

Your Myelofibrosis (MF) Guide



Not actual patients.

You play a key role in navigating your MF journey

No matter where you are in your journey, you have the power to learn more and participate in making decisions about how you and your doctor manage your disease.

Having questions is normal, and finding answers is an important first step when navigating MF. This guide offers valuable information about MF so you can better understand the disease, identify your symptoms, work together with your healthcare team, and learn key details about your MF. The more knowledge you gain, the more confident you will feel partnering with your healthcare team in your MF care.

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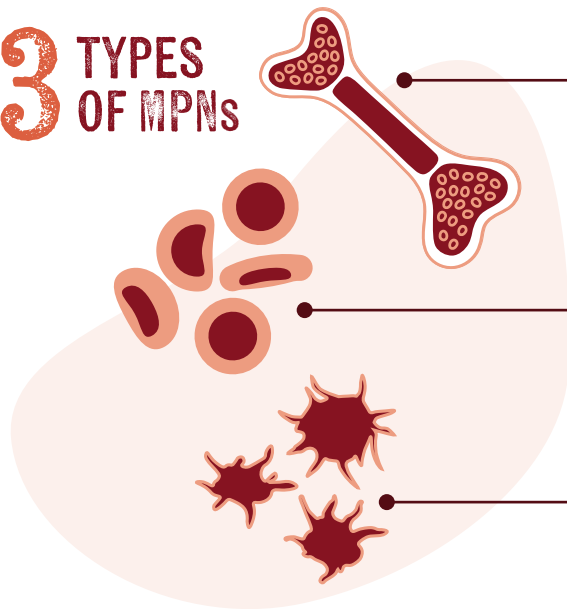
What is myelofibrosis?

Myelofibrosis (my-ah-lo-fye-BRO-sis) is a rare blood cancer. MF is part of a bigger group of blood cancers called myeloproliferative neoplasms, or MPNs.

MPNs happen when there's a change in certain cells in your bone marrow, which is the spongy tissue inside your bones. This change may lead your body to make too many or too few red blood cells, white blood cells, or platelets.

There are different types of MPNs. Each has unique symptoms and different effects on the body. Three common types are:

3 TYPES OF MPNs



Myelofibrosis

In people with MF, blood cells don't function normally and build up inside the bone marrow. This can lead to inflammation and scarring, which is called fibrosis. Fibrosis can cause your body to make too few blood cells.

Polycythemia vera (PV)

PV is a type of MPN that happens when the body primarily makes too many red blood cells. In PV, your body may also make too many white blood cells or platelets.

Essential thrombocythemia (ET)

ET happens when your body makes too many platelets. Having high amounts of platelets in your blood can lead to blood clots.

Both PV and ET can turn into MF. When MF happens on its own, it's called primary MF. When MF develops following PV or ET, it's called secondary MF. Secondary MF is sometimes called "post-PV MF" or "post-ET MF."

MF is a chronic condition, which means that it is long-lasting. Your healthcare team can help you manage MF over time. By working with your healthcare team, you may be able to improve your symptoms.

You are not alone

MF is typically diagnosed in **people 65 or older**, but can occur at a younger age



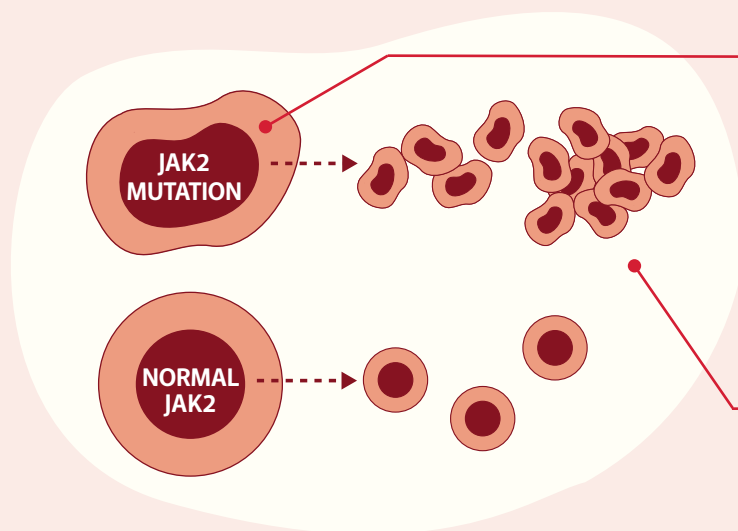
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Understanding the role of JAKs in MF

Scientists are still learning about what causes MF. However, certain proteins are thought to be involved in MF. These are called Janus kinases, or JAKs.

