

Getting the Right Diagnosis

Barrier: Patients may receive a myeloproliferative neoplasm (MPN) diagnosis without understanding how it was confirmed.

- MPNs include essential thrombocythemia (ET), polycythemia vera (PV), and myelofibrosis (MF).
- Diagnosis requires blood counts, driver mutation testing (JAK2, CALR, MPL), and bone marrow biopsy. About 10% of ET and MF cases are “triple-negative” and require extended genetic panels (next-generation sequencing).
- **[ACT]IVATION Tip:** Ask your care team to explain how each test supports your diagnosis and whether it should be revisited over time.

Understanding Your Test Results & Disease Monitoring

Barrier: Understanding ongoing test results and what they mean can be challenging.

What to track:

- CBC blood counts (platelets, hemoglobin, hematocrit).
- Spleen size changes, which are checked
- Symptom scores using tools like MPN-SAF, diaries, or phone apps
- Molecular findings (allele burden, mutation frequency)
- **[ACT]IVATION Tip:** Focus on trends over time, these matter more than single numbers. Context is important. Use tools like symptom diaries to guide conversations with your care team.

[Source](#)

When Symptoms Don't Match Labs

Barrier: Blood counts may look stable even when symptoms persist.

- Symptom examples: Fatigue, itching, night sweats, brain fog, abdominal discomfort

What to Ask:

- Could symptoms be due to iron deficiency from repeated phlebotomies?
- Could cytokine activity be driving inflammation and fatigue?
- **[ACT]IVATION Tip:** Speak up about symptoms even if labs look normal. Discuss therapies that target symptom relief, such as JAK inhibitors.

[Source](#)

Recognizing Disease Changes

Barrier: Knowing which changes may signal disease progression.

- **Warning Signs:** Unintentional weight loss or loss of appetite, night sweats or fevers, anemia (hemoglobin less than 10), enlarged spleen, or rapid spleen growth. Constitutional symptoms (like fatigue, fever, sweat) combined with lab changes.
- **[ACT]IVATION Tip:** Track symptoms and blood counts. Ask your care team which changes warrant a call between appointments.

Accessing Expertise & Treatment Options

Barrier: Limited access to MPN specialists

Strategies:

- Seek second opinions or telemedicine consults with MPN centers. Explore shared care models between your community oncologists and academic specialists.
- Ask about clinical trial opportunities for new therapies.
- **[ACT]IVATION Tip:** Raise questions about new treatment options and risks. Partner with your care team to ensure your goals are part of the plan.



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