



— HEALTHCARE —  
**COMMUNICATION**  
**WORKBOOK**

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# Redefine Your MPN Communication

When you're living with a rare, chronic blood cancer like a myeloproliferative neoplasm (MPN), you may tell others that you're *fine*—even when the physical and emotional challenges associated with your disease take a toll on your daily routines, activity levels, and overall quality of life. As an advocate for your own care, it's important to recognize how your MPN affects you—and to respond by speaking up and seeking out the care and support you need from family, friends, and especially your MPN healthcare team.

The **FINE Healthcare Communication Workbook** is designed to help you take an active role in your MPN journey by promoting more effective communication with your MPN healthcare team. Throughout this workbook, **you may use the interactive fields to complete and print your responses** and share them with your healthcare team. It includes 3 interactive worksheets you can use to have more detailed, informed discussions about your health, including:



## MPN Impact Self-Assessment

Prepare for upcoming MPN healthcare appointments by identifying the physical and emotional impact of your MPN symptoms. Bring the completed form to your MPN healthcare appointment to help guide the conversation around how your MPN impacts your overall quality of life.



## MPN Healthcare Communication Tip Sheet

These practical communication tips and conversation starters are designed to help empower you to advocate for yourself during MPN healthcare appointments.



## MPN Healthcare Appointment Companion

This worksheet is designed to help you better prepare for upcoming healthcare appointments and also to participate in them by documenting questions, concerns, and next steps.



Throughout this guide, you may use the interactive fields to complete and print your responses and share them with your care team.

# 1 MPN Impact Self-Assessment

## RECOGNIZE THE REAL IMPACT OF YOUR MPN

Every journey with a myeloproliferative neoplasm (MPN) is unique, and everyone's individual experience may be a little different. For example, while some people experience severe MPN symptoms that affect their daily lives, others may have few or no symptoms at all.

MPNs are progressive conditions, which means they can change or get worse over time. That's why **keeping an ongoing record of your health** is so important. Not only does it help you better understand the current status of your disease, but it also may help you recognize when something isn't right.

This self-assessment worksheet is designed to help you identify the various ways in which your MPN is affecting you, both physically and emotionally. This includes any impact on your daily routines, activity levels, and overall quality of life. **Share the completed form(s) with your MPN healthcare team** at your next appointment.



**Remember:** Having an honest, detailed discussion about the impact of your MPN symptoms is an important way to partner with your Healthcare Professional and take an active role in your ongoing care.

## IDENTIFYING MY MPN SYMPTOMS

Use this worksheet to identify *all* of the symptoms that you have experienced since your last MPN healthcare appointment—even if you're not sure if they're related to your MPN. Once complete, be sure to share your responses with your Healthcare Professional.

### COMMON MPN SYMPTOMS

- Fatigue (tiredness)
- Inactivity
- Problems concentrating
- Early feeling of fullness when eating (early satiety)
- Abdominal pain or discomfort
- Unintentional weight loss (in the last 6 months)
- Itching (especially after a warm shower)
- Bone pain
- Fever (>100°F)
- Night sweats

### OTHER SYMPTOMS:

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### OTHER MPN SYMPTOMS

- Headache
- Sweating (at night or during the day)
- Blurred vision or blind spots
- Vision changes that eventually go away
- Painful burning or numbness of the hands or feet
- Bleeding from the gums and heavy bleeding from small cuts
- Bruising or bleeding easily
- Shortness of breath
- Pain under the left ribs
- Dizziness, vertigo, light-headedness
- Fainting
- Insomnia
- Reddening of the face, or a burning feeling on the skin
- Angina (chest pain)
- Ringing in the ears
- Enlarged spleen



**Remember:** This information may provide valuable insights that may help guide your ongoing care.

## IDENTIFYING CHANGES IN MY ACTIVITY LEVELS

It's important to be aware of how your myeloproliferative neoplasm (MPN) symptoms affect your daily life, including any impact on your daily routines and activity levels.

Please select all of the activities that you feel have been affected by your MPN symptoms, either currently or within the past 3 to 6 months. Check *all* answers that apply.

