cardiomyopathy (diseases that affect the heart muscle) Angina pectoris (a severe chest pain as a result of blockage of the heart vessels)	Myocardial ischemia (reduced blood flow to your heart muscle)
Skin disorders		Itching Hair loss Rash Redness of skin Psoriasis Dry and scaly skin Acne Thickening of the outer layer of the skin Increased sweating	Sensitivity to sunlight Peeling of the skin Nail disorder		

Besremi (continued)

Body system	Very common	Common	Uncommon	Rare	Very rare
Frequency	10% or more	1–10%	0.1–1%	0.01–0.1%	Less than 0.1%
Lung/breathing disorders		Breathing problems	Inflammation of lung tissue Coughing Nosebleed Sore throat		Breathing problems including shortness of breath Cough and chest pain which may be caused by lung infiltration Pneumonia (lung infection) Pulmonary arterial hypertension (high blood pressure in the blood vessels bringing blood from the heart to the lungs) Pulmonary fibrosis (a lung disease where scars are formed in the lung tissue)
Gastro-intestinal disorders		Diarrhoea Nausea Abdominal pain or stomach discomfort Constipation Dry mouth	Inflammation of the stomach Abdominal wall disorder Intestinal gas Indigestion Painful swallowing Bleeding gums		

Besremi (continued)

Body system	Very common	Common	Uncommon	Rare	Very rare
Frequency	10% or more	1–10%	0.1–1%	0.01–0.1%	Less than 0.1%
Liver	Increase of an enzyme called gamma-glutamyl transferase	Increase in certain liver enzymes (shown in blood tests)	Inflammation of the liver Damage to the liver Enlarged liver Non-acute porphyria (a liver disorder in which substances called porphyrins build up in the skin causing local skin damage, such as rashes, blisters, sores or discomfort upon sun exposure)	Liver failure	
Muscle and bone disorders	Joint or muscle pain		Muscle weakness Neck pain Groin pain		

Taking interferon

How to take interferon

Your doctor or nurse will give you instructions and demonstrate how to inject interferon. Most people inject themselves – it is very straightforward. If you do not feel confident, a relative or friend can be taught to inject you. You can also ask your nurse at your GP surgery to do this. However, you may find this becomes increasingly inconvenient over a long period of time.

Dosage

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

Storage and disposal of interferon

Whilst each brand varies its storage advice slightly, to avoid confusion we recommend the following.

- Store in a fridge between 2-8°C
- DO NOT FREEZE
- Discuss with the issuing pharmacy how best to transport or keep the optimum temperature for your medication if you have a journey of several hours back home
- Keep the syringe and needles in their outer cartons to protect from light. Keep them separate from food by placing them in a plastic container or box
- Interferon can be dangerous to others. Keep your medication and syringes in a secure location, well out of the reach of children and pets
- You will be given a sharps bin to dispose of your needles once you have used them. Please return full sharps bins back to your hospital or GP surgery. Do not return used needles in a bag or any other container that could cause an injury to others
- Return any unused medication and syringes to your local pharmacy or hospital
- Do not dispose of medication and syringes whether new or used in the rubbish bin and do not flush down the toilet

Keeping track

It may be helpful to keep a record to remember when to take your injection and to record any side effects. You may be given a diary or booklet for this purpose.

Long term use of interferon can be linked to changes affecting the retina, (layer at the back of the eye). For this reason it is now suggested to have an assessment and image of the retina before starting interferon and regular eye check ups to monitor any changes.

Beginning treatment

Your first dose

- You may choose to take your first dose in the evening, because side effects can start within several hours of your first dose. Taking your first dose late in the day will allow you to sleep through any initial side effects such as a temperature or fever
- Take two paracetamol with your injection to reduce any flu-like symptoms or headache you may experience. You may only need to take paracetamol for the first one to two weeks you start to take interferon – please discuss this with your haematology team
- Some people can experience flu-like symptoms for several days, headache and tiredness the day after their first dose and for several days after the injection
- Ensure you have any equipment needed laid out in front of you including your syringe, needle, sharps bin and instructions. Do not rush
- If you are worried or unsure about the injection you can arrange to give it in the presence of a nurse (your practice nurse or haematology nurse)

How fast does it work?

The time for interferon to have a noticeable effect on your blood results varies, however it usually takes two to four weeks.

