

# 10 TIPS TO LIVING WELL WITH A MYELOPROLIFERATIVE NEOPLASM (MPN)

An MPN diagnosis can feel overwhelming. This can be true whether you are newly diagnosed, in treatment, or navigating long-term care. It can bring up many emotions – like uncertainty, fear, hope, and everything in between. Whether you are the person diagnosed or a caregiver, know that you are not alone.

The cancer experience is different for each person. What helps one person may not help another. What feels manageable one day might feel different the next. This resource includes 10 tips that have been shared by others living with an MPN. It offers information and support to help you find the path that is right for you.



Visit, [www.CancerSupportCommunity.org/Myeloproliferative-Neoplasms](http://www.CancerSupportCommunity.org/Myeloproliferative-Neoplasms) to learn more about MPNs and find other resources for support.

## 1

### **TAKE TIME TO LEARN ABOUT YOUR DIAGNOSIS AND TREATMENT OPTIONS.**

Having information and knowledge about your diagnosis will help you feel empowered to make the best decisions for you. Learn about your cancer by talking with your doctor and others on your healthcare team. Reach out to cancer support organizations for help.

**Be careful about everything you read online.** If you search for MPN information on the internet, stick to credible sources that are not biased, outdated, or inaccurate. Check the end of the website domain. Look for sites that have “.edu, .gov, or .org” at the end. Check the date of the information and stay with credible organizations that update their sites frequently. Your care team may be able to suggest credible sources as well.

If you have any questions, let your healthcare team know. Keep a notebook and write down a list of your questions before appointments. Ask your caregiver or a friend to help you write down the answers and responses during your visit. In time, you can collect the information and support you need to make the best decisions for you.

**Cancer Support Helpline®** — If you need help finding resources or want help getting information about cancer, call Cancer Support Community’s toll-free Cancer Support Helpline® at 888-793-9355. It is staffed by community navigators and resource specialists who can assist you Monday - Thursday 11:00 a.m. - 8:00 p.m. ET and Friday 11:00 a.m. - 6:00 p.m. ET.

# 2

## **FIND A DOCTOR THAT SPECIALIZES IN THE TREATMENT OF MPNS.**

Since this is a rare disease, you need a doctor that fully understands your diagnosis. They will have a better idea of treatment options that may be best for you. Seeing a provider that specializes in treating MPNs is important. If there is not an MPN specialist in your area, talk with a social worker or patient navigator at your care center. They may be able to connect you to grants or travel assistance programs.

Certain treatments may be a better fit for you than others. Your doctor should let you know of all the treatment options that may be available. Be sure to ask them about genetic testing as well. Genetic testing looks for mutations or changes in your genes that may increase your risk of getting cancer. The test results can help your doctor select the best treatment option for you. Based on your cancer diagnosis, you may even have the option to join a clinical trial.

### **What Are Clinical Trials?**

Consider talking to your healthcare team about clinical trials. Clinical trials find new and better ways to treat cancer. A clinical trial may be the only way to gain access to a promising new treatment option. If you are interested, talk with your doctor to find out if this may be an option for you.

For more information about clinical trials, visit [www.CancerSupportCommunity.org/Clinical-Trials](http://www.CancerSupportCommunity.org/Clinical-Trials).

# 3

## **TAKE PART IN DECISIONS ABOUT YOUR CARE.**

Living with an MPN takes a team approach, especially when it comes to your medical care. Your doctor may recommend several treatment options. This can depend on your age, type of MPN, symptoms, and the risk level of your diagnosis.

Your voice and wishes should be central throughout the decision-making process. As you are making treatment decisions, think about what is important to you and any personal goals you may have. Let your care team know of any important family responsibilities or lifestyle values. Be sure to share any cultural or religious traditions that are meaningful. Work with them to make decisions that balance the goals of treatment with your preferences and values.

If you do not understand something, ask the team to explain it to you in a different way. If you are a visual learner, ask if they can provide you with an image or drawing instead. Ask if they can write down any important terms. Your care team should address your questions and concerns in a way that is most helpful to you.



## Getting a Second Opinion

Cancer treatment can be complicated. It is important that your care team fully understands your MPN diagnosis and the best treatment options. You need a care team you can trust to take the best care of you.