### ACTIVITIES AFFECTED BY MY MPN SYMPTOMS:

CURRENTLY	WITHIN THE PAST 3 MONTHS	WITHIN THE PAST 6 MONTHS
<input type="checkbox"/> Exercising	<input type="checkbox"/> Exercising	<input type="checkbox"/> Exercising
<input type="checkbox"/> Gardening & yard work	<input type="checkbox"/> Gardening & yard work	<input type="checkbox"/> Gardening & yard work
<input type="checkbox"/> Playing sports (e.g., golfing)	<input type="checkbox"/> Playing sports (e.g., golfing)	<input type="checkbox"/> Playing sports (e.g., golfing)
<input type="checkbox"/> Reading	<input type="checkbox"/> Reading	<input type="checkbox"/> Reading
<input type="checkbox"/> Arts & crafts	<input type="checkbox"/> Arts & crafts	<input type="checkbox"/> Arts & crafts
<input type="checkbox"/> Puzzles & games	<input type="checkbox"/> Puzzles & games	<input type="checkbox"/> Puzzles & games
<input type="checkbox"/> Family time	<input type="checkbox"/> Family time	<input type="checkbox"/> Family time
<input type="checkbox"/> Socializing	<input type="checkbox"/> Socializing	<input type="checkbox"/> Socializing
<input type="checkbox"/> Household chores	<input type="checkbox"/> Household chores	<input type="checkbox"/> Household chores
<input type="checkbox"/> Shopping	<input type="checkbox"/> Shopping	<input type="checkbox"/> Shopping
<input type="checkbox"/> Taking care of pet(s)	<input type="checkbox"/> Taking care of pet(s)	<input type="checkbox"/> Taking care of pet(s)
<input type="checkbox"/> Volunteering	<input type="checkbox"/> Volunteering	<input type="checkbox"/> Volunteering
<b>OTHER:</b> _____ _____	<b>OTHER:</b> _____ _____	<b>OTHER:</b> _____ _____



**Remember:** If your ability to participate in the activities and events that you enjoy has been impacted by your MPN symptoms, **stop missing out and start speaking up.** Your MPN healthcare team needs—and wants—to know how your quality of life has been affected.

## IDENTIFYING CHANGES IN MY WELL-BEING

When you're living with a myeloproliferative neoplasm (MPN), it's not uncommon to feel a certain amount of emotional distress, including feelings of sadness, fear, and hopelessness. In fact, these emotions are normal—and even expected—to a certain degree. However, they can also interfere with your ability to function, and can take a toll on your overall health and quality of life. That's why it's important to talk to your Healthcare Professional about how your MPN makes you feel.

Although it may be difficult at first, you can take an active role in your care by speaking up about how your MPN affects your well-being. Be sure to share any symptoms of anxiety, depression or other emotional changes with your MPN Healthcare team. This can help ensure that you receive the specific care *and* support that you need and deserve. **Please review the checklist below and select all answers that apply.** Be sure to share your answers with your healthcare team.



### Talk to your Healthcare Professional if you experience any of the following:

- Feeling sad or depressed
- Irritability
- Anger
- Anxiety
- Feeling out of control
- Panic attacks
- Excessive worrying or fear
- Hopelessness
- Extreme changes in appetite or sleep habits
- Trouble concentrating
- Loss of interest in intimacy
- Loss of interest in activities
- Loss of interest in socializing with others
- Mood swings



**Remember:** Your emotional symptoms are just as important as your physical symptoms because they can both impact your quality of life. Know that you are not alone—and there is a community of support within reach. This includes your family, friends, and your MPN Healthcare team.

## SUMMARIZING THE IMPACT OF YOUR MPN

When it comes to living with a myeloproliferative neoplasm (MPN), it's important to **be an informed and vocal advocate** for your own health. Regularly scheduled appointments with your Healthcare Professional offer opportunities to talk about how your disease may be changing over time and to discuss any impact on your ongoing care management plan.



Before your next MPN healthcare appointment, review your answers to this worksheet, and print a copy to share with your MPN healthcare team. You may also use the **MPN Impact Summary Form** below to recap the overall physical and emotional impact of your MPN.

### Choose the answers that best apply:

1. My MPN symptoms impact my **overall quality of life**:



*For example, my MPN has affected my quality of life in the following ways:*

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2. My MPN symptoms have affected my ability to **participate in the events and activities** that I enjoy:



*For example, my MPN has affected my activity levels in the following ways:*

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3. My MPN affects **how I feel emotionally**:



*For example, my MPN has affected my emotions in the following ways:*

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**Remember:** It's important to make your MPN healthcare team aware of the physical and emotional impact of your MPN. This information may provide valuable insights that can help guide your ongoing care.



Looking for additional resources to help identify the impact of your MPN? 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.

APP STORE

GOOGLE PLAY

# 2 MPN Healthcare Communication Tip Sheet




## SPEAK UP—AND SPELL IT OUT

Having an open, informed conversation with your Healthcare Professional is an excellent way to take an active role in your care. That's why it's important to **spell out exactly how your myeloproliferative neoplasm (MPN) is affecting you.**

The communication tips below are designed to help you fine-tune your MPN conversations and advocate for your care during MPN Healthcare appointments.



