

Understanding Myelofibrosis



Learning that you or a loved one has myelofibrosis (MF) may feel overwhelming. You might have many questions and be unsure of what to expect. Fortunately, there are resources to help you understand MF and get the support you need to navigate this diagnosis.

This fact sheet is designed to help you take more control over your treatment decisions. You will find clear information about what MF is and how it is diagnosed. We also cover treatment options, ways to manage side effects, and where to find organizations and support groups that can help.



To learn more about myelofibrosis and ways to cope with cancer, visit www.CancerSupportCommunity.org/Myelofibrosis

WHAT IS MYELOFIBROSIS?

Myelofibrosis (MF) is a rare blood cancer in the bone marrow. It is caused by a genetic mutation in the bone marrow's blood stem cells. This mutation causes blood cells in the body to overproduce and not work properly. This overproduction of blood cells can cause the bone marrow to develop scar tissue or "fibrosis" over time.

This cancer usually develops slowly. Some people diagnosed with MF may live symptom-free. Others may require treatment over time. In both cases, people living with MF need to visit their doctor regularly to monitor their cancer.

MF is a type of myeloproliferative neoplasm, or MPN. Other MPNs include polycythemia vera (PV) and essential thrombocythemia (ET). MF may develop on its own (this is known as primary MF), or other types of MPNs can progress into MF over time (this is known as secondary MF).

The Bone Marrow

To better understand MF, it helps to know about the bone marrow and its functions. Bone marrow is the spongy tissue inside our bones that houses red blood cells, white blood cells, and platelets. Stem cells are immature cells in the bone marrow that become these blood cells. Each of these cells has a critical function in the body. For example:

- **Red blood cells carry oxygen to tissues.**
- **White blood cells fight infections.**
- **Platelets help with blood clotting.**

DIAGNOSING MYELOFIBROSIS

Since MF develops slowly, you may not notice the early symptoms. As the disease progresses, the number of unhealthy blood cells will increase. This can impact healthy blood cells and cause them to stop working properly.

Your doctor may suspect MF if they notice you have an enlarged spleen and unusual blood test results. Signs of MF may include:

- **A decrease in the number of red blood cells (anemia)**
- **An increase or decrease in the number of white blood cells**
- **An increase or decrease in the number of platelets**



OTHER POSSIBLE SIGNS AND SYMPTOMS OF MF INCLUDE:

Fatigue, weakness, or shortness of breath, due to anemia or the disease itself

Pain or fullness below the ribs on the left side, due to having an enlarged spleen

Easy bruising or bleeding, due to a decrease or increase in the platelet count

Frequent infections, due to a low white blood cell count

Flat, red, pinpoint spots under the skin caused by bleeding

Enlarged liver

Pale skin

Excessive night sweats

Fever

Bone or joint pain

Weight loss

Itchiness

Difficulty concentrating

Numbness/tingling in fingers and/or toes

Inactivity

Early satiety (feeling full after eating)

WHAT IS GENETIC TESTING?

A genetic variant is a change in a gene. These gene changes are also sometimes called mutations. Genes affect the way our cells and bodies work. Changes in your genes can be inherited from your parents and passed on to children. Your genes can also develop changes during your lifetime.

Genetic testing looks for variants or changes in your genes. If you have been diagnosed with cancer, doctors may recommend you see a genetic counselor to test your genes for an inherited variant. The genetic counselor will ask detailed questions about who in your family has had cancer and at what age. The test results can help choose the best treatment option for you. Be sure to share the results of your genetic testing with your family members. They may wish to assess their risk for cancer and make a personal decision to seek testing for themselves.



Your doctor will use a combination of tests to help them learn as much as possible about your type of cancer and determine the best treatment options. In addition to a physical exam and blood tests, your doctor may also suggest:

Ultrasound – Uses sound waves to see if there are any changes with the spleen or liver.

MRI (magnetic resonance imaging) – A scan that uses magnets to see any changes in the bones related to MF.

CBC (complete blood count) – Blood test to examine the cells.

Bone marrow examination – A trained healthcare provider uses a special needle to take two types of samples from your bone marrow:

- **Aspiration** – Removes a small amount of liquid from the marrow to look closely at individual blood cells.
- **Biopsy** – Removes a small amount of bone and marrow tissue to check for scarring (fibrosis), the structure of the marrow, and how the blood cells are arranged.