Getting a second opinion allows you to learn about all possible treatment options available. You can get a second opinion at any point in your care. Many people seek a second or even third opinion.

If you feel that your doctor is not addressing your needs or concerns, consider talking with another care facility. **Do not worry about hurt feelings.** It is important that you feel comfortable with your treatment team. But remember, timely cancer treatment is key when deciding to seek multiple opinions.

# 4

## TALK WITH YOUR CARE TEAM ABOUT HOW YOU ARE FEELING & ANY SIDE EFFECTS.

It helps to learn about the side effects of treatment before you begin. This way you will know what to expect. Talking with your care team can also help you better manage any changes to your day-to-day.

Once you and your care team have agreed on a treatment plan, be sure to follow it. How you are feeling matters as you go through this process. Let the team know of any concerns or side effects right away. It can be helpful to write down and keep track of your side effects so you can discuss these changes with your doctor.

Ask your care team what resources or medications may be available to help you manage any side effects. Seeing a physical therapist can help with the physical side effects of treatment. If you have concerns about eating and nutrition, a nutritionist can provide advice and recommend foods to help.

A palliative care specialist can also help address short and long-term side effects. **Palliative care** is different from hospice care. It is often provided in combination with treatment. Palliative care can help address side effects that occur during and after treatment. You can also meet with social workers or licensed counselors for support navigating any mental health concerns.

To learn more about ways to manage the side effects of cancer treatment, visit:  
**[www.CancerSupportCommunity.org/Managing-Side-Effects](http://www.CancerSupportCommunity.org/Managing-Side-Effects)**.



# 5

## **ASK FOR HELP WHEN YOU NEED IT – IT IS OK TO SAY YES AND ACCEPT.**

Day-to-day life and tasks may become harder when you have an MPN. Do not be afraid to ask others for the specific kind of support you want and need.

Often, your friends and family may want to offer their support but may not know exactly how. An online scheduler, like CSC's MyLifeLine®, can help you and your loved ones stay organized and informed. Visit [www.MyLifeLine.org](http://www.MyLifeLine.org) to get connected.



