Newly diagnosed with myelofibrosis (MF)

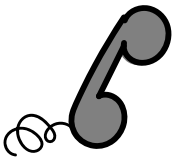
A Guide for Patients

Leukaemia Care
YOUR Blood Cancer Charity

About Leukaemia Care

Leukaemia Care is the UK's leading leukaemia charity. For over 50 years, we have been dedicated to ensuring that everyone affected receives the best possible diagnosis, information, advice, treatment and support.

Our services

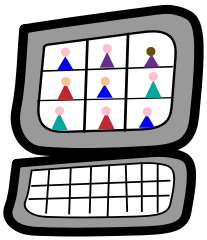


Helpline

Our helpline is available 9am to 4:30pm Monday to Friday. If you need someone to talk to, call **08088 010 444**.

Alternatively, you can send a message via WhatsApp on **07500 068065** on weekdays 9am to 5pm.

Support Groups

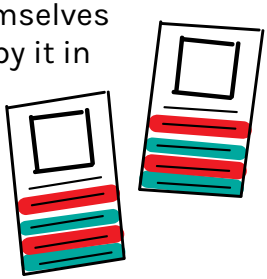


Our nationwide support groups are a chance to meet and talk to other people who have been affected by an MF diagnosis.

For more information, scan this QR code:

Buddy Support

We offer one-to-one phone support with volunteers who have had MF themselves or been affected by it in some way. You can speak to someone who knows what you are going through. For more information on how to get a buddy call **08088 010 444** or email **support@leukaemiacare.org.uk**



Counselling Service

Our counselling service helps MF patients and their loved ones access up to six sessions of counselling.

To apply, scan this QR code:

Advocacy and Welfare

Our advocacy and welfare officers are here to help you find the support you need for many issues surrounding an MF diagnosis. These include insurance, benefits and clinical trials. If you would like support from our advocacy or welfare officer, email **advocacy@leukaemiacare.org.uk** or call **08088 010 444**.

Cost of Living Fund

This fund provides grants to patients and families affected by MF, to help with essential living costs.

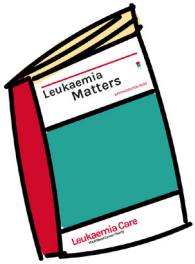
All applications must be made via the form which can be found by scanning the QR code:

Write a Will

Using our complimentary service, you can write a simple Will so you know what happens to your estate when you die. To start writing your free Will today, scan this QR code:

Patient Magazine

Our magazine includes inspirational patient and carer stories as well as informative articles by medical professionals.



To subscribe to our magazine, scan this QR code:

In this booklet

There is a lot of information about cancer on the internet. Some of it may not be reliable or up-to-date, and much of it will not be applicable to you. Your haematology team is best placed to give you information that is specific to you because they know your individual circumstances.

If you want to search for information yourself, look for reputable organisations like the NHS or national charities. Look for a quality mark, such as the Patient Information Forum (PIF) tick.

Introduction

There is a lot of information in this booklet. You might find it helpful to dip in and out rather than reading it all at once. Or you could read the summary at the beginning of each chapter if you'd prefer a short overview.

Myelofibrosis (MF) is a usually slow-growing type of blood cancer that causes scarring of your bone marrow. It stops your bone marrow from making enough healthy blood cells. This booklet covers what MF is, including how it is diagnosed and what treatments you might be offered. We also include practical information about living with MF.

This booklet is only a guide to what you might experience. Your haematology team will give you a copy of your specific treatment plan.

We'd like to thank Professor Mary Frances McMullin, Consultant Haematologist, Belfast City Hospital and Queen's University Belfast, and Irene Caballes, Chronic Leukaemia Clinical Nurse Specialist, Hammersmith Hospital for reviewing this booklet. We'd also like to thank our patient reviewers Andrea, Brian, James, Lucy and Zan.

Throughout this booklet, you will see QR codes and URLs that link to webpages for further support. If you are not able to access the webpages, please email information@leukaemiacare.org.uk or call 08088 010 444.

About myelofibrosis (MF)

Summary

- Myelofibrosis (MF) is a very rare blood cancer. It is usually slow-growing.
- It happens when cells in your bone marrow grow out of control and make too many blood cells.
- This causes scarring and inflammation in your bone marrow, which stops it from making enough healthy blood cells.
- Some people develop MF without any previous bone marrow problems, while others develop it from another bone marrow condition.
- It mainly affects people aged 60 or over, although you can get it in earlier adulthood.
- We do not know the exact cause of MF. It is not due to something you did or did not do.

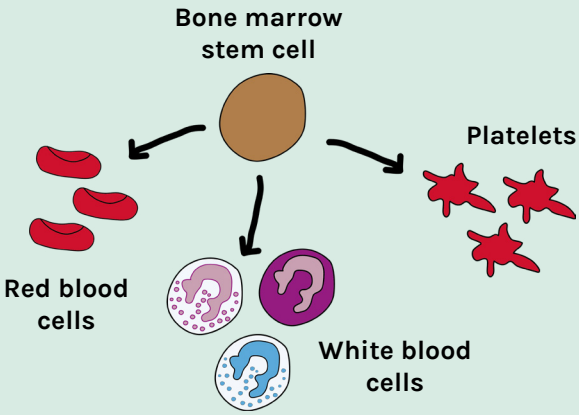
What is myelofibrosis?

Myelofibrosis is a type of blood cancer that causes scarring in your bone marrow. It is usually slow-growing. Over time, your bone marrow is replaced by more and more scar tissue, which gradually stops your bone marrow from working properly. MF belongs to a group of conditions called **myeloproliferative neoplasms** (MPNs).

Bone marrow and types of blood cells

Bone marrow is the soft spongy substance found in the middle of some large bones in your body. Most of your blood cells are made in your bone marrow. They develop from immature cells called stem cells. Stem cells can turn into any of the following types of blood cells:

- Red blood cells – these carry oxygen around your body
- White blood cells – these help you fight infection
- Platelets – these help to stop bleeding by causing blood clots to form



What is a myeloproliferative neoplasm?

MPNs are blood cancers that develop when cells in your bone marrow grow out of control and make too many blood cells. There are different types of MPN depending on which type of blood cell your body is over-producing.

- In MF, your body makes too many immature blood cells that cause your bone marrow to become inflamed and scarred. This stops your bone marrow from making enough healthy blood cells.
- In essential thrombocythaemia (ET), your bone marrow makes too many platelets.
- In polycythaemia vera (PV), your bone marrow makes too many red blood cells. Sometimes other blood cells such as white blood cells and platelets are affected too.

We have separate information about essential thrombocythaemia and polycythaemia vera. Follow the link, scan the QR code or search for 'polycythaemia vera' or 'essential thrombocythaemia' at leukaemiacare.org.uk

Types of MF

There are several different types of myelofibrosis. Your doctor will use your medical history and the results of your tests to work out which sort you have.

- Primary myelofibrosis is when MF develops in people who have not had bone marrow problems before.
- Secondary myelofibrosis is when MF develops from other MPNs. It can happen after:
  - Essential thrombocythaemia (ET)
  - Polycythaemia vera (PV)

Who gets MF?