**Come prepared with questions**—Keep an ongoing list of your questions and concerns to help guide conversations with your MPN care team and bring it with you to your MPN Healthcare appointments. This can help ensure that you don't forget anything. To help you get started, sample questions may include:

-  What is the plan to keep my MPN symptoms under control?
-  What can I do about the changes in my activity levels?
-  Where can I find additional information about \_\_\_\_\_?



**Be specific**—When answering questions about your health, try to provide specific, detailed answers. The more information you share, the more insights your MPN Healthcare Professional may have to help inform your ongoing care.



**Don't withhold important information** about your symptoms, your activity levels or how you've been feeling emotionally. Always be sure to note and *share any and all changes* in your health since your last appointment.



**Take notes**—Bring a notebook and pen (or your mobile phone) so that you can take detailed notes during the appointment. You can also have a loved one or caregiver attend the appointment and take notes for you. Remember, documenting this information means that you don't have to rely on memory alone to recall what was shared.



**Know that it's ok to ask for an explanation**—There is nothing wrong with admitting that you don't understand something. It's important that you are able to fully understand what's going on with your health, so if you need more information, ask for it.



**Be an advocate for your own care**—This is *your* MPN journey, and you have the right to ask for detailed information about your diagnosis, lab results, and care management plan, as well as any follow-up items. This is important information about your health—and it's important to be educated about it.



**Ask for an appointment summary**—When your appointment comes to a close, it's important to feel confident that your questions have been answered and that you understand the topics that you have just discussed. A **printed summary of your visit** can help ensure that you fully understand any changes and next steps.



**Know what happens next**—At the end of your visit, it's important to define next steps so that you know when to schedule your next appointment and whether or not you require any additional lab tests or follow-up appointments.



**Remember:** No matter which topics you choose to discuss with your MPN Healthcare Professional, know that it's important to speak honestly and openly, with as much detail as possible. When you work together as a team it can help ensure that you receive the care that's right for you.

# 3 MPN Healthcare Appointment Companion

## BE PREPARED TO PARTICIPATE IN YOUR MPN HEALTHCARE APPOINTMENTS

Regular healthcare appointments are an important part of managing your myeloproliferative neoplasm (MPN). That's why it's important to be prepared for them—and to actively participate in the discussions and decisions about your health.

The **Healthcare Appointment Companion Worksheet** is designed to help you partner with your MPN Healthcare team by ensuring that you are well-prepared to discuss your questions, concerns and/or topics of interest. It also provides space for you to document notes and next steps.



Before your next healthcare appointments, complete the interactive form fields on the following pages. You may print the worksheet and bring it along to your MPN Healthcare appointment.

## PREPARE

Throughout your MPN journey, you may see a variety of Healthcare Professionals, including a hematologist, oncologist, and MPN specialist, in addition to nurses/nurse practitioners and your primary care physician. To help you keep track of your appointments, use the fields below to identify which Healthcare Professional you are seeing. You may print a copy of this completed form for your records.

### UPCOMING APPOINTMENT DETAILS:

Day \_\_\_\_\_ Month \_\_\_\_\_ Year \_\_\_\_\_ Time \_\_\_\_\_  AM  PM

Reason for Appointment: (eg, routine exam, blood test, phlebotomy, virtual visit, etc.)

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### HEALTHCARE PROFESSIONAL INFORMATION:

Healthcare Professional Name: \_\_\_\_\_

Practice Name: \_\_\_\_\_

Address: \_\_\_\_\_

Phone: \_\_\_\_\_

Email: \_\_\_\_\_

## PARTICIPATE

When you have a chronic condition like an MPN, it's important to actively advocate for your care. Asking questions and addressing your topics of interest can help you do this—enabling you to focus on the information that matters to you. You can use the fields below to identify your areas of interest and to document responses and next steps.

### TODAY, I WOULD LIKE TO TALK ABOUT:



My symptoms:

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My labs:

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Changes in my daily routines and activity levels:

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Mood/emotional changes:

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My questions:

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Topics I want to know more about:

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**NOTES FROM TODAY'S APPOINTMENT:**

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**NEXT STEPS/FOLLOW-UP:**

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**MY NEXT APPOINTMENT:**

Day \_\_\_\_\_ Month \_\_\_\_\_ Year \_\_\_\_\_ Time \_\_\_\_\_  AM  PM

With (Healthcare Professional): \_\_\_\_\_

Practice Name: \_\_\_\_\_

Address: \_\_\_\_\_

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**Remember:** Taking an active role in your MPN healthcare appointments is an important part of being an advocate for your own care. Know that you and your Healthcare Professionals are partners working together to ensure that you have the care and support you need throughout your MPN journey.



### Take Charge of Your MPN Journey

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 related to your MPN.

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### CONNECT WITH THE MPN COMMUNITY



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



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