

MPNs: Improving Communication with Your Patients

Patients with myeloproliferative neoplasms (MPNs) are often overwhelmed by their diagnosis. Many MPN patients report greater anxiety, fatigue, and depression than the general population. A key unmet need for these patients is how to manage their mental health. The emotions they may be experiencing are often just as overwhelming as receiving their diagnosis. These emotions may be new or existing concerns. Existing concerns can be magnified during any part of the treatment process.

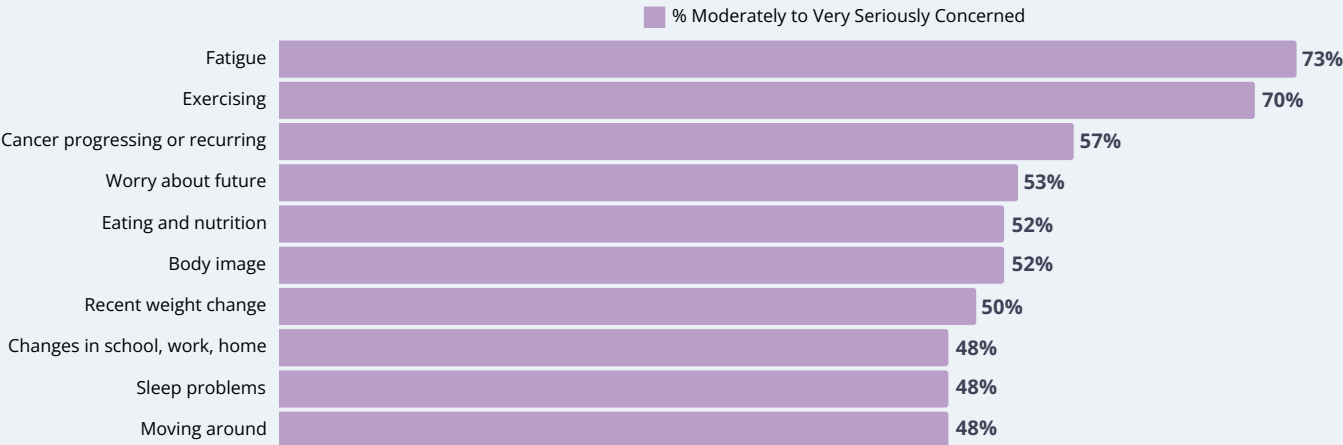


Physicians, nurses, social workers, navigators, and other healthcare professionals play a critical role in educating patients and their loved ones about MPNs. This includes working to address their concerns, helping them understand their treatment options, and supporting the whole person, not just their cancer.

MANAGE EMOTIONS RELATED TO CANCER

Among Cancer Support Community's Cancer Experience Registry participants who were diagnosed with MPNs

Top 10 Concerns Among Patients with MPNs



QUESTIONS TO ASK YOUR PATIENT TO IMPROVE COMMUNICATION AND ELICIT CONCERNS:

How are you feeling in general?

What is worrying you the most?

Is there anyone you can share these concerns with?

How have you been handling your MPN diagnosis?

How is the treatment affecting your life?

What questions do you have about your treatment?

Are you having any side effects? How do they impact you? How are you managing them?

Are you interested in any counseling services? If you are, do you need help finding a provider?

IT IS ALWAYS IMPORTANT TO ADDRESS YOUR PATIENT'S TREATMENT GOALS

Depending on the type of MPN, treatment can aim to:

Prolong survival and delay disease progression

Manage symptoms and improve blood counts

Optimize quality of life

How to Ensure the Patient's Treatment Aligns with Their Personal Goals:

- 1 Understand, consider, and respect individual patient goals.
- 2 Educate patients about all options for treatment with benefits and risks for each one. Allow patients to ask questions after hearing about each treatment. Hearing them all at once may be overwhelming and they may forget questions.
- 3 Provide patients with written information on treatment options and give them time to consider their decision. If needed, schedule a follow-up appointment with your patient to determine the most appropriate plan for them that aligns with their goals.
- 4 Encourage patients to be part of the treatment decision-making process.
- 5 Be sure to mention clinical trials that patients may be eligible for.
- 6 Encourage patients to take notes and have a family member, friend, or other supportive person with them to listen in.
- 7 Understand that emotions impact decision-making. Though MPN treatments need to begin as soon as possible, it is important that your patient's feelings are validated, and they understand their diagnosis and treatment options.