How will I feel?

As your blood counts reduce you may notice your symptoms improving. Any initial side effects experienced often reduce over a period of time.

Tips for coping with common side effects

Flu-like symptoms (including fever and chills, headache, aches and pains, cough and congestion)

- Most people choose to take the injection shortly before going to bed
- Drink plenty of water approximately three litres a day, more in hot weather
- Consider paracetamol as discussed above under “Your first dose”
- If your fever is over 38°C and has not reduced with paracetamol contact your haematology team
- Avoid alcohol or caffeinated drinks prior to taking your injections. These may cause dehydration and headaches
- Always report sudden severe headaches
- Try to keep lights and noise low. A cool flannel or ice pack may offer relief from headaches
- A warm bath, massage or hot pack may help with aches and pains
- Report any new symptoms such as any new aches and pains you are experiencing since starting interferon to your haematology team
- Report any cough to your doctor and do not take any cough medicines until you have spoken to your haematology doctor or nurse

Lack of energy and fatigue

- Try to keep a regular daily routine to your day, listen to your body, and do not push yourself to complete activities or tasks if it feels too much for you
- Take a short nap during the day, but not too late in the day as this may affect your sleep at night. Too much sleep can increase fatigue. If you have an activity planned, try to take a nap prior to this
- Ensure you have a full night's sleep
- Prioritise activities; ask for help with tasks that you do not have the energy to complete

- Try to exercise regularly. If you have not previously exercised, try a walk to the shop and back. Do not over-exercise, take it gently and for short periods until you feel able to increase the duration

Nausea, loss of appetite and taste changes

- Eat small amounts often instead of three large meals a day
- If you feel nauseous, avoid fast foods and foods with strong flavours, such as spicy, sweet, acidic and greasy foods
- Have some ready-prepared meals in the freezer for days when you don't feel like cooking
- Avoid foods and drink that leave a strong aftertaste in your mouth
- Avoid strong cooking smells
- Try not to lie down straight after eating
- Drink plain water. Avoid fizzy water and strong-tasting or caffeinated drinks
- Eat from a small, half-filled plate if you have low appetite
- Eat when you can and whenever you feel hungry
- Eat small amounts of foods that appeal to you
- Try to ensure you continue to eat a balanced, healthy diet
- For reduced taste, try to eat stronger tasting foods, for instance choose strong cheese instead of mild cheese. Add more flavour than you would normally
- For increased taste, avoid metal cutlery, try plainer foods, and avoid sweet and fried greasy foods
- Eat and drink slowly
- Try sucking sweets such as boiled sweets, mints and dark chocolate
- If you notice weight loss tell your doctor or nurse

Mood changes

If you have ever experienced low mood/anxiety or depression before being diagnosed with an MPN, please discuss this with your haematologist at the time of consultation.

You should seek emergency help if you are depressed and have thoughts of hurting yourself or others.

Mood changes are common and it is important to monitor for them. If you have significantly low mood, if you lose enjoyment of activities that usually give you pleasure or are frequently experiencing low mood or tearfulness, you should report this to your haematology team.

Frequently asked questions

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 less frequent checks, perhaps once every two to three months. Your thyroid, kidney and liver function will be checked with blood tests.

Can I take other medicines if I am taking interferon?

Whenever you take interferon (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 with interferon. These include:

- Medicines for asthma
- Anti HIV therapy
- Zidovudine in combination with ribavirin and interferon
- Warfarin (peginterferon)
- Phenytoin (peginterferon)
- Flecainide (peginterferon)
- Sedatives
- ACE inhibitors e.g Lisinopril
- Erythropoietin
- Melphalan
- Prednisolone
- Theophylline
- Aminophylline
- Cyclophosphamide
- Doxorubicin
- Grapefruit juice

What if I have other medical conditions?

All medications have potential risks and side effects. Interferon alpha should be used with caution, (if at all), if you have any of the following conditions:

- An allergy to any of the ingredients in the medicine (these will be listed on the information leaflet that came with your injections) or have had a severe reaction to other formulations of interferon
- Severe heart problems or a history of heart problems
- Kidney problems or liver problems
- Seizures (e.g. epilepsy) and/or other nervous conditions
- Psychiatric illness or difficulties (current or past)
- An autoimmune disease such as thyroid dysfunction or vasculitis
- Eye conditions
- Heart/lung/liver or other organ transplant
- Diabetes
- Hepatitis C
- HIV and are treated with anti-HIV medicines
- Psoriasis
- Blood clotting disorder

If you think you may have one of these conditions please discuss with your doctor. This may not mean you cannot have interferon, but it should be used with caution.