# 6

## **FIND SUPPORT AND CONNECT WITH OTHERS LIVING WITH AN MPN.**

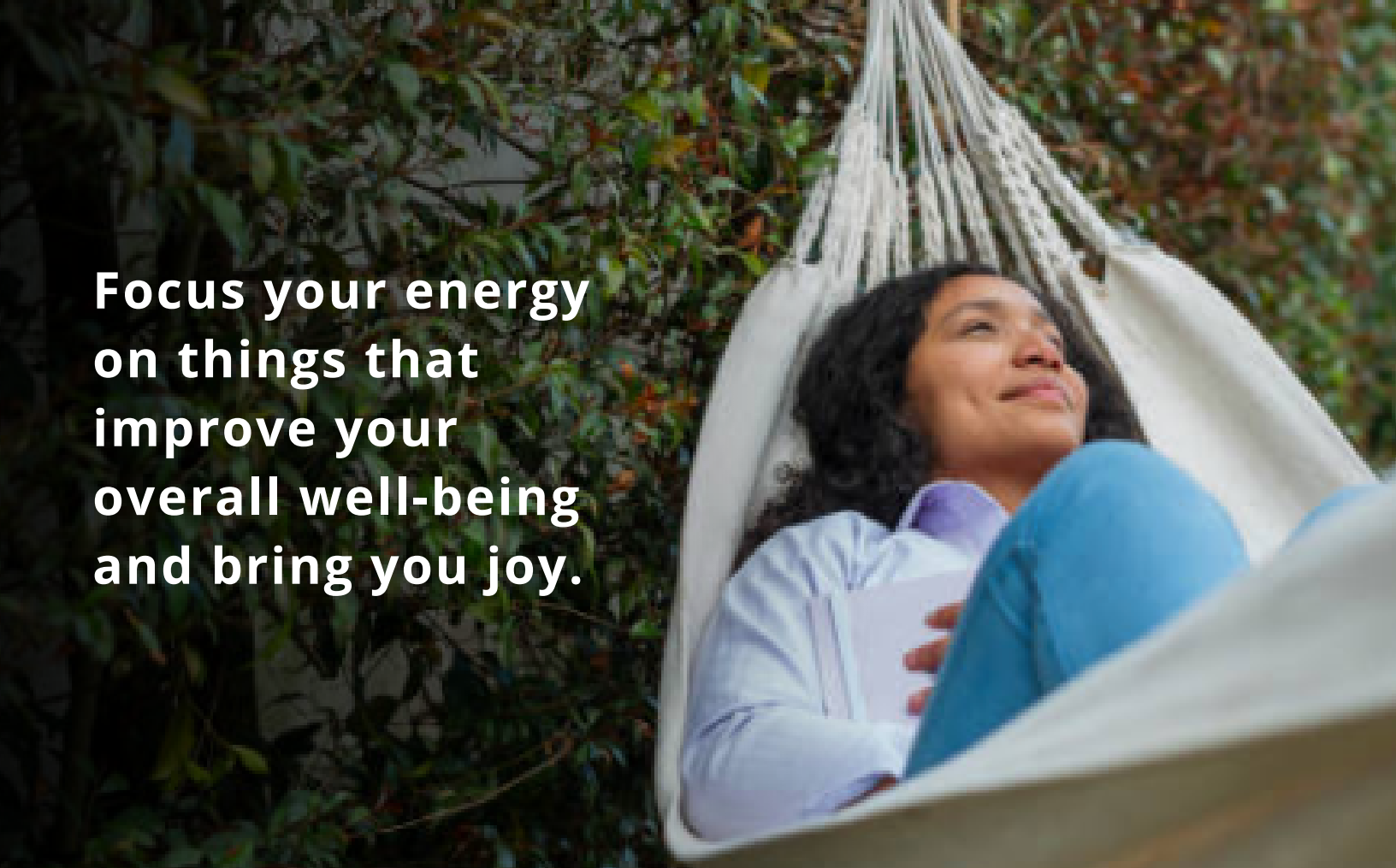
Support can come in many forms. This may include your close loved ones, like family and friends, or your care team. Home care agencies and home health aides may also be a source of support. A trained patient advocate can help you through many parts of the cancer experience. This includes help with talking to your care team or addressing financial concerns.

Consider joining a support group. It can be comforting to talk with others who understand what you are going through. Your doctor, nurse, or social worker may be able to connect you to others living with an MPN.

CSC and Gilda's Club centers provide services free of charge to people impacted by cancer. Attend support groups, educational sessions, wellness programs, and more at a location near you.

**[www.CancerSupportCommunity.org/FindLocation](http://www.CancerSupportCommunity.org/FindLocation)**





**Focus your energy on things that improve your overall well-being and bring you joy.**

# 7

## **TAKE TIME TO RELAX AND MANAGE YOUR STRESS AND MENTAL HEALTH.**

An MPN diagnosis can be life changing. It is important to be aware of your feelings and how you handle them during this time.

To manage stress and maintain your mental health, try activities that help you relax. This can include deep breathing, yoga, or other creative activities. Listening to music, visiting with a friend, or taking a walk may also help.

Focus your energy on things that improve your overall well-being and bring you joy. Set aside a portion of time every day to practice self-care. Even a short amount of time, like 10 minutes each day, can make a big difference.

At times, emotions like sadness or anxiety may last for a long time and begin to impact your daily life. You may also experience other challenging and unexpected emotions, like anger, resentment, or guilt. While these feelings are common, it is important to seek support from a mental health specialist or social worker. They can provide support and help you manage these feelings to find a sense of calm.

To learn more about navigating mental health and cancer, visit [www.CancerSupportCommunity.org/Coping-Mental-Health-Concerns](http://www.CancerSupportCommunity.org/Coping-Mental-Health-Concerns).





# 8

## **EAT WELL AND BE PHYSICALLY ACTIVE.**

Keep in mind your physical wellness. This includes getting enough sleep or coping with fatigue, exercising, and eating well. Eating well will give you more energy and nutrients to help your body. Drinking enough water may help relieve treatment side effects. Reducing the use of substances, like alcohol and tobacco, is also important. If you need support improving your eating habits, talk with a registered dietician.