MF is very rare. Around 380 people are diagnosed with it each year in the UK. This is why you might not have heard of MF or met anyone with it before.

Most people are diagnosed when they are 60 or over, although you can get MF as a younger adult. It is slightly more common in men than women.

"The C word feels like a bombshell. Try to remember that there are many, many people living with cancer, and living well with it. It's not necessarily an immediate disaster."

Lucy, living with MF since 2020

What causes MF?

We do not know exactly what causes MF. It does not happen because of something you did or did not do. But some things might increase your chance of getting it.

These include:

- Age. Your chance of getting MF increases with age.
- Sex. It is slightly more common in men than women.
- Genetic changes. These usually happen by chance as you get older (see page 11).
- Having another MPN. If you already have ET or PV, it might develop into MF.
- Family history. MF is not passed on from parent to child. But if you have a close relative (parent, brother, sister or child) with MF you have a higher chance of developing it too. The risk is still low as MF is very rare.
- Exposure to chemicals. There might be a link between MF and some industrial chemicals, but we need more research to be sure.

Genetic changes

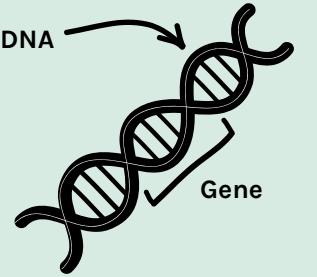
MF happens when genetic changes in some bone marrow cells stop the cells working as they should. These changes usually happen by chance during your lifetime.

You do not usually get these genetic changes from your parents and you cannot usually pass them on to any children you may have. Although there are cases of MF where siblings or other close relatives also have MF, this is unusual. **Most people who have a close family member with MF do not develop MF.**

There are a number of different genetic changes linked to MF. The most common ones affect genes called *JAK2*, *CALR* or *MPL*. They affect how your bone marrow cells make proteins involved in blood cell development.

Your doctor will look for genetic changes in your bone marrow cells because knowing what gene changes you have can help them look after you (see page 23).

Understanding genes and proteins



- DNA is like a thread of code in each cell of your body. Your DNA contains lots of different genes.
- Genes contain instructions for your cells on how to make proteins needed by your body. These proteins are important in the normal growth, development, and function of your cells.
- Sometimes changes occur in a gene. These are known as variants. These variants can cause a different protein to be made.

Symptoms and complications of MF

Summary

- You might not have any symptoms of MF when you are diagnosed. You might start to get signs and symptoms over time.
- Symptoms vary depending on the type and stage of your MF, and whether you have complications.
- Common symptoms include:
  - Extreme tiredness
  - Night sweats
  - Unexplained fever
  - Itchy skin after a warm bath or shower
- You may have other symptoms if you develop complications such as:
  - Swollen spleen
  - Abnormal blood counts
  - Bleeding
  - Blood clots
- In some cases, MF can transform into a faster-growing type of blood cancer called acute myeloid leukaemia. If this happens, your symptoms might get worse.

Symptoms of MF

You might not have any symptoms when you're first diagnosed – this is the case for about 1 in 4 people with primary MF. You might be diagnosed from a blood test done for another reason. You might start to get symptoms as your MF progresses.

Symptoms vary from person to person. They can depend on the type and stage of MF and whether you develop complications.

Common symptoms of MF include:

- Extreme tiredness
- Feeling full quickly when you eat
- Night sweats
- Itchy skin, especially after a warm bath or shower
- Unexplained fever
- Problems with concentration
- Bone pain
- Pressure or bloating in your tummy
- Losing weight without trying to

You may be asked to fill out a symptom assessment form as part of your first appointment and during check-ups. This is a good way to check whether your MF is stable or is progressing and whether any treatments you have are working.

> **"I take pride in knowing my own body. I might look okay on paper, but how I actually feel might be a completely different story. I know what my body needs and what it is asking for. I know this better than anyone."**
>
> Andrea, living with an MPN since 2011

Complications of MF

MF can cause complications in different parts of your body as it works hard to overcome the effects of MF.

Your chance of developing complications can vary depending on the type of MF you have and how it is progressing. Your doctor or clinical nurse specialist (CNS) can explain the complications and symptoms you are most likely to get. They can also advise you on when to seek help.

We cover some of the main complications of MF here.

Swollen spleen

About 8 out of 10 people with MF have a swollen spleen large enough for a doctor to feel during a check-up.

As your bone marrow scars, it becomes less able to make healthy blood cells. Instead, your spleen and liver take over. This causes them to swell.

If your spleen is swollen, you may have:

- Pain under your ribs on your left side
- Pressure or bloating in your tummy
- Feeling full quickly when you eat
- Breathlessness

It is less common for your liver to become swollen enough to cause symptoms. Your doctor will monitor its size and function during your check-ups.

Abnormal blood counts

MF makes it difficult for your body to make healthy blood cells. As a result, you may develop abnormal blood counts. These can be high or low.

- A low red blood cell count (anaemia) can make you look pale and feel tired, breathless or dizzy.
- Low platelets (thrombocytopenia) can make you bruise or bleed more easily than usual.
- A low white blood cell count can make you more likely to pick up infections and make it harder for you to recover from them.
- High platelets can make your blood clot more easily than usual.

Your doctor will monitor your blood counts during check-ups.

Bleeding

Around 1 in 10 people with MF have a bleeding episode before or around the time of their diagnosis. You may experience unusual bleeding or heavier bleeding than normal for you. This is most likely due to low platelets or abnormal platelets.

Contact your haematology team if you develop:

- Nosebleeds
- Bruising easily
- Bleeding gums
- Heavier or longer periods than usual
- Blood in your pee or poo

If you cut yourself, you may find you bleed longer than usual. Applying pressure to small cuts or wounds with a sterile bandage may help stop the bleeding.

Seek urgent medical help if:

- You are coughing up blood
- You cannot stop the bleeding from a cut or a wound
- You have blood in your sick (this may look like coffee granules)

Blood clots

About 1 in 10 people with primary MF have had blood clots by the time they are diagnosed. Blood clots are the first sign that they have MF for some people. This is because they are most likely to happen in the earlier stages of MF when you usually have higher levels of white blood cells and platelets. This makes your blood more 'sticky' and more likely to clot.

You may develop blood clots anywhere in your body. They are more likely to happen in your arteries than your veins and can cause serious problems that can be life-threatening.

- Clots in your brain can cause a stroke or mini-stroke
- Clots in your heart can cause a heart attack
- Clots in your legs or arms may break free and travel to your lungs causing a blockage (pulmonary embolism)
- Clots in your tummy may damage your internal organs

Depending on where blood clots develop, you might also get tummy pain, eye pain, problems with your vision, headaches or fits.

Always trust your instincts and seek medical help if you think you have a blood clot. Go to 111.nhs.uk, call 111 or speak to your haematology team.

