

FRANKLY
SPEAKING
ABOUT CANCER


CANCER SUPPORT
COMMUNITY.



10 TIPS TO LIVING WELL WITH A
**Myeloproliferative
Neoplasm (MPN)**

The journey through a diagnosis of an 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 an 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 MPNs. Be careful about the Internet. If you search for MPN information on the Internet be sure to check the date and that it was written by a healthcare professional, 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 MPNs.** Since it is a rare disease you should see a specialist in the treatment of MPNs. Don't be afraid to get a second opinion. 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 risk level 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 an 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 an MPN can feel isolated. Loss of hope, loneliness and worry about the future are some of the social and emotional challenges of living with an MPN. Connect with others who can understand what you are going through via the Internet, a peer one-on-one program, 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.
- 9. 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, seeking professional help if needed, 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

National Cancer Institute — 800-422-6237 • www.cancer.gov/clinicaltrials

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

Lotsa Helping Hands — www.lotsahelpinghands.com

MPN Education Foundation — www.mpninfo.org

MPN Research Foundation — www.mpnresearchfoundation.org

National Cancer Institute — 800-422-6237 • www.cancer.gov

Patient Advocate Foundation — 800-532-5274 • www.patientadvocate.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®



Have questions, concerns or looking 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®



**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®



Trusted information for cancer patients 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.CancerSupportCommunity.org.

© June 2021 Cancer Support Community. All rights reserved. Photography by Jared Zagha.