Genetic testing – Checking a sample of your blood or bone marrow for genetic changes linked to MF. The most common variant is JAK2, but other variants like CALR and MPL may also be found. These tests help confirm the diagnosis and guide treatment.

CANCER SUPPORT HELPLINE®

If you need help finding resources or want help getting information about your cancer, call CSC's toll-free Cancer Support Helpline® at 888-793-9355. It is staffed by community navigators and resource specialists who can assist you Monday – Thursday 11:00 a.m.- 8:00 p.m. ET and Friday 11:00 a.m.- 6:00 p.m. ET.

WORKING WITH YOUR CANCER CARE TEAM

It's important to find a doctor who has experience treating MF. Because MF is a rare disease, you need a doctor that fully understands your diagnosis and treatment options. If you don't have a specialist in your area, talk with a social worker or patient navigator at your care center. They may be able to connect you with financial grants or travel assistance programs to help get you the care you need.

Your doctor can answer your questions and should make you feel comfortable throughout your care. Here are some questions you can ask to help you decide if a doctor is the right fit for you:

Do you accept my insurance/healthcare plan?
How much experience do you have in treating myelofibrosis?
Are you board-certified in this specialty?
How might my cancer or symptoms change over time? What should I expect?
What are the risks of my disease progressing to acute myeloid leukemia?
How do you stay up to date with the latest treatments for myelofibrosis?
Can you tell me about all the possible treatment options for my cancer?
Why do you recommend this treatment option over the others?
What are the potential side effects of each treatment? How can I best prepare for or manage them?
I am experiencing these symptoms (list symptoms). What can help me best manage them?
Do you or others at your clinic/hospital work with clinical trials? If so, can you tell me more about participating?
Will you refer me to a patient navigator or social worker to help me with education, resources, and support?
What other support services are available to me and my family?
How can I contact the care team with questions? Is there a different way to reach you all after hours?

These questions can help you better understand your doctor's experience, available treatment options, how to manage symptoms and side effects, access to support resources, and ways to communicate with your care team. Feel free to print this list and take it to your appointments so you don't forget to ask what is most important to you.

GETTING A SECOND OPINION

Getting a second opinion gives you a chance to hear about all treatment options available for you. You can get a second opinion anytime during your care — or even a third, if you'd like. Many people do. If you feel that your doctor is not meeting your needs or concerns, consider visiting another care facility. Another care center or doctor may explain your diagnosis and treatment options in a way that makes more sense to you. Some centers may be closer to your home, have more support services, or have a connection to clinical trials.

Do not worry about hurting your doctor's feelings, your comfort and confidence in your care are what matter most. You can always return to your first doctor if you want. But remember, timely cancer treatment is important when deciding to seek multiple opinions.





TREATMENT PLANNING

Treating MF takes a team approach. Your doctor may recommend several treatment options. Your voice and wishes are important throughout the decision-making process. You might work together to decide which treatment to try, when to start, or what order to follow. You may also be able to join a clinical trial as part of your treatment plan. This process of making choices with your care team is called “treatment planning.” As you are making treatment decisions, take time to think about what matters most to you and your loved ones. Share any personal goals you have and let your care team know about any family responsibilities or lifestyle values that are important to you.

Talk openly with your healthcare team about your needs and preferences. Make sure you understand why one treatment might work better for you than another. Ask about the goals of the treatment. Also ask how each treatment might affect your personal goals.

Remember, you are an essential part of your care team, and your choices and goals should help guide your care.

For more information about making treatment decisions, visit
www.CancerSupportCommunity.org/Treatment-Decision-Process.

TIPS FOR TAKING CONTROL



Prepare your questions: Write down your questions before each doctor's visit. Keep a journal to take notes, or use this resource to track your progress over time.



Bring support: Take someone with you to appointments, if you can. They can offer extra support. If you go to an appointment alone, take notes and ask if it is OK to record your conversation with your doctor.



Ask for clarity: If you do not understand certain words your doctor is using, ask them to explain. Your doctor should be able to find other ways to help you better understand your cancer and treatment options.



Plan ahead for costs: Be proactive about the financial impact of treatment. Talk to your healthcare team or financial navigator early on about ways to manage expenses, so you're prepared before starting any new treatments.

These tips can help you feel more in control of your care and more confident as you move through each step of your treatment experience.