Seek immediate medical help if you develop symptoms of serious blood clots including:

- Throbbing or cramping pain, swelling, warmth or redness of your leg or arm (redness may be harder to see on black or brown skin)
- Sudden breathlessness, sharp chest pain, cough or coughing up blood
- A feeling of pressure, heaviness, tightness or squeezing across your chest, which may spread to your arm or jaw (the pain may be severe or feel similar to indigestion)
- Drooping on one side of your face, inability to hold both your arms up, or problems speaking, such as slurred or garbled speech

Gout

MF can lead to high levels of uric acid in your blood. This can cause painful crystals to form in your joints. This is called gout.

Symptoms of gout include:

- Sudden severe pain in a joint, often the big toe but it can happen in other joints, such as your hands, feet, ankles, wrists or elbows
- Red or purplish skin over the affected joint (this may be harder to see on black or brown skin)
- A hot, swollen, shiny area over the affected joint

Bone pain

Over time MF can cause your bones to harden and thicken (osteosclerosis). This can cause severe pain in your joints or bones, usually in the later stages of MF.

"It takes time to get used to having MF. There are always ups and downs that take you by surprise. I've had to learn to roll with it, which has taken a while!"

James, living with MF since 2023

If you'd like to talk to someone who understands what you're going through:

- Call our freephone helpline on **08088 010 444**
- Message us through WhatsApp on **07500 068065**
- Email **support@leukaemiacare.org.uk**

Transformation of MF

MF is a generally slow-growing, life-long blood cancer. Sometimes, though, it can develop or **transform** into a faster-growing blood cancer called acute myeloid leukaemia (AML). If this happens, you will need different treatment.

There is a lot of overlap between AML symptoms and MF symptoms. If your MF transforms, your symptoms might get worse. Your haematology team will also monitor you for signs your MF may have transformed so they can treat it promptly if it develops.

When leukaemia develops from an MPN like MF, one of the signs of transformation is a higher level of immature blood cells in your blood.

The chance of developing AML varies from person to person. In general, up to 1 in 5 people with MF develop AML within 10 years of diagnosis. This means more than 4 in 5 do not. Transformation can happen in primary or secondary MF.

Scientists are working on studies to predict which people with MF are most likely to develop AML. The factors we know about so far are all beyond your control. They include your age, sex, your MF stage at diagnosis and how your MF develops.

For more information on acute myeloid leukaemia (AML), follow the link, scan the QR code, or search for 'AML' at leukaemiacare.org.uk

Diagnosis of MF

Summary

- Your haematology team will diagnose MF based on:
  - Blood tests
  - Bone marrow tests
- You might have other tests or scans, depending on your symptoms.
- Your test results and other factors are used to work out how much of a risk MF poses to your health.
- Your haematology team will work out whether you are in a low, medium or high-risk MF group based on how slow growing your MF is and how likely it is to transform into leukaemia.
- It can be difficult waiting for and coming to terms with test results. We are here for you if you need support. You can:
  - Email us at support@leukaemiacare.org.uk
  - Message us on WhatsApp at **07500 068065**
  - Or call our freephone helpline at **08088 010 444**

Diagnosis of MF

Your doctor may suspect you have MF based on a blood test for something else, or from your symptoms. You'll need further tests to make sure their diagnosis is right.

You'll be referred to a blood specialist (a haematologist) in the hospital. You usually have tests done as an outpatient and go home the same day.

Some tests may be repeated throughout your care to check how your MF is progressing or how you are responding to treatment.

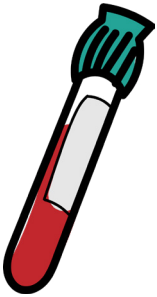
Tests for MF

A range of tests are used to diagnosis MF including blood tests, bone marrow tests and genetics tests.

Blood tests

You will have blood tests to:

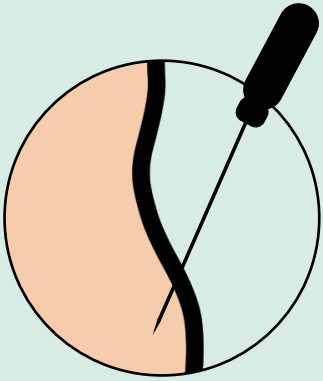
- Measure your numbers of red blood cells, white blood cells and platelets
- Look for abnormal blood cells under a microscope
- Check how well your liver and kidneys are working



Bone marrow test

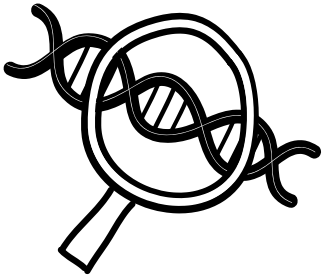
If your team think you might have MF, they will do a bone marrow test. This involves taking a sample of your bone marrow, usually from your hip bone, with a local anaesthetic. They send the sample to the lab for testing.

To have a bone marrow test:



- You have a local anaesthetic to numb the area where you're having the test. This is usually your hip bone (pelvis).
- Your haematologist then uses a special needle to suck out a sample of liquid bone marrow. This is called a bone marrow aspiration.
- They also take a small sample of harder bone marrow using a larger needle. This is called a bone marrow biopsy.
- A bone marrow test can be uncomfortable during and after the procedure. Ask your doctor or nurse what painkillers you can use, if you need them.
- You should avoid vigorous exercise for 24 to 48 hours afterwards.

Genetic tests



Your blood or bone marrow samples will go to the lab for specialised tests to look for genetic changes in your cells. They will test for changes in *JAK2*, *CALR* or *MPL* genes common in people with MF:

- Up to 60 in 100 people have a change to the *JAK2* gene.
- Up to 35 in 100 people have a change to the *CALR* gene.
- Up to 9 in 100 people have a change to the *MPL* gene.

Identifying these genetic changes helps your team diagnose MF. You might have more than one genetic change.

About 10 in 100 people with MF don't have any of these genetic changes. This is called triple-negative MF. In this case, your team will use the results of other genetic tests and your signs and symptoms to make an accurate diagnosis.

"It's very scary being diagnosed but the NHS have been amazing. They are very good at this."

James, living with MF in 2023

Other tests

You might have an ultrasound, CT or MRI scan to check the size of your liver and spleen. Not everybody with MF needs these tests.

Your test results may take a few weeks, which can be a worrying time for you. Your haematology team need all the results to make an accurate diagnosis. It can also help them decide the most suitable treatment options for you if you need treatment.

We are here for you if you need support whilst you are waiting for your results. You can email us at support@leukaemiacare.org.uk, message us on WhatsApp at **07500 068065** or call our freephone helpline at **08088 010 444**.

Risk groups

Your haematology team will use your test results and other factors to work out how much of a risk MF is to your health. They will work out your risk score based on:

- Your age
- Your symptoms
- Your blood counts
- Any genetic changes in your blood cells
- The number of immature blood cells in your blood

They may reassess your score at times, and it could change. Let them know if you think your MF is changing or getting worse.

Your doctor will use your score to work out whether you have low, medium (intermediate) or high-risk MF. In broad terms, risk groups reflect:

- Whether your MF is slow-growing or not
- How likely your MF is to transform into leukaemia

Your haematology team will use your risk group to work out the best treatment plan for you.

