

# Living with Myelofibrosis (MF)

### Take charge of learning about MF

You play an important role in your MF care. Whether you have known about your MF for a while or were recently diagnosed, you have the power to learn more and participate in making decisions about how you and your healthcare team manage your disease.

It's important to understand MF and work with your healthcare team to discuss the best approach to your MF management. Together, you can decide when to report any new or worsening symptoms and how often to come in for tests and checkups.

#### Questions to ask your healthcare team

Knowing what to ask your healthcare provider can help you feel more prepared. It can also help you get the most out of your doctor visit.

The questions you have will likely change with time, depending on where you are in your MF journey. You may use the questions below to get started.

- Are there any symptoms I should watch out for?
- What kind of tests will I need, and how often?
- How can my MF be managed?

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• Can you share information on local MF or MPN support groups and resources?

If you have any other questions, be sure to bring them with you to your doctor visit. You may also want to bring a list of current symptoms you're having and medicines you're taking.



# Make healthy lifestyle changes

In addition to working with your healthcare team to manage your MF, there are other steps you can take to improve your overall health.

### These steps include:



#### Stop smoking

Smoking causes inflammation and affects blood cell counts, both of which are linked to MF. By quitting, research suggests that you may be able to decrease inflammation and keep MF from getting worse.

#### Eat healthy

Leading MPN experts recommend adding anti-inflammatory, healthy foods to your diet (such as fruits, vegetables, whole grains, nuts, oils, and fish) and limiting processed or refined foods (fast food, boxed sweets, sugary sodas, etc). Be sure to check with your healthcare team before making any changes to your diet.



#### Get moving

Exercise can be difficult when you have MF. However, making sure that you move throughout your day is important for maintaining a healthy weight and reducing inflammation. Talk to your healthcare team about different exercises that fit your lifestyle.

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Talk to your healthcare team before making any lifestyle changes



### Seek out social support

You are not alone on your MF journey. In addition to your friends, family, and healthcare team, there are many others who can help you feel supported. Your healthcare provider can work with you to provide helpful information about local support groups or resources available to you. Ask your healthcare team for information about MF resources.



### Ask your healthcare team for information about MF resources

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# Tips for telling others about your MF

Talking to your friends and family about your MF can feel scary, but it's an important part of building your support network. Letting your loved ones know how you are feeling allows them to share their strength and concern with you, which can help you feel less alone.

### When telling others about your MF, consider these helpful tips:



**Make a list.** Write down a list of the important people in your life. Then, decide how you want to tell each person. For example, you may decide you want to tell your close relatives in person and let a designated friend or loved one tell extended family.

You may also choose to use technology to talk about your MF diagnosis. Social media, email, apps, and even certain support websites can allow you to tell a lot of people at once, which may save you the emotional energy of telling them individually. These options can also help you stay connected and share health updates with a larger group of people. They can also help raise awareness of MF.



**Choose the time.** After you have made a list, decide the best time to talk to each person or group. You may want to reach out to your friends and family and ask them when they're available to talk. Try to schedule a time that works for both of you.

Remember that your readiness to share is just as important as your loved ones' readiness to hear the news. Take the time you need to process your thoughts and feelings before letting others know.



**Plan your conversation.** Think about what you want to say and how you want the conversation to go. Consider any questions your friends or family might have and get answers ready if you have them. It may be helpful to ask your loved ones what they already know about MF so you don't have to repeat information.



**Prepare for their responses.** Remember that each person is going to react in their own way to your MF diagnosis, so be prepared for different responses. This is a good opportunity to establish boundaries and let others know what kind of communication is helpful or unhelpful. Be honest in letting your friends and family know how you want to be supported.

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# Staying informed

The following websites can help you learn more about MF and provide additional support:



Learn more about how you can navigate life with MF by visiting MappingMF.com today

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