Quality of Life Impact

MPNs and their treatment can affect a patient's functioning whether it's physically, emotionally, socially, or spiritually. Ask your patients if their disease or treatment(s) interfere with their ability to:

- ▶ Work (lost income, challenges of disability insurance)
- ▶ Sleep
- ▶ Eat sufficiently
- ▶ Think clearly
- ▶ Stay emotionally healthy
- ▶ Be social/enjoy hobbies
- ▶ Maintain relationships/be present in family life
- ▶ Be intimate with a partner
- ▶ Exercise/be physically active
- ▶ Function in other ways

Talk with your patients about specific changes they can make that can help improve their daily functioning in these areas.

Helping Patients Weigh Treatment Options

Most MPN patients say they want to work with their healthcare team to map out their treatment plan. Making decisions about cancer treatment can be overwhelming and patients need support and guidance.

With guidance and support, patients can:

Clarify their goals and concerns

More clearly articulate questions

Benefit from the information provided as a result

Maintain adherence to the prescribed treatment

RESOURCES

MPN RESOURCES AND SUPPORT

Cancer Support Community provides resources and tools that can help you improve communication and shared decision-making in your everyday practice. *Frankly Speaking About Cancer: Myeloproliferative Neoplasms* is Cancer Support Community's highly acclaimed cancer education series that provides accurate medical and psychosocial information and support resources. It includes print and digital materials that can be downloaded at no cost at www.CancerSupportCommunity.org/MPNs or contact our toll-free Cancer Support Helpline® at (888)793-9355.

Cancer Support Community

888-793-9355

www.CancerSupportCommunity.org

MPN Research Foundation

773-977-7216

www.MPNResearchFoundation.org

MPN Education Foundation

www.MPNInfo.org

MPN Connect

www.MPNConnect.com

National Organization of Rare Disorders

www.RareDiseases.org

The Leukemia & Lymphoma Society

800-955-4572

www.LLS.org

CancerCare

800-813-4673

www.CancerCare.org

American Cancer Society

800-227-2345

www.Cancer.org/Cancer/Caregivers.html

National Cancer Institute

800-422-6237

www.Cancer.gov/About-Cancer/Coping/Caregiver-Support

Patient Advocate Foundation

800-532-5274

www.PatientAdvocate.org



Cancer Support Community Resources

Cancer Support Helpline® — Have questions, concerns or looking for resources? Call CSC's toll-free Cancer Support Helpline (888-793-9355), available in 200 languages Mon-Thurs 11am-8pm ET and Fri 11am-6pm ET.

Open to Options® — Preparing for your next appointment? Our trained specialists can help you create a list of questions to share with your doctor. Make an appointment by calling 888-793-9355 or by contacting your local CSC or Gilda's Club.

Frankly Speaking about Cancer® — Trusted information for cancer patients and their loved ones is available through publications, online, and in-person programs.

Services at Local CSCs and Gilda's Clubs — With the help of nearly 200 locations, CSC and Gilda's Club affiliates provide services free of charge to people touched by cancer. Attend support groups, educational sessions, wellness programs, and more:
www.CancerSupportCommunity.org/Find-Location-Near-You

Cancer Experience Registry® — Help others by sharing your cancer patient or cancer caregiver experience via survey at www.CancerExperienceRegistry.org.

MyLifeLine® — CSC's secure, online community welcomes anyone impacted by cancer to easily connect with community to reduce stress, anxiety, and isolation. Create a personal network site and invite friends & family to follow your journey. And participate in our discussion forums any time of day to meet others like you who understand what you are experiencing. Join now at www.MyLifeLine.org.

Grassroots Network — Make sure your voice is heard by federal and state policy makers on issues affecting cancer patients and survivors by joining our Network at www.CancerSupportCommunity.org/Become-Advocate.

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The Cancer Support Community and its partners provide this information as a service. This publication is not intended to take the place of medical care or the advice of your doctor. We strongly suggest consulting your doctor or other healthcare professionals to answer questions and learn more.

This publication is available to download and print yourself at www.CancerSupportCommunity.org/MPNs. For print copies of this publication or other information about coping with cancer, visit Orders.CancerSupportCommunity.org.

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