"A cancer diagnosis can make you feel incredibly lonely, particularly rare ones like MPNs. Leukaemia Care have a brilliant one-to-one buddy service, and they also run support groups online and in person. Support networks can be so helpful, whether you just need to sound off about having a rubbish day or ask advice about symptoms and treatments."

Lucy, living with MF since 2020

You are not alone

Sometimes it can help to talk to someone who really understands what you're going through because they've been there too. Our support services include peer support groups and a buddy service, where you may be able to connect with people with the same or a similar condition as you.

If you'd like to talk to someone who has experienced MF:

- Call our freephone helpline on **08088 010 444**
- Message us through WhatsApp on **07500 068065**
- Email **support@leukaemiacare.org.uk**

Treatment of MF

Summary

- You'll have regular check-ups to monitor your MF.
- You might not need treatment straight away and be offered 'active monitoring' instead.
- If you need treatment, your haematology team will recommend the best options for your individual circumstances.
- Treatment aims to:
  - Improve your blood counts
  - Manage your symptoms
  - Slow the progression of MF
  - Improve your quality of life
- The main treatment options are JAK inhibitors, chemotherapy and interferons.
- Although uncommon, some people might be offered a stem cell transplant. This is the only possible cure for MF but it is not suitable for everyone.
- You might also have treatment to prevent or manage complications of MF.

Treatment of MF

Your doctor will regularly monitor your MF and offer treatment if you need it. Not everyone needs treatment straight away. If you are in a lower MF risk group, you may be offered 'active monitoring' instead (page 30).

You might have treatment to:

- Lower your blood counts
- Manage your symptoms
- Shrink your spleen
- Prevent blood clots or bleeding, if you're at risk
- Increase your red blood cell count, if you have anaemia
- Slow the progression of your MF
- Improve your quality of life

Most current treatments aim to control MF rather than cure it. Some people with higher-risk MF might be able to have a stem cell transplant, which can cure it. However, it is a very intensive treatment and not suitable for everyone.

Your haematology team will talk to you about your treatment options. Your loved ones or carers can also be involved in these discussions if you'd like them to be. This can help you reach an informed decision that is right for you.

Your haematology team

The multidisciplinary team looking after you often includes:

- A haematologist
- A clinical nurse specialist
- A pathologist
- A pharmacist
- A radiographer
- A radiologist

"I've always felt supported whilst I've been ill and have experienced a fantastic set of health professionals at the hospital who really care and who always cheer me up when I see them!"

James, living with MF since 2023

Monitoring MF

Whether you are having treatment or not, you will have regular check-ups.

What happens during check-ups?

Regular check-ups usually include blood tests, including a full blood count, and an examination of your tummy to check how swollen your spleen is. You may need other tests depending on your symptoms.

Your team will ask if you've noticed any new symptoms or changes to your symptoms. You might be able to download an app onto your smartphone or tablet to help track your symptoms (see page 30). Your team may ask you to share information from your app or your symptom diary if you've been keeping one, or to fill out a symptom assessment form. This can help monitor your health.

You may also need regular check-ups with your GP to monitor your heart health. This may be the case if you are at risk of blood clots or bleeding or have other conditions, such as heart disease or diabetes.

"Get on board with the healthcare team who are looking after you, both at your GPs and your hospital. If you feel they're not the right fit for you, find an MPN specialist and request a referral from your GP. This is your MPN journey and it's too important for you to accept any unsupportive treatment."

Lucy, living with MF since 2020

My MPN Voice app

You can use the free My MPN Voice app to track your symptoms for your records or as part of a patient-led research study too. The study aims to find out whether a smartphone app could improve symptoms and quality of life for people with MPN.

For more information, follow the link, scan the QR code or visit www.mpnvoice.org.uk and search for 'my MPN Voice app'.

Active monitoring for MF

If you don't have any symptoms and your MF is not causing you any problems, you're unlikely to need treatment straight away. Instead, you may be offered regular monitoring. This is called 'active monitoring' or 'watch and wait'.

It can be confusing and unexpected to be told you have MF but not be offered treatment.

However, if you are symptom-free and have lower-risk MF, it's often better to wait to start treatment if and when you need it. That way you can avoid treatment side effects for as long as possible and ideally enjoy a better quality of life.

If you are worried about your health or become concerned about new or worsening symptoms at any time, contact your GP or haematology team. You don't have to wait until your next check-up.

Treatment for MF

If you need to start treatment, your haematology team will discuss your options with you. They will recommend treatments based on:

- Your preferences
- Your MF risk group
- Your symptoms
- Any genetic changes in your blood cells
- Your age, general health, and any other health conditions you may have

They will also discuss the side effects of treatments with you (see page 39).

Treatment options for MF

Some treatments for MF work by improving levels of blood cells. They include:

- Targeted medicines called JAK inhibitors
- Chemotherapy
- Peginterferon

Your haematology team may recommend a single treatment or a combination of treatments.

Targeted medicines

These are medicines designed to block specific proteins on cancer cells. This means they kill cancer cells with as few effects on healthy cells as possible.

JAK inhibitors

JAK inhibitors are targeted medicines that block proteins involved in blood cell production. These proteins are often abnormal in people with MF. They encourage your bone marrow to make too many blood cells.

By blocking these proteins, JAK inhibitors reduce the number of blood cells your body makes. They are often used to treat MF either on their own or in combination with other drugs as part of a clinical trial (see page 38).

JAK inhibitors can:

- Reduce the size of your spleen
- Improve your symptoms
- Improve your blood counts
- Improve your quality of life

JAK inhibitors come as tablets or capsules that you take at home once or twice a day. They include:

- Ruxolitinib
- Momelotinib
- Fedratinib

The Electronic medicines compendium has more information about JAK inhibitors and other MF medicines. Follow the link or scan the QR code and search for your medicine at www.medicines.org.uk/emc

You will have tests and scans before starting JAK inhibitors to make sure they are right for you. You will also have regular blood tests while you're taking them, to check your blood counts.

Like all medicines, JAK inhibitors can cause side effects. Your haematology team will explain what to look for and what to do if you get them. If you get troublesome or severe side effects, tell them. They may be able to adjust your dose or offer you a different treatment option.

Some food and medicines interact with JAK inhibitors. Tell your haematology team about any medicines or supplements you are taking. This includes any you have bought yourself without a prescription. Depending on which JAK inhibitor you take, you may need to avoid grapefruit or grapefruit juice.

Do not stop taking ruxolitinib, momelotinib or fedratinib without talking to your haematology team first. You might become seriously ill from suddenly stopping these medicines.

Ask your haematology team for a Medication Alert Card to keep in your wallet or handbag. In a medical emergency, these cards let people know what medicine you are taking and help keep you safe.

Chemotherapy

Your doctor may recommend a chemotherapy drug called hydroxycarbamide to lower your blood counts and help control your symptoms. Hydroxycarbamide is also known as hydroxyurea.

Your doctor might recommend hydroxycarbamide if you have a high white blood cell count, particularly in the early stages of MF.

You take it as a tablet or capsule by mouth. Most people take it every day. But some people only take it on certain days of the week. Your haematology team can tell you which dose is best for you based on your individual case.

