



— THE MPN —  
CAREGIVER  
COMMUNICATION  
WORKBOOK



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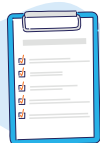
# Understanding why “**Fine**” is not enough for their MPN journey

When someone you care about has been diagnosed with a rare, chronic blood cancer like a myeloproliferative neoplasm (MPN), the role of caregiver is very important. Not only do you provide invaluable care and support, like helping with chores and other responsibilities, but you may also serve as an additional set of “eyes and ears” to help guide and inform your loved one’s MPN journey.

**Because MPNs are progressive diseases, they can change or get worse with time. That’s why it’s essential for you and your loved one to work together to keep track of *any and all* changes in their physical and emotional health, as this can help identify possible signs of disease progression.**

When it comes to their MPN symptoms, you’ve probably heard them say, “I’m *fine*,” even when it may not always be true. You can help encourage your loved one to take an active role in their own care by **speaking up and spelling out** how their MPN affects them—especially with their MPN Healthcare Professional. Not only does this help you both understand the current status of their disease, but it may also help you recognize when something may require attention and/or intervention.

Use the following interactive worksheets to help you document and discuss how your loved one’s MPN may be changing over time:



## **MPN Symptom Discussion Guide**

Help your loved one prepare for upcoming MPN healthcare appointments by encouraging them to quantify the impact of their MPN symptoms. Use the completed forms to guide conversations with their Healthcare Professional.



## **Caregiver Communication Tip Sheet**

These practical communication tips are designed to help you and your loved one have more effective MPN communication before, during, and after MPN healthcare appointments.

# 1 MPN Symptom Discussion Guide

## SPELLING OUT THE IMPACT OF THEIR MPN SYMPTOMS

Because MPNs can worsen with time, consistently monitoring symptom changes can be helpful in identifying possible signs of disease progression. That's why it's so important to work with your loved one to keep track of *any and all* symptom changes, no matter how minor—and to **speak up** and share those insights with the MPN Healthcare team. This includes symptoms that you aren't sure are MPN-related (because they could be).



Use the questions below to help them prepare to **spell out** exactly how MPN symptoms are impacting their daily routines, activity levels, and overall quality of life. For example:

- Are their MPN symptoms causing them to skip events and activities? If so, explain.

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- Have their sleeping or eating habits been affected? If so, how?

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How frequently does this symptom occur? (e.g., daily, every night, at every meal, etc.)

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How long has this been happening? (e.g., every day for the past 4 weeks)

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How does this symptom affect their well-being and overall quality of life? (e.g., I can no longer participate in activities that I was able to enjoy X number of months ago)

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**Remember:** Sharing specific details that **quantify the impact of your loved one’s MPN symptom burden** can provide valuable insights to help guide their ongoing care. Be sure to share this information with their Healthcare Professional.



### Help Them Stay on Track

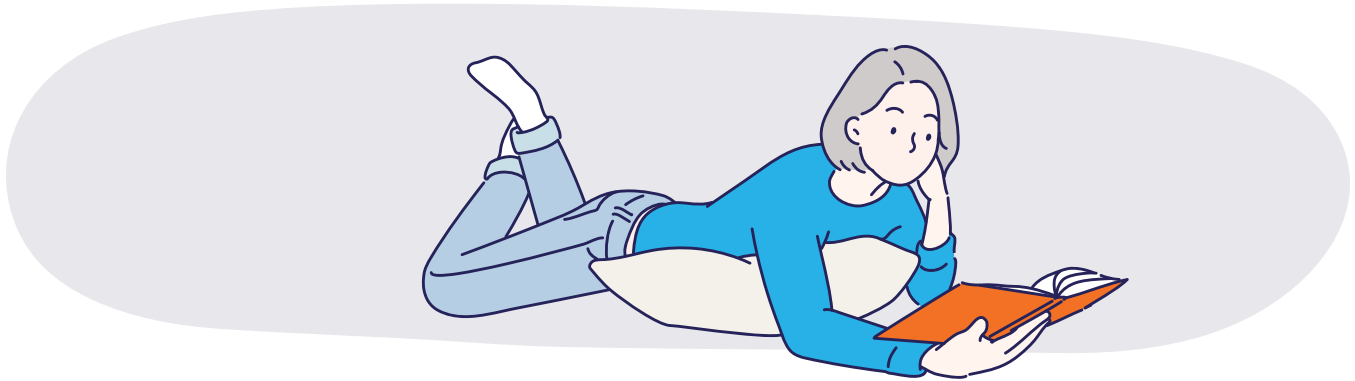
Encourage your loved one to use the **MPN Tracker Tool on [VoicesOfMPN.com](https://VoicesOfMPN.com)** or download the **Voices of MPN Mobile App** to consistently document changes in MPN symptoms, blood counts, and medical procedures.

