FRANKLY SPEAKING







10 TIPS TO LIVING WELL WITH 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.
- 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, your type of MPN, your 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-today 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 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/myeloproliferative-neoplasms 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 Lotsa Helping Hands www.lotsahelping hands.com

MPN Education Foundation www.mpninfo.org

MPN Research Foundation 855-258-1943 www.mpnresearch foundation.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®

CANCER SUPPORT HELPLINE 888-793-9355 Whether you are newly diagnosed with cancer, a longtime cancer survivor, or caring for someone with cancer, CSC's toll-free Cancer Support Helpline (888-793-9355) is staffed by licensed CSC Helpline Counselors available to assist you Monday-Friday from 9 am - 9 pm ET.

Cancer Experience Registry® CANCER EXPERIENCE REGISTRY

The Registry is a community of people impacted by cancer. Help us gain insights about the social and emotional needs of patients, families and caregivers throughout the cancer journey. Together, this collective voice of people touched by cancer will advance research, care and policy toward the benefit of patients and caregivers. Connect with others: Advocate as active members of a community: Learn from experts; Share your unique story. Your experience is powerful! Join now at www.CancerExperienceRegistry.org to share, connect and learn.

Frankly Speaking About Cancer® FRANKLY CSC's landmark

SPEAKING ABOUT CANCER cancer education series provides trusted information for cancer patients and their loved ones. Information is available through publications, online and in-person programs.

Affiliate Network Services

Almost 50 locations plus more than 100 satellites around the country offer on-site support groups, educational workshops, and healthy lifestyle programs specifically designed for people affected by cancer at no cost to the member.

Open To Options®



If you are facing a cancer treatment decision, this research-

proven program can help you. In less than an hour, our trained specialists can help you create a written list of specific questions about your concerns for your doctor.

The Living Room, Online

Here you will find support and connection with others on discussion boards, a special space for teens, and personal web pages to keep your family and friends up-to-date.

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