We have separate information about hydroxycarbamide. Follow the link, scan the QR code or search for 'downloads' at www.leukaemiacare.org.uk

Peginterferon

Peginterferon is a targeted medicine that changes how your immune system works. It is a form of immunotherapy that helps stop cancer cells from growing and multiplying. Peginterferon is also known as interferon or peg-IFN.

Your team might recommend peginterferon if you are young or pregnant.

You have peginterferon as an injection, usually once a week or less. You can be taught to inject it yourself, or a carer can inject it for you. Otherwise, a GP or nurse can give you the injection.

Peginterferon can affect your central nervous system. It is not recommended for people with a history of severe psychiatric conditions, including depression.

Cancer Research UK have more information about peginterferon. Follow the link, scan the QR code or visit www.cancerresearchuk.org and search for 'peginterferon'.

Other treatments

You may be offered other treatments depending on your symptoms and MF risk group.

Having your spleen removed

This is very rarely needed because MF medicines are usually effective. However, if your spleen becomes very swollen and does not improve with medicines, your team may suggest an operation to remove it (splenectomy). This may be a good option for you if your spleen is so big that it is causing:

- Severe pain or discomfort in your tummy
- High blood pressure in the vein that runs through your liver (portal hypertension)
- Frequent need for blood transfusions

Your doctor will discuss the risks and benefits of having your spleen removed for you as an individual. Another option they might discuss with you is radiotherapy to your spleen.

Macmillan have more information on having your spleen removed. Follow the link, scan the QR code or search for 'splenectomy' at www.macmillan.org.uk

Stem cell transplant

A stem cell transplant replaces damaged or destroyed blood-forming cells in your bone marrow with healthy ones from a matched donor. A stem cell transplant has the potential to cure MF in some people but it is a very intensive form of treatment. It is not suitable for everyone.

Your team might recommend one for you if you are fit enough to have one and:

- You have higher-risk MF or
- You have medium-risk MF and:
  - You have particular genetic changes in your blood cells
  - Your MF has not responded to other treatments

If a stem cell transplant is an option for you, your team will explain the risks and benefits.

We have separate information on stem cell transplants. Follow the link, scan the QR code or search for 'stem cell transplant' at leukaemiacare.org.uk

Clinical trials

Your haematology team may ask if you'd like to take part in a clinical trial, if there is one suitable for you. This is a research study that aims to find out what treatments work best for particular conditions.

Taking part in a clinical trial may give you access to treatments that are not routinely available. There are risks and benefits to taking part, which your haematology team should explain to you.

It is your decision whether to join a clinical trial. You can withdraw from a trial at any time.

"Consider taking part in medical trials. My consultant found a research trial for me, and now my care is shared between my local hospital team and the research doctors. This has honestly been invaluable; in practice it means I get a second opinion on my treatment and my local consultants are more than happy with this."

Lucy, living with MF since 2020

Cancer Research UK have more information about clinical trials. Follow the link, scan the QR code or visit www.cancerresearchuk.org and search for 'find a clinical trial'.

Side effects

Most medicines have side effects including treatments for MF. Some side effects can be temporary while your body gets used to a medicine.

They vary depending on what treatment you are having. They can also vary from person to person, even with the same treatment.

In MF, some of the more common side effects include changes to your blood counts and frequent infections. Some medicines might increase your risk of skin cancer, so you need to protect your skin from the sun and regularly check for skin changes.

When to call your doctor about side effects

Contact your haematology team if you develop:

- Bleeding that is heavier than usual or takes longer to stop such as nose bleeds, bleeding gums or heavy periods
- Unusual bruising such as tiny spots under your skin. These may look red or purple on white skin or purple or darker brown on black or brown skin.
- Feeling weak or very tired
- Dizziness or fainting
- Tummy upset such as feeling sick, being sick or diarrhoea
- Fever or chills
- Sore throat, body aches or other flu-like symptoms
- Changes to a mole or new or unusual marks on your skin that don't go away on their own

Side effects can make a big difference to your quality of life and not just while you're being treated. Some may cause health problems months or years after treatment. It's important to consider possible side effects when deciding which treatments are right for you.

Your haematology team should explain the most common side effects of the treatments they are offering you. They should also discuss severe side effects to be aware of, and how and when to seek help if you are worried.

If you are pregnant or breastfeeding, it is particularly important to discuss treatment safety and side effects. Many medicines used to treat MF are not safe to use during pregnancy or while breastfeeding, and you may be advised to avoid pregnancy if you are taking one.

The Electronic medicines compendium has more information about JAK inhibitors and other MF medicines. Follow the link or scan the QR code and search for your medicine at www.medicines.org.uk/emc

Supportive treatments

Your haematology team may offer you other treatments to help prevent or manage complications of MF. These supportive treatments help you to have a better quality of life.

Treatments for anaemia

If you have a low red blood cell count (anaemia), your haematology team might recommend a medicine called erythropoietin, or EPO for short. It is a type of growth factor that stimulates your body to make red blood cells.

You have EPO as an injection under the skin, usually once a week although this may vary depending on the product. You can learn how to give yourself an EPO injection at home, or a carer can inject it for you.

If your red blood cell count is very low, causing symptoms, or if the injections don't improve your red blood cell count, you might need a blood transfusion. This is a procedure to give you donated blood through a drip into a vein.

Some people need regular blood transfusions. In this case, you may also need medicine to stop your body from taking in too much iron.

The NHS has more information about blood transfusions. Scan the QR code, click the link or search for 'blood transfusion' at www.nhs.uk

Treatments to prevent bleeding

If your platelets are low and you're at risk of bleeding, JAK inhibitors (page 32) often help. But they can also cause low platelets as a side effect, especially at the start of treatment. Your haematology team will monitor your platelet count and might adjust your dose or stop treatment for a while if it drops too low.

Sometimes, your haematology team might suggest other treatment options. It depends on how low your platelets are.

Some people with bleeding need to have a platelet transfusion. This is when you have platelets from a donor through a drip into a vein.

Treatments to prevent blood clots

Your haematology team might recommend daily low-dose aspirin to thin your blood if your blood is 'sticky' and you're at risk of blood clots (page 16).

Treatments to prevent gout

Your haematology team might recommend a medicine called allopurinal if your uric acid levels are high. It comes as tablets that you take every day. It lowers levels of uric acid in your blood and helps prevent gout.

Treatments for infections

Some MF treatments can weaken your immune system and make you more likely to get infections. You might be more likely to get coughs, colds or tummy upsets, which might be more severe than usual.

A pre-existing infection might also flare up. You might get shingles, which can develop if you've ever had chicken pox. Your haematology team will screen you for some infections that might cause problems, such as hepatitis and HIV. You may have these conditions without realising it.

Make sure you have any vaccinations or preventative medicines your haematology team recommend to help keep you well. Live vaccines may not be suitable for you but it is safe to have non-live vaccines. Ask your haematology team if you are not sure which vaccines you should have.

If you get an infection, you might need antibiotic, antiviral or antifungal medicines to help you recover.

Talk to your haematology team

Always seek advice from your haematology team if you're unsure about the right supportive treatments for you. Or if you have any questions about how they might help.

