FRANKLY SPEAKING ABOUT CANCER





Myeloproliferative Neoplasms (MPN)

he journey through a diagnosis of MPN is different for each person and there is no road map that will work for everyone. Different people need different things. Whether you are the person diagnosed with an MPN or a caregiver we hope these ten tips that have been shared by others living with MPN will help you along the way.

- 1. Learn as much as you can about your diagnosis and treatment options. Be an information seeker. Read about MPN. Be careful about the Internet. If you search for MPN information on the Internet be sure to check the date, stay with credible organizations that update their sites frequently, and most important, talk with your health care team and ask questions if there is something you don't understand.
- 2. Find a specialist in the treatment of MPN. Since it is a rare disease you should see a specialist in the treatment of MPN. Talk with your doctor about a clinical trial and if it might be a treatment option for you.
- 3. Actively work with your health care team. Depending on your age, type of MPN, symptoms, and stage of your disease, your doctor may recommend a variety of treatments. Once you and your health care team have agreed on a treatment plan, be sure to follow it. Living with MPN takes a team approach, especially when it comes to your medical care. Be sure to report any side effects or changes quickly.

- 4. Find others in a similar situation.

 People with MPN can feel
 isolated. Loss of hope, loneliness,
 and worry about the future are
 some of the social and emotional
 challenges of living with MPN.
 Connect with others who can
 understand what you are going
 through via the Internet or a local
 support group.
- 5. Accept help when it is offered.
 Coping with some of the day-to-day tasks when you have an MPN can be hard. Don't be afraid to ask others for the specific kind of help you want and need. Give your friends and family an opportunity to feel good by accepting their help. Use an online scheduler (see the recommended resources) to help you get the kind of help you need when you need it.
- 6. Learn to manage your stress. To manage stress, you can learn to meditate, do yoga or tai chi, listen to music, visit with a friend, or take a walk. Set aside a portion of time every day to practice your stress management techniques. Even a short time can make a big difference.

- 7. Eat a healthy diet. Besides its many health benefits, such as providing much needed energy and nutrients to your body, maintaining a balanced diet is something you can control.
- 8. Get regular exercise. Regular exercise can give you an emotional uplift, boost your energy, and reduce stress. Finding something you like to do and setting reasonable goals will help you make exercise a part of everyday living. At times when you experience fatigue, a little physical activity can help you feel energized.
- Don't sweat the small stuff –
 focus on what is important to
 you. Identify the sources of
 frustrations in your daily life. Focus
 on the positive aspects of your life

- by keeping a personal journal or forming a new habit or hobby. Direct your energy towards activities that improve your quality of life.
- 10. Live the best possible life every day. An MPN diagnosis should not put your life on hold. Set goals, build genuine connections, make it a priority to do something that makes you feel good every day. Accept that some days will be better than others but that doesn't mean that you can't enjoy some small moments every day.

Visit www.CancerSupportCommunity. org/MPNs to watch videos of people sharing their experience of living well with an MPN diagnosis.

RECOMMENDED RESOURCES

American Society of Clinical Oncology

888-282-2552 www.asco.org

CancerCare

800-813-4673 www.cancercare.org

Clinicaltrials.gov

The Leukemia & Lymphoma Society 800-955-4572 www.lls.org

MPN Education Foundation

www.mpninfo.org

MyLifeLine

www.MyLifeLine.org

MPN Research Foundation

312-683-7247 www.mpnresearch foundation.org

National Cancer Institute

800-422-6237 www.cancer.gov

Patient Advocate Foundation

800-532-5274 www.patientadvocate.org

Unlocking Answers in MPN

www.mpnunlocked.org

CANCER SUPPORT COMMUNITY RESOURCES

The Cancer Support Community's (CSC) resources and programs are available free of charge. To access any of these resources below call 888-793-9355 or visit www.CancerSupportCommunity.org.

Cancer Support Helpline®



HELPLINE concerns or looking 888-793-9355 for resources? Call

CSC's toll-free Cancer Support Helpline (888-793-9355), available in 200 languages Mon-Fri, 9 am-9 pm ET.

Cancer Experience Registry®



Help others by sharing your cancer patient or caregiver experience via survey at www. CancerExperienceRegistry.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.

Frankly Speaking About Cancer®

FRANKLY PEAKING

Trusted information for cancer patients ABOUT CANCER and their loved ones is available through publications, online, and in-person programs. www.CancerSupportCommunity.org/ FranklySpeakingAboutCancer.

Services at Local CSCs and Gilda's Clubs

With the help of 170 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 at a location near you. www.CancerSupportCommunity.org/ FindLocation.

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

MyLifeLine

CSC's private, online community allows patients and caregivers to easily connect with friends and family to receive social, emotional, and practical support throughout the cancer journey and beyond. Sign up at www.MyLifeLine.org.

This program was made possible through an unrestricted educational grant from



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