

Interferon

A publication of the MPD Support Charity

What is this leaflet about?

This leaflet is for people with myeloproliferative disorders. It offers information about the medicines interferon alpha and peginterferon.

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 myeloproliferative disorders in general please ask your local hospital or visit our website at www.mpd-support.co.uk

What is interferon?

Interferons are substances which occur naturally in our bodies. These substances are commonly used in medication form to treat people who have viral conditions or cancer and are also used to treat myeloproliferative disorders (MPDs). Interferon is used to

treat all three main types of myeloproliferative disorders: polycythaemia vera (PV), essential thrombocythaemia (ET) and myelofibrosis (MF). You can learn more about all the MPDs on our website at www.mpd-support.co.uk

Interferon alpha and peginterferon are available as clear to light/pale yellow liquids and are given by injection just under the skin. Interferon alpha is usually given up to five times a week and peginterferon just once a week.

Types of interferon

Interferon is made by a variety of drug companies and is known under several brand names according to the manufacturer. The most common brand names for interferon are Roferon-A®, IntronA® and PEGASYS®.

Peginterferon is a slow releasing interferon that is currently used only in research and special cases. Although it causes fewer side effects than interferon, it is currently still under investigation.

Interferon alpha comes in a variety of packages and formulas. The most common are:

Single-dose syringe A syringe containing the exact amount of drug required for one injection

Multi-dose vial A glass vial containing multiple doses of interferon liquid. You will be required to draw up a specific amount of fluid into a syringe and administer this dose to yourself.

Multi-dose injection pen An injection pen containing a cartridge with multiple doses of interferon. The pen is set to inject the required dose each time.

How interferon works

Interferon is a substance which occurs naturally; small amounts of this substance are found in our bodies. Our immune system produces interferon to help fight viruses, bacteria and tumours, and interferon also suppresses the 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. Peginterferon works the same way but is a longer acting form of interferon alpha.

How can interferon treat my MPD?

Interferon alpha is currently recommended as the first choice therapy for younger people with MPDs and women with MPDs 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 fibrosis in some people
- Reduce itching in some people

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 in injection format and therefore is not suitable for individuals unable to self-inject or tolerate injections.

Are there any side effects?

Whilst interferon is an effective treatment for MPDs, 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.

Side effects of interferon

Body System	Very common	Common	Uncommon	Rare	Very rare
<i>Frequency</i>	<i>10% or more</i>	<i>1-10%</i>	<i>0.1-1%</i>	<i>0.01-0.1%</i>	<i>Less than 0.01%</i>
General disorders and administration site conditions	Flu-like illness; reduced appetite; temperature; rigors/shivering; fatigue	Chest pain; fluid retention/swelling			Injection site reaction
Blood and lymphatic system disorders	Reduced white blood cells	Reduced platelets; reduced red blood cells			
Immune system				Autoimmune disorders; acute hypersensitivity reactions	Sarcoidosis (rare immune condition)
Endocrine disorders				Thyroid dysfunction	
Metabolism and nutrition disorders	Loss of appetite; nausea		Dehydration	Diabetes	High cholesterol levels

Side effects of interferon (con't)

Body System	Very common	Common	Un-common	Rare	Very rare
Frequency	10% or more	1-10%	0.1-1%	0.01-0.1%	Less than 0.01%
Mental health			Depression; anxiety; mental status changes; confusion; abnormal behavior; nervousness; memory impairment; sleep disorders	Suicidal thoughts/attempts	
Nervous system disorders	Headache	Taste changes	Tingling/numbness in hands, legs and feet; dizziness; tremor; drowsiness/sleepiness	Coma; stroke; convulsions or fitting; problems with erection	Altered brain function
Eye disorders			Visual disturbances; eye infection	Blood clot/bleeding/inflammation/damage in retina of eye	
Ear and labyrinth disorders			Dizziness		

Side effects of interferon (con't)

Body System	Very common	Common	Un-common	Rare	Very rare
Frequency	10% or more	1-10%	0.1-1%	0.01-0.1%	Less than 0.01%
Kidney and urine			Protein in urine	Kidney impairment/failure	
Cardiac (heart) disorders		Palpitations; blue tinge to skin and lips		Heart/lung failure; heart attack; heart failure; build up of fluid in the lungs	
Vascular disorders			High/low blood pressure	Inflammation of blood vessels	
Lung disorders				Breathlessness; cough	
Gastro-intestinal disorders	Diarrhoea	Vomiting; abdominal pain; nausea; dry mouth		Pancreatitis; intestinal overactivity; constipation; heart burn; excessive wind	Reactivation of stomach ulcer; gastrointestinal bleeding (non life-threatening)
Liver				Liver dysfunction/inflammation	

Side effects of interferon (con't)

Body System	Very common	Common	Un-common	Rare	Very rare
Frequency	10% or more	1-10%	0.1-1%	0.01-0.1%	Less than 0.01%
Muscles, joints, skin and bones	Hair thinning/loss (reversible); sweating increased; pains in joints and muscles		Psoriasis; itching	Rash; dry skin; nose bleeds; mucosal dryness; runny nose; lupus; arthritis	

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

- Store in a fridge between 2-8°C. 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. Do not freeze. Please refer to the chart on the next page for your particular brand.
- 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's 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 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.