Outcomes of MF

Summary

- Outcomes of MF vary from person to person. They depend on lots of different factors, including your MF risk group.
- People with lower-risk MF usually have better outcomes and a longer life expectancy than people with higher-risk MF.
- Survival rates are only averages. It is not possible to predict for certain what will happen for you.
- Your haematology team are best placed to discuss what they expect for you because they know your individual circumstances.

Outcomes of MF

Outcomes for people with MF vary from person to person depending on their risk group and other factors.

It is important to understand that your risk group helps your haematology team look after you and offer you the best treatment for your situation. It cannot tell you how and when your MF will affect you, or how your MF may respond to treatment.

As a general guide, the lower your MF risk group the better your outlook. This is because lower-risk MF is slow-growing and less likely to pose a risk to your health. You are less likely to develop the faster-growing blood cancer, acute myeloid leukaemia.

For more information on acute myeloid leukaemia (AML), follow the link, scan the QR code, or search for 'AML' at leukaemiacare.org.uk

If you are interested in general survival rates for MF, we include some figures on the next page. You may prefer not to look at these.

It is important to remember that survival numbers cannot tell you what will happen in individual situations. They look at what happened to groups of people with a similar diagnosis in the past. They are based on data collected over many years, when people may not have received treatments available now.

In blood cancers, 5-year survival rates are commonly quoted. This is the proportion of people with a particular condition who are still alive 5 years after diagnosis.

Survival rates do not tell us anything about what people who are not alive 5 years after diagnosis died from. It may have been the condition or from another cause.

Your overall chance of surviving 5 years after diagnosis of MF is estimated to be:

- About 75 in 100 if you were diagnosed under 60 years of age
- About 54 in 100 if you were diagnosed at 60 years or more

Your MF risk group can make a big difference to your outcomes. Looking at the longer term, your chance of surviving 10 years after diagnosis is estimated to be:

- Up to 92 in 100 for low-risk MF
- About 30 in 100 for medium-risk MF
- Up to 13 in 100 for high-risk MF

If you want to know as much as possible about your outlook, talk to your haematology team. They will consider everything they know about you, your MF and the care they can offer you.

Remember, your team will recommend the best treatment for your risk group and your individual situation.

If you are struggling to come to terms with your diagnosis, you can speak to us on our helpline on 08088 010 444.

Living with MF

Summary

- Having MF can affect your day-to-day life and impact you emotionally and physically.
- You may experience a variety of emotions. There is no right or wrong way to feel. If you think you may be depressed, contact your GP.
- You might want to talk to your friends and family about your condition. Remember, this is your choice. You can choose when to tell them and how much.
- You might experience fatigue. Pacing yourself and saving energy for things that are important to you can help.
- Keep active and eat a healthy, balanced diet, if you can, to help your general fitness.
- Having MF can affect your work and finances. You are entitled to reasonable adjustments to help you cope at work. You may also be eligible for financial support.
- You probably have a lot of questions. Make a list of them so you don't forget to ask them when you see your haematology team.
- If you are struggling, ask for help from friends, family, your haematology team or Leukaemia Care.

Living with MF

Being diagnosed with MF can be overwhelming. It can affect you both physically and emotionally. Your symptoms, side effects of treatment, and hospital appointments may all impact your day-to-day life. Here, we cover some practical information about living with MF and where to get support.

Managing your emotions

Being diagnosed with cancer can be very upsetting. You may experience a range of complex thoughts and emotions, which may be strange and unfamiliar to you.

You may feel:

- Shock or disbelief
- Uncertainty, anxiety or fear about the future
- Sadness or depression
- A sense of loss of the person you used to be, and how safe you felt
- Worry about other people's reactions
- Isolation, or a feeling that other people don't understand what you're going through
- Guilt, anger, frustration or irritability
- A loss of self-confidence

Everybody reacts differently. You may experience some of these emotions but not others. You might have different feelings at different times. There is no right or wrong way to feel.

"Find your support tribe. I found MPN patients local to me through an MPN support page on Facebook; now we have an active WhatsApp group and regularly get together for coffee and lunch. No one understands what you're going through - even the most supportive people - like other MPN patients."

Lucy, living with MF since 2020

Sadness and depression

You might be feeling low, which is a natural effect of your diagnosis and treatment. However, you may have depression if:

- Your low mood persists for several weeks
- You feel hopeless
- You lose interest and pleasure in life

If you think you may be depressed, it is important to contact your GP. They can help you access the support and treatment you need.

If you are in crisis, the NHS has urgent mental health helplines that offer 24-hour advice and support. Scan the QR code for details or go to the 'mental health' section at www.nhs.uk

Telling other people

When you are first diagnosed with MF, there is a lot to take in. You may need to give yourself time to adjust before you decide when and how you tell others about it. There will be some people that you want to tell and others you prefer not to. It is up to you who you tell and how much you tell them.

People may be anxious to know what is happening, which can make you feel under pressure to tell them. Let them know you need time to process the information yourself first.

In the conversation with your loved ones, you might want to:

- Explain that you have a condition that means your bone marrow doesn't work properly and this affects the blood cells it produces.
- Tell them what symptoms you get and how they affect you.
- Explain what treatment you might be offered. You might want to talk about your possible outcomes.
- Explain your needs. Your family and friends may be happy to know they can support you by helping around the house or doing the food shop.
- Be open and honest about how you feel. People who care about you will want to help you as best as they can.
- Have a print-out or factsheet handy so you don't have to remember everything. Or you could use this booklet.

"Sometimes all we need is to just talk about our health. I don't need people to get a violin out for me, but I do want empathy and understanding."

Andrea, living with an MPN since 2011

Coping with fatigue

One of the main symptoms of MF is fatigue. This feeling of extreme tiredness or lack of energy can interfere with your usual activities. Fatigue can be very frustrating as it doesn't get better with rest and cannot be treated with medicines. If you are having treatment for MF, you might find your fatigue gets better over time as the treatment starts to work.

Tips for coping with fatigue

- Plan activities and pace yourself:
  - Prioritise things that are important to you and save energy for these
  - Accept help where you can
- Balance rest and exercise:
  - Take regular, gentle exercise
  - Rest when you need to
  - Try yoga or meditation as these can help
- Keep to a regular sleep schedule:
  - Try to go to bed and wake up at around the same time each day
  - Keep your bedroom quiet and at a comfortable temperature
  - Avoid eating or drinking alcohol, coffee, tea, or chocolate before bedtime
  - Avoid using laptops, tablets, or smartphones before going to bed

Tell your haematology team if you are experiencing fatigue. They may be able to suggest things to help or refer you for support if you need it.

We have more resources to help you cope with fatigue on our website. Scan the QR code to find out more, or search for 'fatigue' at leukaemiacare.org.uk

Healthy living

It is important to look after yourself well. Making small changes to your lifestyle can help you stay as well as possible after diagnosis and during treatment.

Living healthily has many benefits. Besides improving the quality of your life, it can help you cope with fatigue and other effects of MF and reduce your risk of blood clots.