Can I eat and drink normally?

Yes. We recommend a normal healthy diet and drinking plenty of water.

Can I drink alcohol?

While it is safe to drink alcohol in moderation whilst taking interferon, we recommend you do not exceed the recommended limit of 14 units of alcohol a week for both 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?

Whilst it is safe to conceive or father a child whilst taking interferon we always recommend you discuss any plans you have to try to conceive with your

doctor or nurse and inform him or her as soon as you find out you or your partner is pregnant.

Can I breastfeed while taking interferon?

Whilst it is known that interferon transfers into the breast milk in small amounts, there has to date been no reports of adverse effects on babies. The decision to breastfeed should be made by balancing benefits against the risk. Your haematologist and maternity team can help you make this decision.

Who will prescribe interferon for me?

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

Can I drive?

You may find that when you begin taking interferon your ability to drive and operate machinery is affected. We recommend when you begin taking this medication that you wait to see how you react before deciding if you are able to drive. If you are in any way feeling tired or fatigued do not drive and please discuss this with your doctor or nurse.

Can I travel whilst taking interferon?

Yes! We recommend you discuss all travel plans with your nurse or doctor prior to travelling. Ensure you have suitable travel insurance and enough of your medication to take with you. Most airline companies require a covering letter from your doctor to take injections on board, therefore we advise you check when you book your flight. Keep your injections in your hand luggage, as the temperature of the hold may not be appropriate. You will need to ensure your interferon is stored at the correct temperature. One way of keeping your interferon cold is to carry it in a coolbag with a cold pack, however you need to ensure you do not freeze it. Some airlines may offer to refrigerate it for you – ask as you go on board.

How do I dispose of my sharps bin once it is full?

Please ensure that full sharps bins are properly closed. Return full bins to the hospital or surgery which provided it to you. Do not use a bag or any other container apart from a sharps bin to return used syringes – this is dangerous and may not be accepted.

Can I have vaccinations such as the flu jab whilst taking interferon?

It is always advisable to consult your doctor or nurse prior to having a vaccination. Your medical team will check your overall health and immune system status prior to vaccination to ensure that vaccination is safe for you. It is not recommended that you take any live vaccinations whilst taking interferon – e.g some shingles vaccines, although there is now a non live shingles option called Shingrix.

What to do if...

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

If you have taken an extra dose or if another person has taken your medication please contact your nurse or doctor as soon as possible.

You were sick shortly after having an injection

Being sick will not affect the absorption of an injection into your body. If you are persistently sick after injecting please contact your nurse or doctor.

You forget to take a dose

If you have forgotten to take a dose, take it as soon as you remember. If you have forgotten to take several doses, contact your haematology team before resuming treatment.

You bleed after having an injection

A small drop of blood immediately after injecting is nothing to worry about – your skin has tiny blood vessels just below the skin and you may have nicked these vessels with the needle. Continuous bleeding or heavy bruising at the injection site should always be checked by a nurse or doctor.

Your skin becomes sore, red or weepy

You must always see your nurse or doctor if you notice your skin becomes sore, broken, red or weeping.

If you need to have a medical procedure or operation

If you need to have an operation or procedure (including dental work), you may occasionally be required to adjust or stop your interferon. It is important that you inform the doctor or dentist planning the procedure or operation that you are taking interferon and that they discuss plans for your procedure with your haematology doctor or nurse. We always recommend that you inform your haematology doctor or nurse if you have 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 interferon

If you have concerns, please discuss this with your doctor or nurse. You can also watch a video about taking the injections on the videos part of our website – www.mpnvoice.org.uk

If you do not want to take this medication

It is entirely your decision as to whether to start treatment with interferon. 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 interferon 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.

If you prefer an alternative

There are other treatment alternatives available, and you can discuss these with your haematologist. If you wish to read up about treatment alternatives, 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 interferon 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'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 "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

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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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



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Registered charity No. 1160316-15

This leaflet was first published in October 2009

Revision 5.00 in March 2025

For review in two years (March 2027)

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www.mpnvoice.org.uk