Myelofibrosis (MF)

Myelofibrosis (MF) is a very rare, slow-growing type of blood cancer. It causes scarring in your bone marrow, stopping it from making enough healthy blood cells. Find out about the signs and symptoms of MF, tests to diagnose it and treatment you may have.

Summary

- Myelofibrosis (MF) causes scarring in your bone marrow, stopping it from making enough healthy blood cells. It is a very rare, slow-growing blood cancer.
- It can develop in people who have not had any bone marrow problems before. Or it can develop from another bone marrow condition.
- We do not know the exact cause of MF. It is not due to something you did or did not do, and you cannot usually pass it on to any children you may have.
- You might not have any symptoms of MF at first but you might get signs and symptoms over time. You may get:
    - Extreme tiredness
    - Night sweats
    - Unexplained fever
    - Itchy skin following a warm bath or shower
- You may develop other health problems caused by MF, such as a swollen spleen or gout. Sometimes, MF can transform into a faster-growing type of blood cancer.
- Your haematology team will use blood tests and bone marrow tests to diagnose MF.
- You'll have regular check-ups to keep a watch on your MF. If you don't need treatment straight away, you'll be on 'active monitoring'.
- Most people who need treatment for MF take tablets called JAK inhibitors. Other options include oral chemotherapy or peginterferon injections.
- You may also need treatments to prevent or manage complications of MF.
- Outcomes of MF vary from person to person. It depends on how your MF affects you, how it progresses and how your MF responds to treatment if you need it.

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What is MF?

Myelofibrosis (MF) is a slow-growing blood cancer. It belongs to a group of conditions called myeloproliferative neoplasms (MPNs).

MF happens when your body makes too many immature blood cells. This causes your bone marrow to become inflamed and scarred. Over time your bone marrow becomes so scarred that it can no longer make enough healthy blood cells.

There are two main types of MF:

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

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Who gets MF?

MF is very rare. Around 380 people are diagnosed with it each year in the UK.

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.

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What causes MF?

We do not know exactly what causes MF. It happens when genetic changes in some bone marrow cells stop the cells working as they should. These changes stop your bone marrow from making enough healthy blood cells.

The most common genetic changes affect genes called *JAK2*, *CALR* or *MPL*. These changes usually happen by chance as you get older. They are not due to anything you did or did not do, and you cannot usually pass them on to any children you may have.

If you have a close relative (parent, brother, sister or child) with MF you might have a higher chance of developing it too. The risk is still low as MF is very rare.

MF can also develop from other MPNs.

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Signs and symptoms of MF

About 1 in 4 people with primary MF do not have any symptoms when they are first diagnosed. But you might get signs and symptoms over time. These might 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

At your first appointment and later check-ups, you may fill out a symptom assessment form. This helps to check whether your MF is stable or is progressing. If you are on treatment, it helps to see if it is working.

Transformation of MF

MF is generally a slow-growing, life-long blood cancer. Sometimes, though, it can develop or **transform** into a faster-growing blood cancer. This is a cancer called acute myeloid leukaemia (AML).

The chance of developing AML varies from person to person and it can happen in primary or secondary MF. Overall, up to 2 in 10 people with MF develop AML within 10 years of diagnosis. This means that more than 8 in 10 people with MF do not develop it.

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 regularly check you for signs and symptoms of transformation. If it happens, you will need treatment for AML.

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Possible complications of MF

MF can cause problems in different parts of your body. These include:

Swollen spleen

As your bone marrow scars, it becomes less able to make healthy blood cells. Instead, your spleen and liver take over, causing them to swell. You may feel:

- Pain under your ribs on your left side
- Pressure or bloating in your tummy
- Full quickly when you eat
- Breathless

Abnormal blood counts

MF makes it difficult to make healthy blood cells. You may get abnormal blood counts, which 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. It can be harder for you to recover from them too.
- High platelets can make your blood clot more easily than usual.

Bleeding

If you have low platelets or abnormal platelets, you may have unusual bleeding. You might have heavier bleeding than normal for you. If you cut yourself, you may find you bleed

longer than usual. You might need to apply pressure to small cuts or wounds to stop the bleeding.

Contact your haematology team if you have any of the following:

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

> **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

You are most likely to get blood clots in the earlier stages of MF. This is when you often have higher levels of white blood cells and platelets. This makes your blood more 'sticky' and more likely to clot. Blood clots can be the first sign of MF for some people.

You can develop clots anywhere in your body. This can cause serious problems:

- 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

Your symptoms will depend on where blood clots develop. You might get tummy pain, eye pain, problems with your vision, headaches or fits as a result of clots.

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 slurred or garbled speech**

Gout

MF can cause painful crystals to form in your joints. This is called gout. Symptoms of gout include:

- Sudden severe pain in a joint. This is often your 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.

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Diagnosis of MF

Some people do not have symptoms when they are first diagnosed. Your doctor may suspect you have MF from a blood test for something else. You will have further tests to confirm an MF diagnosis.

Your haematology team will diagnose MF based on:

- Blood tests
- Bone marrow tests
- Genetic tests on your blood and bone marrow samples to check for changes in your *JAK2*, *CALR* or *MPL* genes
- Other tests, such as an ultrasound to check if your spleen is swollen

You might not need all these tests.

