

Talking With Loved Ones About Myelofibrosis

Good communication is key to any strong relationship, and that is even more important when it comes to discussing myelofibrosis. Whether you were just diagnosed or have been living with the disease, it's important to communicate what you are feeling with your loved ones. This may help your loved ones better support you and may help you feel less alone.



TIPS FOR TALKING ABOUT YOUR HEALTH

Talking about myelofibrosis can be tough, but it helps to communicate clearly. Here are some simple tips to make it easier:



Use "I" statements. Talk about how you feel and think.

Share as much as you know about myelofibrosis. It's ok to not know everything.



Ask how the other person is feeling.

It's ok to ask, don't assume you know.



Let yourself and others feel any emotions that may come up.

This allows for more honest and open communication.



If you feel comfortable, invite them to a doctor's appointment.

This can help them learn more and ask questions.



Use humor when it feels right.

Sometimes a little joke can lighten the mood.



Allow silence.

Give the other person time to process what you are saying.



HELP YOUR LOVED ONE BETTER UNDERSTAND MYELOFIBROSIS AND HOW IT MAKES YOU FEEL

The bottom line is to be honest and candid. You may not want to talk about your symptoms, but the only way your loved ones will understand how you're feeling is if you tell them. Whether it's with a family member, an old friend or a new romantic partner, here are some conversation starters to help start the discussion.



Explain myelofibrosis

Look for online sources you can trust, such as websites that end with .gov or .org. You can also refer to the [What is Myelofibrosis?](#) section of MappingMF.com for an overview.



Explain how you're managing or treating your myelofibrosis

Tell them what it takes, day to day, to live with myelofibrosis — and any ways you have had to adjust your life because of it. Outside appearances may not always reflect what is happening inside the body. Discuss the medication(s) you may be taking, if it feels right.



Describe what your symptoms feel like

Compare your symptoms to something relatable. For instance, you could describe fatigue as feeling constantly weighed down, or night sweats causing you to frequently wake up at night.



List out all your symptoms to give the full picture

The symptoms of myelofibrosis can be diverse, and they vary from person to person. It's important to share the specific symptoms you're experiencing to give your loved one a better idea of what you're dealing with. In addition to fatigue, symptoms can include weakness, shortness of breath, dizziness, bone pain, night sweats, severe itching, excessive bleeding and brain fog.

FILLING IN THE BLANKS ON HOW YOU'RE FEELING

Opening up about your health can feel scary because it's so personal. Because of that, you may not know where to begin. To help get you started, on the next page is a fill-in-the-blank template you can use as either a script to guide the conversation or as a written letter, depending on how you prefer to communicate with your loved ones. You can use the whole template or just choose the parts that feel most important for you to get across.

Dear _____ ,

I'm writing to share something important about my health because I want you to know what's going on in my life and I could really use your support right now.

I've been _____ with myelofibrosis (MF), a rare and complex type of blood cancer. Only about 25,000 people in the US have MF. I know this probably comes as a bit of a surprise, and especially since it's not a commonly known type of cancer, I wanted to explain what it means and how it's affecting me.

With MF, scar tissue forms in the bone marrow, which is where blood cells are made. That can lead to anemia, low platelet count, enlarged spleen and other symptoms, most of which are outwardly invisible. Some of the symptoms I've been dealing with are _____.

The one that has the biggest impact on my daily life is _____.

It feels like _____.

I haven't been able to do as much as I used to, and I ask that you give me grace.

Fortunately, I am working with my care team to manage my MF symptoms. My treatment includes _____.

It has helped with _____.

but most/some days I still feel _____.

Beyond the physical effects, MF has been isolating and emotionally challenging. Getting the diagnosis felt _____.

Now that I'm managing the chronic symptoms, I feel

_____.

I'm also worried about the future and whether my MF will progress. I'm afraid I won't be able to _____

or be there to see _____.

For me, one of the toughest challenges about MF is

_____.

Some days are harder than others, but I'm learning to cope by

_____.

Your support means a lot to me. You can support me by

For example: coming with me to doctor appointments or support group meetings / making a list of questions to ask my doctor / helping me keep track of follow ups and medications / nudging me to do things that make me feel better / providing emotional support / spending time with me on things that take my mind off my MF, like yoga or walks

Even just knowing that you're there for me makes a huge difference.

Thank you for taking the time _____
to read this / talk to me about this

I know it's a lot to process, but I'm hopeful that with your understanding and support, talking about the effects of my MF might get a little easier. Please feel free to ask me any questions or share any thoughts you have. I'm here to talk whenever you're ready.

With love,

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Mapping
Myelofibrosis
NAVIGATING A RARE BLOOD CANCER