TREATMENT OPTIONS FOR MYELOFIBROSIS

Treatment for MF will depend on several factors. This includes:

- **Your overall health**
- **Your preferences and personal goals**

Be sure to share your preferences and work with your healthcare team to find the best treatment for you. You know your body and your needs the best.



Your doctor should let you know all the treatment options that may be available. The cancer experience is unique to each person. Certain treatments may be a better fit for you than others. **Some of the common methods to treat MF include:**

WATCH AND WAIT



People who do not have symptoms and do not have abnormal lab results, an enlarged spleen, or other complications are generally not treated when they are first diagnosed. Some people remain symptom-free for many years. **During this period, staying up to date on regular checkups and periodic lab monitoring are important.** This allows your doctor to catch any changes or signs that the cancer is progressing.

TARGETED THERAPY



Uses drugs to target specific changes in cancer cells that help them grow, divide, and spread. This treatment is more precise. It fights cancer cells while causing less harm to other cells in the body. JAK inhibitors are a type of targeted therapy used to treat MF.

CHEMOTHERAPY



Also known as chemo, this treatment uses drugs to destroy or damage fast-growing cells like cancer cells. Chemo may be given in different ways (orally by a pill, an injection, or through an IV in a vein).

RADIATION THERAPY



Uses high-energy rays to kill or damage cancer cells. It can help reduce the size of the spleen, when surgical removal is not possible. It is also used to treat bone pain and tumors outside the bone marrow.

STEM CELL TRANSPLANTATION



This treatment involves receiving stem cells from a donor. It is the only type of treatment that has the potential to fully cure MF. Still, it can come with higher risks. Several factors are considered to determine if a person with MF is eligible for this treatment.

OPEN TO OPTIONS®

If you are facing a cancer treatment decision, the Cancer Support Community's Open to Options® program can help you prepare a list of personalized questions to share with your doctor. Our Open to Options® specialists can help you create a written list of specific questions about your treatment plan for your doctor. Call 888-793-9355 to schedule an appointment or to find a Cancer Support Community near you.

To learn more about the treatment options for myelofibrosis, visit www.CancerSupportCommunity.org/Myelofibrosis.



WHAT ARE CLINICAL TRIALS?

Consider talking to your healthcare team about clinical trials. Clinical trials are research studies. They help us learn new and better ways to treat cancer. A clinical trial may be the only way to gain access to a promising new treatment option. For more information about clinical trials, visit www.CancerSupportCommunity.org/Clinical-Trials.

MANAGING TREATMENT SIDE EFFECTS

It helps to learn about the side effects of treatment before you begin. This way you will know what to expect. Remember, everyone responds differently to treatment. The side effects you experience may be different from what someone else experiences. It is important to work closely with your healthcare team. They can help you better manage and navigate any changes to your day-to-day.

Common treatment side effects for MF include:

- **Anemia:** Low red blood cell counts
- **Thrombocytopenia:** Low platelet counts
- **Cytopenia:** Low blood cell counts overall (including red or white blood cells or platelets)
- **Pain or discomfort:** Can occur after surgery
- **Graft-versus-host disease:** A condition where the new stem cells react against your body's healthy tissues after a stem cell transplant
- **Fatigue**
- **Shortness of breath**
- **Nausea**
- **Constipation/diarrhea**

Talk to your care team about how you are feeling. They can help you monitor and manage any side effects. They can give you medications and strategies to reduce discomfort.



For side effects like anemia, you may feel very tired or weak. In some cases, your doctor may suggest a blood transfusion to help. There are things you can also do at home to help:

- **Get plenty of rest**
- **Take breaks and pace yourself**
- **Eat healthy foods and a balanced diet to keep up your strength**

To learn more about how to cope with these side effects, visit www.CancerSupportCommunity.org/Cancer-Treatment-Side-Effects.



PALLIATIVE CARE

Palliative care is a type of support that helps you feel better during or after cancer treatment. It focuses on relieving symptoms, like pain or fatigue. A palliative care specialist can help you manage any side effects and feel more comfortable. The goal of palliative care is to help you live as well as possible throughout your cancer experience.

Palliative care is different from hospice care. It is available at any point during your cancer experience. It can be available as early as the time of diagnosis. Palliative care is available for people with any stage of cancer. You can receive it at the same time as your cancer treatment.





SUPPORT FOR CAREGIVERS

Caregivers play such an important role on the cancer team. They provide important physical, emotional, and logistical support. While caregiving can be rewarding, the responsibilities can be overwhelming and stressful and take up a great deal of time. It's important that caregivers also feel supported and cared for.