It can be difficult waiting for and coming to terms with test results. We are here for you if you need support.

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MF risk groups

MF is divided up into low, medium (intermediate), and high-risk groups. They help your haematology team assess and monitor how much of a risk MF is to your health. They use your risk group to work out the best treatment plan for you.

In broad terms, risk groups reflect:

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

Your haematology team will work out your risk group 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 risk group at times, and it could change. Let them know if you think your MF is changing or getting worse.

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Treatment for MF

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

If you need treatment, you might have medicines to help:

- 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. They often work by improving levels of blood cells. They include:

- Targeted medicines called JAK inhibitors
- Chemotherapy tablets or capsules
- Peginterferon injections

Your haematology team may recommend a single treatment or a combination of treatments. They may also offer you treatments to manage other problems caused by your MF.

Rarely, some people may be offered a stem cell transplant. This is the only possible cure for MF. But it is an intensive treatment and not suitable for everyone.

JAK inhibitors

JAK inhibitors are targeted medicines that are often used to treat MF. They block proteins involved in blood cell production. JAK inhibitors can:

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

Before taking them, you'll have tests and scans to ensure they are right for you. You will also need regular blood tests while you're taking them, to check your blood counts.

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

- Ruxolitinib
- Momelotinib
- Fedratinib

You may take a JAK inhibitor on its own or in combination with other medicines as part of a clinical trial.

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 an alternative treatment.

Some food and medicines interact with JAK inhibitors. Tell your haematology team about **any** medicines or supplements you are taking. This includes prescribed medicines and ones you buy yourself.

You need to avoid grapefruit or grapefruit juice when taking some JAK inhibitors.

> **Do not stop taking JAK inhibitors without talking to your haematology team first. You might become seriously ill from suddenly stopping ruxolitinib, momelotinib or fedratinib. Ask your haematology team for a Medication Alert Card to keep in your wallet or handbag.**

Chemotherapy

You may have a chemotherapy medicine called hydroxycarbamide. This can lower your blood counts and help control your symptoms. It is also known as hydroxyurea.

You take it as a 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.

Peginterferon

This is a targeted medicine that changes how your immune system works. It is an immunotherapy medicine that stops cancer cells from growing and multiplying. It is also known as interferon or peg-IFN.

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

You have peginterferon as an injection, usually no more than once a week. You can learn how to inject 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 mental health conditions. This includes depression.

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Treatment to help you live well

This is called supportive treatment. It includes medicines to treat or prevent:

- Symptoms of MF
- Complications of MF
- Side effects of treatment for MF.

You might have:

- **Erythropoietin (EPO) for anaemia**. EPO is a type of growth factor that stimulates your body to make red blood cells. You might need weekly EPO injections, which you or a carer can learn how to do for yourself at home.
- **Blood transfusions for anaemia**. These can be useful if your red blood cell count is very low and EPO injections are not helping. A blood transfusion is a procedure to give you donated blood through a drip into a vein.
- **Platelet transfusions to treat bleeding.** A platelet transfusion is a procedure to give you donated platelets through a drip into a vein.
- **Low-dose aspirin to prevent blood clots.** A daily dose of low-dose aspirin can help thin your blood if your blood is 'sticky' and you're at risk of blood clots.
- **Allopurinol to prevent gout.** This medicine lowers uric acid levels in the blood. It's useful if your uric acid levels are high. You take it daily as a tablet and it reduces your risk of developing gout.

- **Vaccinations to prevent infection.** Live vaccines may not be suitable for you but it is safe to have non-live vaccines.
- **Medicines to treat underlying infections.** Your haematology team will offer you screening for hepatitis and HIV. You might have these infections without realising. If needed, you can have treatment for them to help keep you well.
- **Medicines to treat everyday infections.** Some MF treatments can weaken your immune system. You might be more likely to get infections or take longer to get better. Antibiotics, antiviral and antifungal medicines can help you recover more quickly.

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Active monitoring for MF

Some people don't need treatment for MF straight away. If you don't have any symptoms and your MF is not causing you any problems, you may be offered regular monitoring instead. 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. You can still have treatment later, when you need it. You can avoid treatment side effects for as long as possible on active monitoring. And, ideally, enjoy a better quality of life.

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

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Outcomes of MF

Your consultant is the best person to advise you on your outlook. They can take account of your individual circumstances and test results.

Outcomes from MF vary from person to person. They depend on many different factors, including your risk group.

In general, outcomes are better for people with lower-risk MF. They usually have a longer life expectancy than people with higher-risk MF. This is because lower-risk MF is slow-growing and less likely to pose a serious risk to your health.

Outcomes are less favourable for people with high-risk MF but it does depend on other factors. Your general health, your treatment options and how you respond to them all make a difference.

Remember that your risk group helps your haematology team look after you. It helps them plan 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.

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Need support?

You are not alone. We're here for you whether you have a diagnosis yourself or know someone who has. If you'd like advice, support, or a listening ear, call our freephone helpline on 08088 010 444 or send a WhatsApp message to 07500 068 065.

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Help us improve our information

We aim to provide information that's reliable, up-to-date, and covers what matters to you. Please complete our short survey to help us improve our information and make sure it meets your needs.

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