> **"I strongly advise people with an MPN to take good care of their general health, watch their weight, exercise, don't smoke, monitor their blood pressure and cholesterol - this also reduces their risk of blood clots including stroke and heart disease."**
>
> Professor Claire Harrison, Consultant and Deputy Chief Medical Officer

Having a healthier lifestyle

Adopting a healthier way of living is about making small, manageable changes to your lifestyle. If your current lifestyle is less than ideal, it's best to pace yourself and avoid changing too much at once.

Diet

If you can, try to eat a healthy, well-balanced diet. This will help you:

- Feel stronger
- Have more energy
- Cope better with your treatment
- Improve your heart health

Side effects from some treatments, such as sickness and diarrhoea can make it difficult to eat a healthy diet. If you are struggling, ask your haematology team for advice.

The NHS website has information and guidance on eating a healthy, balanced diet. Scan the QR code, or go to the 'live well' section at www.nhs.uk

Exercise

Exercise can improve your heart health, quality of life and wellbeing. It can also help to reduce some of the side effects and symptoms you may be experiencing, such as fatigue.

You may not feel like being active, especially if you are experiencing fatigue. Remember, even a gentle walk can help. Choose a level of exercise that works for you and how you are feeling.

Sun safety

Skin cancer has become much more common in the UK. Some medicines for MF, such as hydroxycarbamide and ruxolitinib, can also increase your chance of getting skin cancer. You need to protect yourself from the sun and be particularly mindful of any skin changes.

Tips for preventing skin cancer

- Keep to the shade between 11am and 3pm on sunny days.
- Cover your skin with clothes, including a hat, shirt and sunglasses.
- Use a high-protection sunscreen of at least SPF 30 with UVA protection too. Apply it generously and often.
- Get to know what's normal for your skin by checking it regularly.
- Tell your doctor about any changes to a mole or any new or unusual marks on your skin that haven't gone away within 2 months.
- Go for annual skin checks if you're referred for them.

Work and education

Being diagnosed with MF and having to juggle work or education with hospital or GP appointments can be challenging. Your diagnosis, managing symptoms or side effects, or going to appointments may mean you need time off from work.

Your haematologist or GP can write letters to your employer to confirm your diagnosis and how this may affect your work life. This can help your employer have arrangements in place for when you need time off and to discuss how else they can support you.

If you are diagnosed with MF while you are at school or university, you should contact them. They might be able to offer you extra support, pause your studies, or defer your attendance for a while if you need it.

"One thing I'll say for MF is that it's chronic, not acute. That means I've had time to adjust and reconcile with my cancer, a luxury which isn't the experience of many cancer patients. My life may not be the life I envisaged but I consider myself really fortunate. I have MF treatment which suits me, healthcare which is free at the point of access, a home, love, and support."

Lucy, living with MF since 2020

Money and financial help

Your MF diagnosis may also affect your finances, whether or not you are working. Being diagnosed with MF can come with extra costs, such as travel to and from hospital, childcare costs or parking charges.

You should be able to get free NHS prescriptions as a person with cancer. Your haematology team or GP can tell you how to apply.

Charities and financial support

We have a range of **services that can help you**, including a welfare service and cost of living hub. Follow the link, scan the QR code or search for 'support for you' at **leukaemiacare.org.uk**

Macmillan have **information on benefits and financial support**. Follow the link, scan the QR code or search for 'benefits and financial support' on **www.macmillan.org.uk** for more information. Or contact them on **0808 808 0000** to discuss your eligibility for benefits, grants and support available.

Going to appointments

Hospital and GP appointments often involve a lot of waiting around. You could download a podcast or TV programme to keep you occupied while you wait. Or take something physical like a book or travel game.

Once you're in your appointment, it can be hard to take in everything your doctor or nurse is telling you.

Here are some tips to help you get the most from your appointment:

- It can help to take a family member or friend with you for support.
- Ask any questions that you may have. If you don't understand something, ask your medical team to explain. They will be used to this.
- You can take notes on your phone or paper to help you remember. You can always ask your doctor or nurse to make notes for you or ask if they are happy for you to record the conversation.
- Be open and honest when discussing your symptoms and how you are coping. You and your haematology team are working together to keep you well.

"The confidence to push back or ask questions doesn't always come naturally or quickly; it takes time to build. But when you do, you know you're advocating for your best care, and it is empowering to be able to do that."

Andrea, living with an MPN since 2011

Questions for appointments

Sometimes it can be overwhelming to know what to ask in your appointments. Some questions you might want to ask include:

- What tests will I need?
- What might these tests show?
- How long will it take to get the results back?
- What treatment will I need and how long for?
- How will I know if my treatment has worked?
- What might the side effects be?
- Are there any foods or medications I need to avoid?
- Will I be able to go back to work?
- Where can I get help claiming benefits and grants?
- Where can I get help dealing with my feelings?

Medical terms you might hear

Acute myeloid leukaemia (AML): a fast-growing type of blood cancer that starts in blood-forming cells called myeloid stem cells.

Anaemia: a low red blood cell count.

Bone marrow: the spongy centre of some of your larger bones where blood cells are made.

***CALR* gene:** the gene that codes for a protein called calreticulin (CALR). CALR helps your cells to function normally.

Cancer: an illness that happens when abnormal cells grow and divide uncontrollably.

Chemotherapy: medicine that kills cancer cells or stops them dividing and multiplying.

Clinical nurse specialist (CNS): an experienced nurse who has specialised in a particular area of nursing. They can offer you advanced care, support, advice and guidance.

CT scan: a scan that uses X-rays and a computer to make detailed pictures of the inside of your body.

Diabetes: a common lifelong condition that causes your blood sugar level to become too high.

DNA: the genetic code that tells your cells how to grow and behave.

Essential thrombocythaemia (ET): a type of myeloproliferative neoplasm where your body makes too many platelets.

Gene: a section of DNA that tells your cells how to make a particular protein.

Genetic changes: changes to genes that can affect the proteins a cell makes. This may change how a cell behaves and grows. They are also known as genetic variants.

Gout: a type of arthritis in which small crystals of uric acid form inside and around your joints. This can cause sudden, severe joint pain.

Haematologist: a doctor who specialises in diseases of the blood.

Haematology: the branch of medicine that deals with diseases of the blood.

Hydroxycarbamide: a chemotherapy medicine that helps lower your blood cell counts.

JAK inhibitors: targeted medicines that block proteins involved in blood cell production.

***JAK2* gene:** the gene that codes for the JAK2 protein, which helps regulate blood cell production.

Liver: a large organ in your body that sits under your ribs on the right. It helps fight infection and disease, balances your hormones, cleans your blood and processes food.

Local anaesthetic: a medicine to numb part of your body so you don't feel any pain during medical procedures.

Mini-stroke: a temporary disruption in the blood supply to your brain. Also called a transient ischaemic attack (TIA).

MRI scan: a scan that uses strong magnets to take detailed pictures of the inside of your body.

***MPL* gene:** the gene that codes for a protein that helps control the number of blood cells in your bone marrow, particularly your platelets.

Multidisciplinary team: the healthcare professionals who work together to treat you.

Myelofibrosis (MF): a type of cancer where your bone marrow becomes filled with scar tissue, which stops it making enough healthy blood cells.

