

CARD 1: Intro



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Strengthening Your Voice

Discussing MPNs with the people in your life can be tough. Use these cards to help you start the conversation, keep it focused, and express yourself.

These conversations may feel unfamiliar. That's OK. With a little practice, you can get more comfortable talking in a way that may help strengthen your relationships and help people better understand your experience.

Caregivers can use these cards too! If you're caring for someone with an MPN, practice these conversation tips to better support your loved one.

As always, your healthcare team is the best source of information about your health.

Learn more about how to use these cards 

Using these cards:

- 1**
Read the front of each card to explore a communication challenge.
- 2**
Then flip the card over to see tips and ideas for how to strengthen the conversation.



CARD 2: Everyday needs



Your Needs



Voicing your everyday needs

Many people don't feel comfortable asking for help with chores, errands, or other tasks. You may not want to cause your friends and family extra work.

But when you live with an MPN, it may not be practical for you to do it all yourself—you may need to lighten your load.

? How can you ask for help without feeling like you're burdening others?

Flip to back for more 

Find people ready to provide support

You may know people who want to help, but don't know how. Giving them a chance to assist you may make them feel good.

Think about what they can handle, and let them know exactly how they can help. If someone offers help you don't need, just redirect them to another task. And let them know how much their help means to you.

If you're a caregiver, you can support your loved one by asking others for help on their behalf.

Play to their strengths:
*You're really good at ____.
I could use your help with ____.*

Be specific: *Would you be willing to help with ____ on [day] at [time]?*

Redirect if necessary:
Thanks for offering! I don't need help with ____ right now, but I would love your help with ____.



CARD 3: Feelings

Voices of MPN Your Feelings



Voicing your feelings

It can be tough to talk about difficult emotions and describe what you're really feeling. Are you concerned that people might

- **Feel uncomfortable or burdened?**
- **Treat you differently?**
- **Think you're being negative?**

Expressing your feelings about your condition may help to relieve stress and bring you closer to your loved ones.

? **How can you open up about what you're feeling in a helpful way?**

Flip to back for more 

Be specific about your emotions

Try labeling your emotions—it can help keep the conversation focused and productive, and allow others to understand where you're coming from. You can even invite them to share a time when they felt similarly.

Or if you just want someone to listen, you might not invite them to share—it's OK to let them know you just want to be heard.

Caregivers, remember that sometimes all you need to do is listen.

Be upfront about what you need:
Can I talk to you about how I'm feeling? I'd just like you to listen, so don't feel like you have to respond.

Label how you feel and why:
I feel ___ when we discuss ___ because ___.

After sharing, check in with the listener: *Perhaps you could tell me about a time you also felt this way? How does what I'm saying make you feel?*

Flip to back for more 

CARD 4: Experience

Voices of MPN Your Experience



Voicing your experience with friends and loved ones

MPNs can affect your life in ways that aren't apparent to others. People around you might not understand why you need to miss an event. They may say, **"You don't look like you have cancer."**

It can be tough to explain the experience to friends or loved ones, especially if you're still working through your own feelings about it.

? **How can having these conversations help you move forward?**

Flip to back for more 

Move forward as a team

When you talk with people about your health and experiences, you put them in a better position to support you.

Involving them and sharing information not only helps bring you closer to each other, it can help you manage stress and feel less alone.

If you're a caregiver, encourage your loved one to talk freely about what they're experiencing.

Let them in on your experience:
One thing I'd like you to know about my MPN is ___.

Share how it affects you:
This symptom makes it hard for me to ___ /makes me feel ___.

Tell them if you need a break.
Because of my MPN, I feel ___ today. Would it be OK if we rescheduled our get-together?

Keep them up to date: *I received some news yesterday. Could we talk about it?*

Flip to back for more 

CARD 5: Shape your goals

Voices of MPN Shape Your Goals



Using your voice to shape your goals

You may feel overwhelmed by all the conversations you have with your healthcare professional. Whatever you feel, it's valid, and you don't have to navigate your journey alone.

Remember this: **While your healthcare professional is an expert in their field, you're an expert on your own experience.** You are equipped to have these important conversations.

? What can you do to be an active partner in the decision-making process?

Flip to back for more 

Prepare and participate

You may find it helpful to organize your thoughts and concerns before each appointment.

Try writing out the questions you have. Prioritize to make sure you ask the 1 or 2 most urgent or important questions.

Bring your notes and medical documentation. It may also help to bring a supportive person to write things down.

General types of questions you may ask:

- What's your experience with treating MPNs and others like me?*
- What's my diagnosis/prognosis and what do you think are my next steps?*
- What are my options? How will we know if each option is working?*
- What does each option require and how will it affect other parts of my life?*

Flip to back for more 

CARD 6: Healthcare team

Voices of MPN Your Healthcare Team



Voicing your experience with your healthcare team

Your healthcare team is the best source of information about your condition.

Healthcare appointments can sometimes feel hurried or overwhelming, and some people may be reluctant to talk about details or concerns.

Remember that speaking up about your experience and medical conditions can help your healthcare team provide the best care possible.

? What can you share to give them a complete picture of your health?

Flip to back for more 

Share every detail about your health

Let all healthcare professionals know you have an MPN. This includes all medical work—dentistry, dermatology, surgery, and ER visits.

Carry your MPN specialist's contact info with you, just in case.

Speak up from the start:
...I'm doing well today. I'd like to let you know a couple of things before we get started. Is it OK if I share those now?

Ask about possible symptoms:
I've been feeling ___ lately. Could that be related to my MPN?

Be thorough and consistent:
I have a short list of personal details I tell all of my healthcare professionals. May I share it with you now?

Flip to back for more 

CARD 7: Enhance your voice

Voices of MPN Enhancing Your Voice



Finding other ways to enhance your voice

Plan ahead:
Ask friends or loved ones when would be a good time to talk. Think about where you'd like to have this conversation (or where you'd rather NOT have it).

Imagine:
Prepare what you'd like to say. Think about how your friends or loved ones might respond.

Say I:
Use "I" or "we" instead of "you" when you're talking about how you feel. You're letting them know about your own personal experience, instead of assuming what others may think or feel.

Flip to back for more 

You can do it!

Keep practicing!
You can become more comfortable with communicating this way.

Share these cards.
Feel free to show these cards to your loved ones, healthcare professionals, and others.

Start the conversation.
Talk through things to find what works best for you and your support circle. Each conversation can help you strengthen your communication skills.

Voices of MPN For more information about MPNs, visit VoicesofMPN.com.



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