Regular exercise can lift your spirits, boost your energy, and reduce stress. Finding something you like to do and setting reasonable goals will help you make exercise a part of your everyday. This may look like dancing or walking for 10 minutes each day. On days when you are tired, a little physical activity may help you feel more energized. Every small step you take can help you feel better overall.

Talk with your doctor about the types of activities you want to do. They can advise you on how and when to do them safely. Your doctor may suggest staying away from contact sports. This can help avoid injury and keep some side effects from getting worse.

# 9

## **FOCUS ON WHAT YOU CAN CONTROL.**

At times you may feel frustrated by the changes to your daily life. Focus on things within your control and appreciate the “small wins”. Talk to your healthcare team. Work with them to create a plan that gives you as much control as possible over your treatment and care.

Focus on what is important to you. Direct your energy towards activities that improve your quality of life. Make note of the positive aspects of your life by keeping a personal journal.

Try making a list of your stressors, separating them into the things that feel within versus outside your control. Each day, consider a small goal that is within your control and try to achieve it. Finishing even one simple task can put you on a positive path.



# 10

## MAKE THE MOST OF EACH DAY, IN YOUR OWN WAY.

Receiving an MPN diagnosis does not mean life stops. Focus on what brings you joy. This may be family, culture, spirituality, or simple daily moments. Do something each day that makes you smile.

Practice gratitude by noticing what went well or what you are thankful for. Staying positive is not always easy, and that is OK. Some days may be better than others, but you can still find joy in small, meaningful moments.

Support can come in many forms. This may include your close loved ones, like family and friends, or your care team. Home care agencies and home health aides may also be a source of support. A trained patient advocate can help you through many parts of the cancer experience. This includes help with talking to your care team or addressing financial concerns.

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### Myeloproliferative Neoplasms (MPNs) Resources

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#### **Cancer Support Community**

888-793-9355

[www.CancerSupportCommunity.org/](http://www.CancerSupportCommunity.org/)

#### **Caregiver Action Network**

855-227-3640

[www.CaregiverAction.org](http://www.CaregiverAction.org)

#### **MPN Research Foundation**

773-977-7216

[www.MPNResearchFoundation.org](http://www.MPNResearchFoundation.org)

#### **MPN Education Foundation**

[www.MPNInfo.org](http://www.MPNInfo.org)

#### **MPN Connect**

[www.MPNConnect.com](http://www.MPNConnect.com)

#### **National Alliance for Caregiving**

202-918-1013

[www.Caregiving.org](http://www.Caregiving.org)

#### **National Organization of Rare Disorders**

[www.RareDiseases.org](http://www.RareDiseases.org)

#### **The Leukemia & Lymphoma Society**

800-955-4572

[www.LLS.org](http://www.LLS.org)

#### **CancerCare**

800-813-4673

[www.CancerCare.org](http://www.CancerCare.org)

#### **American Cancer Society**

800-227-2345

[www.Cancer.org/Cancer/Caregivers.html](http://www.Cancer.org/Cancer/Caregivers.html)

#### **National Cancer Institute**

800-422-6237

#### **Patient Advocate Foundation**

800-532-5274

[www.PatientAdvocate.org](http://www.PatientAdvocate.org)

# RESOURCES



## Cancer Support Community Resources

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**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. To order printed copies of this publication and others, visit

**Orders.CancerSupportCommunity.org**

**Find Your Local CSC or Gilda's Club** — CSC and Gilda's Club centers provide services free of charge to people impacted 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 online community welcomes anyone impacted by cancer to easily connect with others. Create a personal network site and invite friends & family to follow your journey. Participate in our discussion forums to meet others who understand what you are experiencing. Join now at **www.MyLifeLine.org**.

**Grassroots Network** — Share your voice with federal and state policy makers on issues affecting cancer patients and survivors. Join our Grassroots Network at **www.CancerSupportCommunity.org/Become-Advocate**.

This publication is available to download and print yourself at **www.CancerSupportCommunity.org/Myeloproliferative-Neoplasms**.

For print copies of this publication or other information about coping with cancer, visit **Orders.CancerSupportCommunity.org**.

**Frankly Speaking About Cancer:**  
**MPNs Program Partner:**



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