JAKs can contribute to MF in the following ways:



JAK2 gene mutation

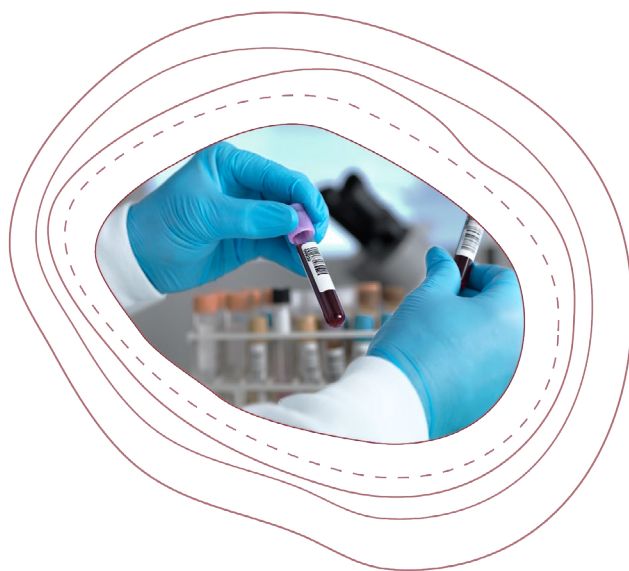
About half of people with MF have a change in their DNA, called a mutation, in a gene called *Janus kinase 2*, or *JAK2*. Scientists have found other gene mutations that lead to MF, including the myeloproliferative leukemia virus proto-oncogene (MPL) mutation and the calreticulin (CALR) mutation. Sometimes, MF can happen in people with no genetic mutations.

Overactive JAK proteins

The *JAK2* gene tells your cells to make JAK proteins. In some people, these JAK proteins are too active. This can cause your body to make the wrong number of blood cells and creates inflammation. Other overactive proteins may also cause MF and are being studied.

You can have a *JAK2* mutation and overactive JAK proteins at the same time, or you may have overactive JAK proteins but no genetic mutation. Your healthcare team can partner with you to help you understand your MF and your treatment options.

Scientific understanding of the role of JAKs in MF has helped advance research of the disease



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Each person experiences MF differently

The symptoms of MF can be different for each person, which means you may not experience all of them. Some of the key signs and symptoms are anemia, enlarged spleen, low platelets, and other symptoms.



Anemia

Red blood cells carry oxygen to all the cells in your body. Having a low red blood cell count is called anemia. Your doctor may call it low hemoglobin.

Anemia can cause symptoms like:

- Tiredness/fatigue
- Weakness
- Shortness of breath
- Migraines

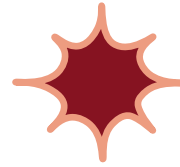


Enlarged spleen

Your spleen acts like a filter for your blood. Having an enlarged spleen is called splenomegaly.

Splenomegaly can cause symptoms like:

- Feeling full too fast
- Pain under the left ribs
- Severe abdominal discomfort



Low platelet count

Platelets are important to help your blood clot. Having a low platelet count is called thrombocytopenia.

Thrombocytopenia can cause symptoms like:

- Bleeding easily
- Bruising easily
- Bleeding for a long time when cut



Other symptoms

MF can cause different symptoms because it affects the body in many ways.

Other symptoms of MF may include:

- Tiredness/fatigue
- Abdominal pain
- Itchy skin
- Night sweats
- Bone pain
- Weight loss



Your symptoms can change over time. It's important to keep track of your symptoms and communicate any new or worsening symptoms with your healthcare team

**CHECK YOUR
SYMPTOMS**

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Take an active role in your care

You know your body best. By working with your healthcare team, you can take an active role in your MF care. Ask your healthcare team questions, keep an eye on your symptoms, and speak up when you notice a change in your symptoms or health. Partner closely with your healthcare team to discuss MF and how often you should come in for tests and checkups.