Here are a few key ideas to help recognize and support caregivers:

- **Acknowledge their role:** Caregivers do so much, from helping with daily tasks and doctor's visits to offering emotional comfort. Recognizing their efforts makes a big difference.
- **Encourage self-care:** Remind caregivers that it is OK to take time for themselves. Their well-being is important for both the patient and themselves.
- **Connect to resources:** There are organizations, support groups, and counseling services designed specifically for caregivers. Encourage them to reach out if they need help or someone to talk to. Caregivers can connect with others and exchange ideas on CSC's Caregiver Support discussion forum. Visit www.MyLifeLine.org.
- **Share the load:** Whenever possible, involve other friends, family, or community resources. No one should feel like they have to do everything alone.
- **Communicate openly:** Foster honest conversations between caregivers, patients, and the care team. Caregivers should feel comfortable sharing their concerns and asking questions.


For more information and resources to support your caregiver(s), call 888-793-9355 or visit www.CancerSupportCommunity.org/Caregivers.



COPING WITH MYELOFIBROSIS

Living with a slow-growing, or “chronic,” cancer like MF can bring a unique set of challenges. Managing this disease can take a lot of physical and emotional energy, especially since you will need to see your care team regularly. Ongoing treatment and frequent appointments can take up more of your time and may increase financial pressures. Because MF is not always curable, some changes it brings — like shifts in your daily routine or self-care habits — may be long-lasting. You might also find that you need different kinds of support from friends, family, and others in your life. But remember, living with MF doesn’t define who you are. You are much more than your diagnosis.

It is important to make self-care a priority — sometimes, that means putting your own needs front and center. Advocate for yourself, especially if you feel uncomfortable or are experiencing pain. Getting the support you need can make a big difference. It may feel frustrating to deal with “watch and wait.” You might worry that your concerns are not being taken seriously, but your voice matters. If you ever feel unheard, reach out to someone you trust on your care team. Social workers and patient navigators are there to support and advocate for you, helping to ensure you get the care, understanding, and resources you deserve.



You don’t have to go through this alone — lean on your care team and those close to you as you move forward. Your needs and experiences are important every step of the way.

COPING WITH MENTAL HEALTH CHALLENGES

Managing both the emotional and physical impact of cancer can lead to a lot of stress. You may experience feelings of anxiety, depression, or overall distress.

It is important to let your care team know about any mental or physical changes you experience. They may recommend medication or other resources to support.

Here are some other ways to take care of your mental health:

Be aware of your feelings and stressors. Make note of how you handle them.



Participate in activities that help you relax. Some examples include deep breathing, yoga, or other creative activities.

Focus your energy on things that improve your overall well-being and provide happiness.

Take time to think about your life goals. Explore what is important to you and what brings you joy.



Talk to a mental health specialist or social worker. This is especially important if you find that certain emotions last for a long time or start to impact your daily life. These experts can help you manage these feelings to find a sense of calm.

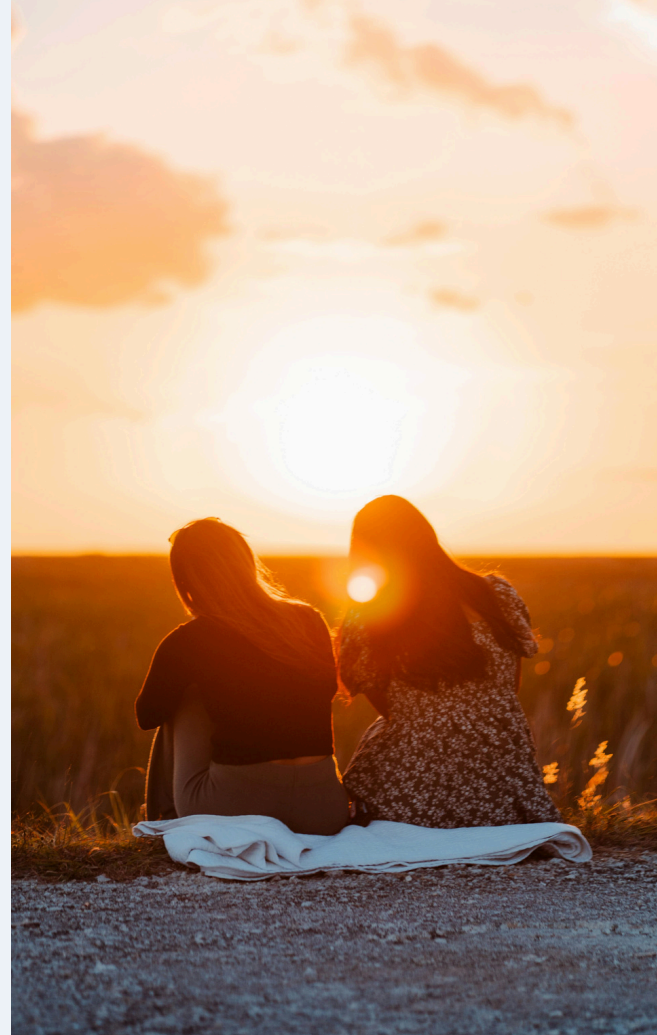
To learn more about coping with mental health and cancer, visit www.CancerSupportCommunity.org/Coping-Mental-Health-Concerns.



