

A patient resource from Decera Clinical Education and Smart Patients.

Supported by independent medical education grants from GSK, Incyte Corporation, and Sobi.

This resource was developed to help you understand your diagnosis, partner with your oncology care team on treatment decisions, and make the most of your appointments. It is organized into 4 short sections; use whichever fits where you are right now and bring it with you to your next visit. This is not medical advice. Always talk with your own care team about decisions that affect your care.

1. Knowing your diagnosis and treatment options

Myelofibrosis (MF) is a rare bone marrow cancer in a group of blood cancers called **myeloproliferative neoplasms (MPNs)**. MPNs include essential thrombocythemia (ET), polycythemia vera (PV), and MF. Some people with ET or PV may later develop secondary MF, also called post-ET or post-PV MF. Current diagnostic criteria also recognize prefibrotic, or early-stage, primary myelofibrosis. **Why your exact diagnosis matters:** It shapes which treatments fit your case. Your care team can walk you through where your diagnosis sits and how it informs the options they are considering.

Common treatment paths include watch-and-wait monitoring, JAK inhibitors (such as ruxolitinib, fedratinib, momelotinib, or pacritinib), interferon, hydroxyurea, stem cell transplant for some patients, and clinical trials. Your blood counts, especially anemia and platelet levels, can influence which JAK inhibitor your team recommends. Supportive treatments, such as transfusions or medications that help with anemia, may also be part of your plan, depending on your blood counts and symptoms. The right combination for you depends on your blood counts, mutations (*JAK2*, *CALR*, *MPL*), risk score, age, other health conditions, and your own goals.

Two things that help patients work with their care team:

- 1. An MPN specialist consultation can add helpful expertise.** MF is rare, and specialists who focus on MPNs have deep experience with diagnosis and treatment decisions. Many specialists offer telehealth consultations and can partner with your local hematologist for in-person care. Your care team can help you decide whether a specialist consultation makes sense for your situation.
- 2. Knowing your own goals helps your team match treatment to your life.** Goals that matter most to you should be shared with your care team so they may recommend treatments that fit your priorities. Goals such as:
 - Better energy or fewer symptoms
 - Smaller spleen or less abdominal discomfort
 - Fewer transfusions or improved anemia
 - Staying in your job or usual activities
 - Avoiding hospital visits
 - Slowing disease progression, when possible

Questions to bring to your appointment

- What is my exact diagnosis under current criteria?
- What were my mutation results and risk score?
- Why are you recommending this treatment for me, specifically?
- What other options should we consider, including clinical trials?
- What medication am I starting, and what dose are you starting me on?
- How can we adjust if it is not the right fit?
- What is the goal of treatment for me: symptom control, slowing progression, or both?
- Is an MPN specialist consultation something we should add?

Find an MPN specialist:

- MPN Research Foundation (mpnresearchfoundation.org)
- MPN Voice (mpnvoice.org.uk)
- Smart Patients MPN community ([Myeloproliferative Neoplasm - Smart Patients](https://myeloproliferative-neoplasm-smartpatients.com))

2. Watching for side effects and speaking up

Most MF treatments come with possible side effects. Catching them early can mean staying on a treatment that is working, instead of having to stop it. **You will often be the first to notice a change in how you feel.** Sharing what you are noticing, even small things—gives your care team valuable information.

Watch for:

- New or worse tiredness
- Easy bruising or bleeding
- More frequent infections, slow-healing cuts
- Stomach problems (nausea, diarrhea, loss of appetite)
- Skin changes (rashes, hives, color changes in nails)
- Mood, sleep, or energy changes you cannot explain
- Sexual health changes

Disease symptoms or treatment side effects? It can be hard to tell the two apart, especially with fatigue and brain fog. You do not need to figure this out on your own. Tell your care team what you are noticing, and they can help sort it out together.

A note on interferon and autoimmune conditions. Interferon medicines can cause or worsen autoimmune and certain other serious conditions in some people. If you have an autoimmune condition, such as lupus, rheumatoid arthritis, Sjögren disease, or another condition or if autoimmune disease runs in your family, tell your care team before starting interferon so you can discuss the risks and monitoring plan together.

Do not stop your MF medication without talking to your care team. Some MF treatments, especially certain JAK inhibitors, may need to be reduced gradually rather than stopped suddenly. Stopping abruptly may cause symptoms to return or worsen.

Ask about vaccines. MF treatments can affect how your immune system responds to infections. Your care team can tell you which vaccines (such as flu, COVID, pneumonia, and shingles) are right for you and the best time to get them.

