Mapping your myelofibrosis management

This guide is designed to empower you in partnering effectively with your healthcare team during the treatment and management of your myelofibrosis (MF), ensuring you receive the most comprehensive care and access to the right information throughout your journey.

Disease progression and monitoring:

Each person's experience with myelofibrosis is unique. Myelofibrosis can develop slowly and can remain stable for a long period of time. People experience a range of symptoms, and some people may not experience any symptoms depending on how their myelofibrosis is progressing.

1. Based on my latest blood tests (red cells, white cells, platelets, blast cells) and spleen measurements, what do these indicators tell us about the current state and trajectory of my myelofibrosis?
2. What specific signs or changes should I be looking for that might indicate my cancer is changing or progressing? What are the next steps if that happens?
3. What is the overall long-term outlook for someone with my myelofibrosis profile? Are there any long-term complications of myelofibrosis that I should be aware of or proactively monitor for?
4. What different or new interventions or treatment options might be considered for me as my disease progresses?

Symptom management and quality of life:

1. I'm experiencing symptoms (e.g., fatigue, itching, bone pain, night sweats, early satiety). What are the most effective strategies available to better manage this symptom?
2. How is the size of my spleen currently affecting me, and what are the best strategies for managing symptoms related to it?
3. My (platelet/neutrophil/red blood cell) count is [current level]. What does this mean for my current risk of (bruising/bleeding/infection/fatigue), and are there any adjustments needed to my management plan or daily precautions?
4. I'm struggling with fatigue/energy levels. What are the most effective strategies for managing this, and how can I communicate its impact to others (family, friends, employers)?

Treatment and adjustments:

1. How well is my myelofibrosis responding to my current treatment?
2. Is there anything I can do beyond treatment for managing the impact of myelofibrosis on my daily life?
3. If my current treatment needs adjustment, what are the next steps?

Communication and support:

1. Beyond our appointments, what are the best ways to communicate with my healthcare team if I have questions or concerns between visits?
2. Are there any new or updated reliable resources or patient organisations you recommend for ongoing information and support for patients living with myelofibrosis?

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Fill out this page digitally by typing directly into the fields, or print it out and handwrite your responses.

I'm concerned about:

- ☐ My diagnosis
- ☐ Blood transfusions
- ☐ Adjusting my lifestyle
- ☐ Everyday fatigue
- ☐ Other symptoms (e.g., enlarged spleen, night sweats, bone pain)
- ☐ Burden on my loved ones and care partner(s)
- ☐ Financial impact
- ☐ Emotional impact

Other

With my myelofibrosis, I want to be able to:

A month from now

A year from now

5+ years from now

Notes

Feeling prepared for your doctor appointments can help you understand myelofibrosis. If you have any additional questions, write them in the notes section below.

For more information, please visit
yourcancerourchallenge.com

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