Storage times by brand

Brand name	Format	Storage temp	Storage time
Roferon-A®	Cartridges	Room temperature (below 25° C) after the first dose	Up to 28 days at room temperature after first dose
Roferon-A®	Pre-filled syringes	Room temperature up to 28° C.	Stable out of the fridge for 28 days
PEGASYS®	Pre-filled syringes	Room temperature	Stable out of the fridge for a maximum of 21 days for one occurrence only.
IntronA®	Solution for injections	At or below 25° C for a period up to 7 days before use	Can be put back in the refrigerator at any time during a 7-day period prior to use. If the product is not used during the 7-day period, must be discarded. It cannot be put back in the refrigerator for a new storage period and must be discarded.

What should I expect when I begin treatment?

Your first dose

- 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.
- Try to ensure you have the day off from work when you take your first injection. Some people can experience flu-like symptoms, headache and tiredness the day after their first dose and for a 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).
- Take two paracetamol with your injection to reduce any flu-like symptoms or headache you may experience. You may only take paracetamol for the first one to two weeks you take interferon – please discuss this with your doctor.

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)

- Take the injection shortly before you go 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 doctor.
- 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 aches and pains you are experiencing since starting interferon to your doctor.
- Report any cough to your doctor and do not take any cough medicines until you have spoken to your 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 (40 minute) 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

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 doctor.

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 kidney and liver function may also 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 or peginterferon. These include:

- Medicines for asthma
- Anti HIV therapy
- Zidovudine in combination with ribavirin and interferon
- Warfarin (peginterferon)
- Phenytoin (peginterferon)
- Flecainide (peginterferon)
- ACE inhibitors
- Erythropoietin
- Melphalan
- Prednisolone
- Theophylline
- Chinese herbal remedies
- Aminophylline

- Cyclophosphamide
- Doxorubicin
- Teniposide
- Narcotics / sedatives
- 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
- 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 weekly limits of a maximum of 21 units of alcohol per week for a man and maximum of 14 units of alcohol a week for a woman. Alcohol can cause dehydration and it is important to avoid becoming dehydrated if you have an MPD. 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, hospital pharmacist or sometimes your GP will prescribe your medication.

Can I drive?

You may find that when you begin taking interferon that 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 (see chart on storing interferon). One way of keeping your interferon cold is to carry it in a cold bag 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.

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. Do not take two doses on the same day. If you have forgotten to take several doses, start taking them again and contact your doctor.

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.

If you feel anxious about taking interferon

If you have concerns, please discuss this with your doctor or nurse. You can also visit the Support section of our website www.mpd-support.co.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.mpd-support.co.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 MPD 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 MPDs 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 MPD 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 MPDs have had similar experiences. You may want to discuss your concerns with a family member or friend. The MPD Support Charity offers a “buddy” programme for interested patients. Contact us at info@mpd-support.co.uk for more information.

It's worth bearing in mind that many people with MPDs 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.mpd-support.co.uk under “Support.”

Resources for patients and families

MPD Support

A support group led by people with MPDs, haematologists and specialist nurses based in London that provides support and information for individuals with MPDs, their relatives and friends. The group provides a buddy scheme, regular newsletters and meets two to three times a year. Visit:
www.mpd-support.co.uk

Leukaemia CARE

An organisation which runs a helpline and website with information on MPDs as part of its more general support of those with blood disorders.
Tel 0800 1696680 or www.leukaemiacare.org.uk

Medicines.org

A website run in collaboration with the NHS providing up to date, reliable and understandable information about medicines – a handy resource for all medicines.
www.medicines.org.uk

Cancerbackup (now merged with Macmillan)

A charity which offers a website with information on MPDs, chemotherapy drugs, side effects and how best to manage side effects.
0808 800 1234 (Mon–Fri 9am–8pm) or www.cancerbackup.org.uk

About this publication and MPD Support

This document was written by Yvonne Francis, an NHS MPD specialist nurse, with input from consultant haematologists, specialist nurses, psychologists and members of the MPD-support group.

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