A simple log helps you and your team. Track your energy level, any new symptoms, and sleep. Consider keeping notes on your phone for convenience. Bring the log to your appointments.

Go to the emergency department or call 911 if you have:

- Severe headache, chest pain, or trouble breathing
- Sudden weakness, especially on one side of your body
- Heavy bleeding that does not stop

When in doubt, call. Your care team would rather hear from you than not.

Call your care team the same day if you have:

- Fever over 100.4°F (38°C)
- Easy bruising or bleeding that is new
- Signs of infection (chills, severe fatigue, painful urination)
- Any new symptom that worries you

3. Working with your care team

Your care team may include a hematologist or oncologist, an MPN specialist (sometimes by telehealth), a nurse or nurse practitioner, a pharmacist, a social worker or patient navigator, your primary care doctor, and **you**, the most important person on the team.

The hub-and-spoke model. Many patients with MF see a local hematologist for routine care and an MPN specialist (sometimes farther away or by telehealth) for treatment decisions. This kind of arrangement can give you both convenient local care and specialist expertise.

Helping information flow across your team. Sharing information across providers can take some effort, but a few habits make it easier:

- Ask each provider whether their patient portal can share notes with your other providers
- Bring a 1-page health summary to each appointment: current medications, recent test results, your questions
- Ask for written visit summaries and keep them in one folder (paper or digital)

- ▲ Ask your team whom you should call first when something comes up
- ▲ Bring a family member or friend, especially to the first appointment after diagnosis or when treatment is changing; they can take notes and help you remember what was said

Speaking up when something is not clear. Shared decision-making works best when both sides are speaking up. If something your team says is not clear, ask them to explain it again. If you have a concern about a treatment recommendation, share your concern. If you would like a second opinion or an MPN specialist consultation, ask your team for help to arrange it. None of this means you do not trust your team—it means you are partnering with them.

Shared decision-making is a partnership. You bring what you know about your own life, body, and values. Your team brings clinical knowledge. Together, you make the best decisions that are right for you.

Questions to bring to your appointment:

- ▲ Whom should I call first when something comes up between visits?
- ▲ How do my providers share information with each other?
- ▲ Is there a patient navigator or social worker who can help me coordinate?
- ▲ Can I get a written summary of today's visit?

4. Getting help with cost, distance, and daily life

MF treatment can be expensive, and travel to specialists can add up. Many patients qualify for help they did not know was available. **Program availability and eligibility can change, so ask your pharmacist, social worker, or patient navigator to help you check what is currently open. Asking for help is the first step.**

Help with medication costs:

- ▲ **Manufacturer patient assistance programs:** Each MF medication has its own program. Your specialist's office or pharmacist can help you apply for the program.
- ▲ **Copay assistance foundations:** You may be eligible for assistance through foundations such as PAN Foundation ([PAN Foundation – Patient financial assistance, advocacy, and education](#)), Blood Cancer United Co-pay Assistance Program ([Co-Pay Assistance Program | Blood Cancer United](#)), HealthWell Foundation ([When health insurance is not enough – HealthWell Foundation](#)), and Patient Advocate Foundation ([Financial Aid Funds – Patient Advocate Foundation](#)).
- ▲ **Hospital financial assistance:** Most US hospitals offer charity care. Ask the billing office for an application.

Help with travel and access:

- ▲ **Telehealth visits** can replace many in-person follow-ups. Ask your team what is possible by video.
- ▲ **Hope Lodge** (American Cancer Society) provides free lodging for patients with cancer receiving treatment far from home.
- ▲ **Travel grants** are available through Blood Cancer United and the MPN Research Foundation.

Help with daily life: A social worker or patient navigator at your treatment center can help with disability benefits, FMLA leave, work accommodations, insurance appeals, and mental health referrals. Many treatment centers have these team members on staff. Ask—they often know about programs you have not heard of.

Connecting with other patients: Many patients with MF find peer communities helpful for understanding what to expect day to day, hearing how others have handled specific treatments, and helping you to feel less alone with a rare disease. Use peer wisdom as a starting point for conversations with your care team, not as a replacement for medical advice.

Online communities for patients with MPN:

- ▲ Smart Patients MPN community ([Myeloproliferative Neoplasm – Smart Patients](#))
- ▲ MPN Voice ([mpnvoice.org.uk](#))
- ▲ HealthUnlocked MPN community ([healthunlocked.com/mpnvoice](#))
- ▲ Blood Cancer United ([bloodcancerunited.org/](#))

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This resource is informed by patient experiences shared in a Smart Patients qualitative focus group, April 2026; all patient information deidentified. Not medical advice.