Myeloproliferative neoplasms (MPN): blood cancers that develop when cells in your bone marrow grow out of control and make too many blood cells.

Pathologist: a doctor who specialises in testing blood and tissue samples.

Pharmacist: a specialist in medicines and how they work.

Platelet: a type of blood cell that helps your blood clot and stops bleeding.

Polycythaemia vera (PV): a type of cancer where your bone marrow makes too many red blood cells.

Post-ET MF: secondary myelofibrosis (MF) that develops from another type of blood cancer called essential thrombocythaemia (ET).

Primary myelofibrosis (MF): when myelofibrosis develops in a person who has not had bone marrow problems before.

Proteins: the building blocks of every cell, tissue and organ in your body. Your body needs proteins for growth, repair, and to fight infections.

Radiographer: a healthcare professional who uses specialist equipment to take images of the inside of your body. They work as part of a team to diagnose and treat illnesses.

Radiologist: a doctor who specialises in using medical imaging to diagnose, treat and monitor diseases and injuries.

Radiotherapy: treatment that uses high doses of radiation to kill cancer cells.

Red blood cell: a type of cell in your blood that carries oxygen around your body.

Ruxolitinib: a targeted medicine sometimes used to treat myelofibrosis.

Secondary myelofibrosis (MF): when myelofibrosis develops from another myeloproliferative neoplasm MPN, such as essential thrombocythaemia (ET) or polycythaemia vera (PV).

Spleen: a fist-sized organ that sits under your ribs on the left side. It filters and stores blood and makes some blood cells.

Stem cells: immature cells in your bone marrow that can develop into all the different blood cells your body needs.

Stroke: a serious medical condition that happens when the blood supply to a part of your brain is suddenly cut off.

Targeted medicines: medicines designed to block specific proteins on cancer cells.

Transformation: when one type of blood cancer develops into another type, usually a faster-growing one.

Transfusion: having blood or blood products through a drip into a vein.

Ultrasound: a scan that uses sound waves to look at the inside of your body.

Uric acid: a waste product your body makes when it breaks down chemicals called purines. These are naturally produced in your body and also come from foods or drinks.

White blood cells: cells in your blood that help your body fight infections.

Useful contacts and further support

There are a number of helpful sources to support you during your diagnosis, treatment and beyond, including:

- Your haematologist and healthcare team
- Your family and friends
- Your psychologist (ask your haematologist or CNS for a referral)
- Reliable online sources, such as Leukaemia Care
- Charitable organisations

Leukaemia Care

Helpline: 08088 010 444 (Monday to Friday, 9am to 4:30pm)

WhatsApp: 07500 068065 (Monday to Friday, 9am to 5pm)

www.leukaemiacare.org.uk

support@leukaemiacare.org.uk

Macmillan

Provide free practical, medical and financial support for people facing cancer.

0808 808 00 00

www.macmillan.org.uk

MPN voice

Provide information, community and advocacy for MPN patients, their families and carers.

07934 689 354

www.mpnvoice.org.uk

Blood Cancer UK

Leading charity into the research of blood cancers.

0808 2080 888

www.bloodcancer.org.uk

Cancer Research UK

Leading charity dedicated to cancer research.

0808 800 4040

www.cancerresearchuk.org

Maggie's

Offer free practical, emotional and social support to people with cancer and their loved ones.

0300 123 1801

www.maggies.org

Carers UK

Offers advice, information and support for carers.

0808 808 7777

www.carersuk.org

Citizens Advice

Offers advice on benefits and financial assistance.

0800 144 8848 (England)

0800 702 2020 (Wales)

0800 028 1456 (Scotland)

www.citizensadvice.org.uk

The Citizens Advice service does not cover Northern Ireland but their website lists contact details for local community advice agencies, depending on where you live.

How you can help us

If you've been affected by myelofibrosis, sharing your story can help others going through a similar situation and help the public to better understand.

Scan the QR to share your story:

Alternatively, you can email our Communications team at communications@leukaemiacare.org.uk.

Tell us what you think of this booklet

We aim to provide information that's reliable, up-to-date, and covers what matters to you. We want you to feel supported and able to be involved in decisions about your care. Please follow the link or scan the QR code to complete our short survey to help us improve our information and make sure it meets your needs. Or get in touch with us by email, phone or post.

You can also contact us if you'd like a list of the references we used to compile this booklet.

- Email our Information team at information@leukaemiacare.org.uk
- Call our Head Office on **01905 755 977**
- Write to us at Leukaemia Care, One Birch Court, Blackpole East, Worcester, WR3 8SG
- Leave us a review if you've ordered a booklet online

If we've helped you - here's how you can give back

Fundraising is at the core of what we do here at Leukaemia Care, and without it we wouldn't be able to provide the support we do.

Fundraising isn't all about running a marathon, and there are plenty of ways to give thanks and show your support.

You could:

- Ask your local shop or workplace to host a collection tin
- Ask your place of work about charity of the year partnerships or grants
- Take on one of our more accessible walking challenges
- Host a quiz night or get your friends together for a catch-up and a meal
- Host a bake sale at work or school, or even a coffee morning with friends
- Share information about the activities we have going on to get friends and family joining in
- Stream online from the comfort of your own home

However, if you can run a marathon or want to do a thrilling skydive, we've got you covered!

Whatever you want to do, we can support you to raise money for Leukaemia Care. Get in touch with the fundraising team by email fundraising@leukaemiacare.org.uk or calling **08088 010 444**.

You can also find out more about how to get involved by scanning the QR code.

Plenty of ways to give

There are so many ways you can give in support of those affected by a leukaemia diagnosis, the possibilities are endless - find one that fits you and let's get giving!

By bank transfer

You can transfer your donation straight from your account to ours. Our bank details are:

Sort code: **20-98-61**

Account number: **80823805**

Account name: **Leukaemia Care**

By cheque

Please make your cheque payable to Leukaemia Care, and then pop it in the post to: **Leukaemia Care, One Birch Court, Blackpole East, Worcester, WR3 8SG**

Online

Simply pop onto our website at www.leukaemiacare.org.uk/donate or scan the QR code to donate.

By phone

You can call us to pay by debit or credit card over the phone. Simply call **01905 755977**.

Leukaemia Care is the UK's leading leukaemia charity. For over 50 years, we have been dedicated to ensuring that everyone affected receives the best possible diagnosis, information, advice, treatment and support.

Every year, 10,000 people are diagnosed with leukaemia in the UK. We are here to support you, whether you're a patient, carer or family member.

Want to talk?

Helpline: **08088 010 444**
(free from landlines and all major mobile networks)

WhatsApp: **07500 068065**

Office Line: **01905 755977**

www.leukaemiacare.org.uk

support@leukaemiacare.org.uk

Leukaemia Care,
One Birch Court,
Blackpole East,
Worcester,
WR3 8SG

Leukaemia Care is registered as a charity in England and Wales (no. 1183890) and Scotland (no. SC049802).

Company number: 11911752 (England and Wales).

Registered office address: One Birch Court, Blackpole East, Worcester, WR3 8SG

Leukaemia Care
YOUR Blood Cancer Charity

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Patient Information Forum

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