Having support during the cancer experience can make a big difference. Your needs may change over time, and that is OK. Talking with people who understand what you are going through can help you feel less alone and more empowered and in control.

Ask your healthcare team about support for your emotional, social, or practical needs. They may be able to connect you with MF support groups or other helpful programs.

At the end of this resource, you will find a list of trusted organizations — including Cancer Support Community — that offer helplines, support groups, online discussion boards, and many other ways to connect with people who understand what you are going through. Reaching out is not always easy, but you do not have to go through this alone.



RESOURCES

MYELOFIBROSIS RESOURCES

Cancer Support Community

www.CancerSupportCommunity.org/Myelofibrosis

www.CancerSupportCommunity.org/Myeloproliferative-Neoplasms

MPN Research Foundation

www.MPNResearchRoundation.org

American Cancer Society

[www.Cancer.org/Cancer/Types/Myelodysplastic-](http://www.Cancer.org/Cancer/Types/Myelodysplastic-Syndrome/About/Myeloproliferative-Disorders.html)

[Syndrome/About/Myeloproliferative-Disorders.html](http://www.Cancer.org/Cancer/Types/Myelodysplastic-Syndrome/About/Myeloproliferative-Disorders.html) | 800-227-2345

National Cancer Institute

www.Cancer.gov/Types/Myeloproliferative/Patient/Chronic-Treatment-Pdq |

800-422-7237

Cancer Support Community Resources

Cancer Support Helpline® — Have questions, concerns, or looking for resources? Call CSC's toll-free Cancer Support Helpline (888-793-9355), available in 200 languages Mon-Thurs 11am-8pm ET and Fri 11am-6pm ET.

Open to Options® — Preparing for your next appointment? Our trained specialists can help you create a list of questions to share with your doctor. Make an appointment by calling 888-793-9355 or by contacting your local CSC or Gilda's Club.

Frankly Speaking About Cancer® — Trusted information for cancer patients and their loved ones is available through publications, online, and in-person programs.

Services at Local CSCs and Gilda's Clubs — With the help of over 200 locations, in 50 markets, CSC and Gilda's Club centers provide services free of charge to people impacted by cancer. Attend support groups, educational sessions, wellness programs, and more
www.CancerSupportCommunity.org/FindLocation.

Cancer Experience Registry® — Help others by sharing your cancer patient or cancer caregiver experience via survey at **www.CancerExperienceRegistry.org**.

MyLifeLine® — CSC's secure, online community welcomes anyone impacted by cancer to easily connect with community to reduce stress, anxiety, and isolation. Create a personal network site and invite friends & family to follow your journey. And participate in our discussion forums any time of day to meet others like you who understand what you are experiencing. Join now at **www.MyLifeLine.org**.

Grassroots Network — Make sure your voice is heard by federal and state policy makers on issues affecting cancer patients and survivors by joining our Network at **www.CancerSupportCommunity.org/Become-Advocate**.

This publication is available to download and print yourself at **www.CancerSupportCommunity.org/Myelofibrosis**.

For print copies of this publication or other information about coping with cancer, visit **Orders.CancerSupportCommunity.org**.

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The Cancer Support Community and its partners provide this information as a service. This publication is not intended to take the place of medical care or the advice of your doctor. We strongly suggest consulting your doctor or other healthcare professionals to answer questions and learn more.

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