

MYELOFIBROSIS PATIENT JOURNEY GUIDE

As navigators caring for patients diagnosed with myelofibrosis (MF), you will find each journey to be unique. The path forward for patients may not always be the same, and nurse and patient navigators work to support patients and families by guiding them along their individualized journey through a MF diagnosis and management. The following roadmap describes the MF patient journey.

TREATMENT APPROACHES

- The key goal in the management of MF is relief of symptoms and improvement in QOL^{2,3}
- Allogeneic hematopoietic stem-cell transplantation (HSCT) is currently the only treatment modality that offers potentially curative therapy for patients with primary MF³

Low risk, without symptoms⁴

1. Observation
2. Clinical trial

My treatment is: _____

Low risk, with symptoms⁴

1. Ruxolitinib
2. Peginterferon alfa-2a
3. Hydroxyurea

My treatment is: _____

Intermediate and high risk⁴

Platelets $<50 \times 10^9/L$

1. HSCT
2. If not a candidate for HSCT:
 - a. Pacritinib
 - b. Clinical trial

My treatment is: _____

Platelets $>50 \times 10^9/L$

1. HSCT
2. If not a candidate for HSCT:
 - a. Ruxolitinib
 - b. Fedratinib
 - c. Clinical trial
 - d. Alternate JAK inhibitor

My treatment is: _____

NAVIGATOR CONSIDERATIONS

- Review potential side effects and their management with patients
- Explain the schedules for treatment, blood work, and laboratory tests
- Schedule appointments
- Set expectations regarding when to expect improvement in laboratory tests and symptoms
- Aid in clinical trial enrollment if applicable
- Assess potential barriers to adherence and ensure patients adhere to their medication

Offer psychosocial support throughout the treatment journey by providing referrals to behavioral health, integrative services, social work, pastoral care, and local and national advocacy resources

DIAGNOSIS

Diagnosis consists of¹:

- Patient signs and symptoms
- Laboratory tests (complete blood count, comprehensive metabolic examination, coagulation studies, bone marrow biopsy, molecular testing)
- World Health Organization diagnostic criteria for MF
- Risk stratification

BEGIN

NAVIGATOR CONSIDERATIONS

- Evaluate patient's symptoms and the impact on their quality of life (QOL)
- Review patient's goals of therapy
- Review treatment options and ensure that the patient understands which options may be best for their MF
- Provide appropriate patient education (based on patient culture, literacy) at diagnosis and throughout the various phases of the treatment journey
- Help patients navigate financial concerns and barriers to care prior to starting treatment



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SUPPORTIVE CARE

Navigators may conduct barrier assessments to identify potential roadblocks to treatment adherence (eg, financial, transportation issues) and make early referral to local and national support services



NAVIGATOR CONSIDERATIONS

- Evaluate with the patient whether the current therapy still meets the patient's goals of care
- Communicate roles and expectations for caregivers during treatment
- Provide educational materials (eg, financial resources, patient and caregiver support)
- Continue to assess barriers to adherence



MF-ASSOCIATED ANEMIA

Management considerations:

- Treat coexisting causes: replace iron, folate, and vitamin B12, if needed¹
- The criteria for red blood cell transfusion depend on individual treating institution guidelines
- If serum erythropoietin (EPO) is <500 mU/mL, use erythropoiesis-stimulating agents^{1,4}
- If serum EPO is >500 mU/mL, consider a clinical trial or immunomodulatory agents^{1,4}



NAVIGATOR CONSIDERATIONS

- Review symptoms associated with anemia: fatigue, weakness, and shortness of breath¹
- Discuss the impact of anemia and red blood cell transfusions on QOL
- Explain the frequency of red blood cell transfusions as MF progresses
- Assist with arranging laboratory tests and chair time for red blood cell transfusions
- Review side effects of red blood cell transfusions
- Assess patient's improvement of symptoms after receiving red blood cell transfusions



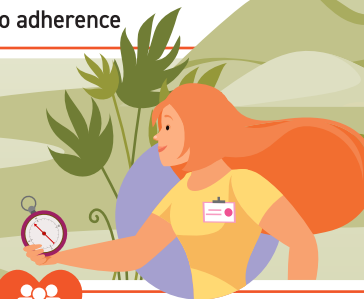
FOLLOW-UP

Monitor patients for signs and symptoms of disease progression every 3 to 6 months using the Symptom Assessment Form and Total Symptom Scores (MPN-SAF TSS)



NAVIGATOR CONSIDERATIONS

- Provide patients with information regarding follow-up visits
- Provide patients with an MPN-SAF TSS to track their symptoms
- Provide patients with the best form of contact if they need to reach the healthcare team (eg, email, phone number)
- Discuss potential situations that would require that patients go to the emergency department (fever >100.4° F, chest pain, extreme shortness of breath, or bleeding concerns)



My Care Team: _____

Contact Information for My Care Team (email; phone number; portal): _____

References

1. Leukemia & Lymphoma Society. Myeloproliferative Neoplasms. Accessed April 2023. <https://www.lls.org/myeloproliferative-neoplasms>
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3. O'Sullivan JM, Harrison CN. Myelofibrosis: clinicopathologic features, prognosis, and management. *Clin Adv Hematol Oncol*. 2018;16(2):121-131.
4. Gerdts AT, Gotlib J, Harris A, et al. Myeloproliferative Neoplasms, Version 3.2022. NCCN Clinical Practice Guidelines in Oncology. *J Natl Compr Canc Netw*. 2022;20(9):1033-1062.

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