Medical care for MF may include:



Medicine

Your doctor may prescribe medicine to treat MF.



Supportive care treatment

Additional treatments beyond medicine—like blood cell transfusions—may be needed for certain signs and symptoms of MF, like anemia or thrombocytopenia.



Bone marrow transplant

A bone marrow or stem cell transplant is the only cure for myelofibrosis at this time. A decision to have this procedure should be made with your entire healthcare team, family, and caregivers.



Talk to your healthcare team about how to approach your care together

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Make healthy lifestyle changes

In addition to working with your healthcare team to manage your MF, there are other steps you can take to improve your overall health.

These steps include:



Stop smoking

Smoking causes inflammation and affects blood cell counts, both of which are linked to MF. By quitting, research suggests that you may be able to decrease inflammation and keep MF from getting worse.



Eat healthy

Leading MPN experts recommend adding anti-inflammatory, healthy foods to your diet (such as fruits, vegetables, whole grains, nuts, oils, and fish) and limiting processed or refined foods (fast food, boxed sweets, sugary sodas, etc). Be sure to check with your healthcare team before making any changes to your diet.



Get moving

Exercise can be difficult when you have MF. However, making sure that you move throughout your day is important for maintaining a healthy weight and reducing inflammation. Talk to your doctor about different exercises that fit your lifestyle.



Talk to your healthcare team before making any lifestyle changes

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Seek out social support

You are not alone on your MF journey. In addition to your friends, family, and healthcare team, there are many others who can help you feel supported. Your healthcare provider can work with you to provide helpful information about local support groups or resources available to you. Ask your healthcare team for information about MF resources.



Staying informed

The following websites can help you learn more about MF and provide additional support:



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Start the conversation about MF

You know your MF symptoms best.

It's important for your doctor to know how you're feeling. By monitoring your symptoms, your healthcare team can get a better idea of how you're doing. This can also help guide how you approach your MF care together.

How are you feeling today?

It may be hard to remember your MF symptoms when talking to your healthcare team. Use the worksheet below to help pinpoint any new or worsening MF symptoms that you want to discuss. Put a check mark next to the symptoms you're having, then print this sheet and take it with you to your next doctor visit.

Check your MF symptoms

- | | | |
|--|---|---------------------------------------|
| <input type="checkbox"/> Tiredness/fatigue | <input type="checkbox"/> Feeling full too fast | <input type="checkbox"/> Night sweats |
| <input type="checkbox"/> Weakness | <input type="checkbox"/> Weight loss | <input type="checkbox"/> Itching |
| <input type="checkbox"/> Shortness of breath | <input type="checkbox"/> Pain under the left ribs | <input type="checkbox"/> Bone pain |
| <input type="checkbox"/> Dizziness | <input type="checkbox"/> Abdominal pain | <input type="checkbox"/> Fever |

Tip

It's helpful for your healthcare team to know how often you are having symptoms. Keep track of when your symptoms happen, and how frequently they occur.

Other Symptoms

The top 3 MF symptoms bothering me right now are:

- 1

- 2

- 3

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Questions to ask your healthcare team

Knowing what to ask your healthcare provider can help you feel more prepared. It can also help you get the most out of your doctor visit.

The questions you have will likely change with time, depending on where you are in your MF journey. You may use the questions below to get started.

MF symptoms

- Are there any symptoms I should watch out for?
- How often should I report my MF symptoms?
- What else can I do to reduce my symptoms?

MF testing

- What kind of tests will I need?
- How often will I need to come in for lab work?
- Which signs should I tell my healthcare team about that may suggest I need to come in sooner for testing?

MF management

- How can my MF be managed?
- When will MF management start?
- How will my MF management be monitored?

Living with MF

- Can you share information on local MF or MPN support groups or resources?
- Are there any kinds of food and drink you recommend to help with my symptoms or condition? What should I avoid?
- What kinds of exercises are OK for me? What should I avoid?

If you have any other questions, be sure to bring them with you to your doctor visit.



Visit MappingMF.com to learn more about the signs and symptoms of myelofibrosis and how to help manage your care

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