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## TAKING CARE OF YOURSELF

As a caregiver, you play an essential role in helping to advocate for your loved one's health and well-being. However, the responsibilities of caregiving can be stressful at times, and it can be easy to overlook your own physical and emotional health.



In order to effectively support *their* care, **you also need to take good care of yourself.** Consider creating a self-care plan that includes:

- Scheduling (and keeping) your own healthcare appointments
- Finding an outlet for your feelings, such as journaling, meditation, or connecting with friends
- Setting aside regular “me time” to take a break and unwind
- Keeping up with your favorite hobbies
- Getting enough rest
- Eating a well-balanced diet
- Exercising on a regular basis
- Accepting help from others if you need it
- Creating and maintaining your own emotional support system
- **Speaking up and spelling out** how *you* truly feel



**Remember:** “fine” is not enough for your loved one, and it isn’t enough for you.

# 2 Caregiver Communication Tip Sheet

## COMMUNICATING AS AN MPN CAREGIVER

Having open, honest, and informed conversations with your loved one is an excellent way to help support their MPN journey. Whether or not you are new to the role of MPN caregiver, the following tips can help you re*define* how you communicate with each other.



**Communicate with compassion**—It’s not always easy to know what to say to someone who is struggling with a chronic condition. Try to be calm, understanding, and patient as your loved one learns to adapt to living with their MPN (and expect some ups and downs along the way). Remind them that they are not alone on this journey, and that you are there to support them in whatever way they need. It can go a long way toward letting your loved one know that you care and want to help.



**Listen carefully**—As a caregiver and companion, sometimes the best thing you can offer is an ear to listen. You don’t have to have all the answers. Just knowing that they have been heard can make a difference in how they feel.



**Encourage honesty**—While it’s helpful to be encouraging and to show empathy, it’s equally important to promote honest, open communication about how their MPN affects their daily life—and to share this information with their healthcare team. If your loved one has a habit of saying “I’m fine” when it isn’t true, be sure to remind them to **speak up and spell out** how their MPN truly makes them feel. Because **fine is not enough** for their MPN journey.

## ADVOCATING FOR THEIR CARE DURING MPN HEALTHCARE APPOINTMENTS

If you accompany your loved one to healthcare appointments, you may sometimes hear them say “I’m fine,” even when it may not be true. Unfortunately, if they aren’t sharing specific details about how their MPN is affecting them, they may not get the optimal care and support that they need.

The communication tips below can help you and your loved one fine-tune your MPN conversations and advocate for the best possible care during MPN healthcare appointments:



**Come prepared with questions**—Working with your loved one to create and maintain an ongoing list of questions and concerns can help guide conversations and help ensure that you both get the information and answers you seek.



**Take notes**—As a caregiver, your role during appointments might be listening, asking questions, or simply taking notes. Be sure to bring a notebook and pen (or your mobile phone) to capture important information that you and your loved one can discuss later. Remember, documenting this information means that you and your loved one won’t have to rely on memory alone to recall what was shared.



**Encourage regular symptom tracking**—Encourage your loved one to keep track of changes in their symptoms, blood counts and the frequency of certain medical procedures. Be sure to share this information with their Healthcare Professional during every appointment.



**Share specifics**—When discussing your loved one’s health with the MPN Healthcare team, remind them to provide specific, detailed answers that can help quantify the impact of their MPN. For example, instead of saying “I’ve been very tired,” try something like “I’ve had 25 days of extreme fatigue that has prevented me from walking to the mailbox.”



**Ask for an explanation if you need one**—Some healthcare topics can be complicated, and it’s okay to ask for clarification. It’s essential that you and your loved one are well-informed about their ongoing care management approach.





**Be an advocate for their care**—As a caregiver, you play an important role in supporting your loved one’s MPN journey. Work together to seek out detailed information about their disease, lab results, and care management plan.



**Ask for an appointment summary**—When your loved one’s appointment comes to a close, it’s important to feel confident that both of you fully understand the information shared during the visit. A printed summary can help ensure that everyone feels confident about what was discussed.



**Define next steps**—You can support your loved one by confirming next steps, such as when to schedule another appointment and whether or not any additional lab tests or follow-up appointments are required.



### Do You Need a Symptom Tracker?

Encourage your loved one to use the [MPN Tracker Tool on VoicesOfMPN.com](https://www.voicesofmpn.com/mpn-tracker-tool) or download the **Voices of MPN Mobile App** to consistently document changes in MPN symptoms, blood counts, and medical procedures.

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CONNECT WITH THE MPN COMMUNITY



**F**INE  
I**S**  
**N**OT  
**E**NOUGH



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