

If you or a loved one has recently been diagnosed with a myeloproliferative neoplasm (MPN), you may have many questions. These may include questions about the disease, treatment options, and questions about how the diagnosis will affect your quality of life. The good news is that recent advances in research have allowed doctors to better understand MPN. As a result, in many cases, people are able to manage with MPN as a chronic or long-lasting disease. It is very important for someone diagnosed with a MPN to work with their health care team to manage symptoms and view their care with a long-term treatment approach.



About Myeloproliferative Neoplasms

Myeloproliferative Neoplasms are a group of blood cancers caused by a mutation in the blood's stem cells. The mutation causes the bone marrow to make too many white blood cells, red blood cells, or platelets. MPN consists of a family of conditions that include:

■ **POLYCYTHEMIA VERA (PV)**, a type of blood cancer that leads your bone marrow to make too many red blood cells. PV is diagnosed through a blood test and a test to confirm if your blood cells have a genetic mutation known as JAK2.

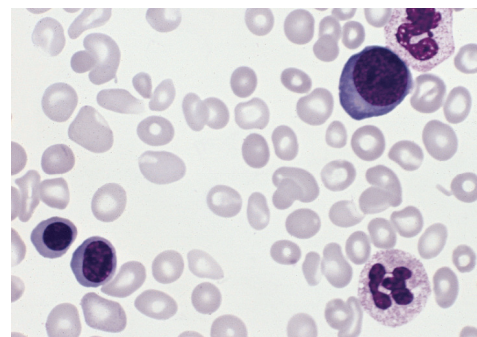
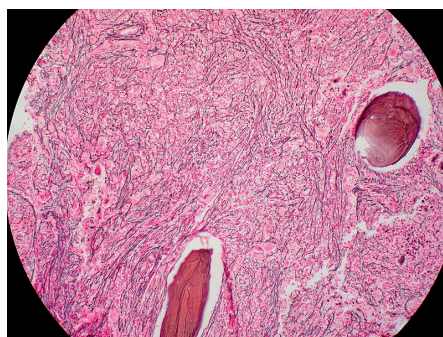
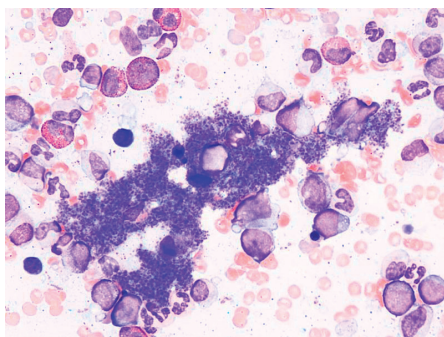
■ **ESSENTIAL THROMBOCYTHEMIA (ET)**, a type of blood cancer that leads your bone marrow to make too many platelets. ET is typically diagnosed through a blood test, and with a bone marrow biopsy, which is the removal of soft tissue from within your bone. People are also tested for the genetic mutation known as JAK2.

■ **MYELOFIBROSIS**, a type of blood cancer that is the result of a mutation in the blood-forming stem cells. The mutation leads to excessive scar tissue forming in the marrow. Myelofibrosis is

diagnosed through a blood test, followed by a bone marrow biopsy and a test to check if your blood cells have a genetic mutation known as JAK2.

Signs and symptoms of a MPN may vary by type. Some people have no symptoms of their disease. Others notice symptoms, including:

- Headache
- Lightheadedness or dizziness
- Fevers
- Weakness
- Itching
- Sweating at night
- Pain in bones, joints, or below the ribs on the left side
- Enlarged liver
- Enlarged spleen
- Changes in how the skin looks, including bruising or redness



LEFT TO RIGHT: ESSENTIAL THROMBOCYTHEMIA; MYELOFIBROSIS; POLYCYTHEMIA VERA

Treatment Options

Treatment depends on many factors including your age, your type of MPN, your symptoms, and stage of your disease. If your disease is diagnosed early and you have no symptoms, your doctor may recommend a “watch and wait” approach to your care. This means your doctor may not recommend any treatment when you are diagnosed. It is possible that your MPN will not progress and remain stable and symptom-free for months or years. Schedule regular checkups and exams with your doctor. If you notice any changes to your health or more symptoms of the disease, tell your doctor and discuss your treatment options.

If your doctor recommends treatment right away, the first step may be phlebotomy. This procedure removes blood to reduce the number of red blood cells in your body. Your doctor may also tell you to take a low-dose aspirin daily to help reduce your risk of clotting.

There are many different drugs to treat the symptoms of MPN and reduce the number of platelets in your body. Most of these drugs can be taken by mouth but some may need to be given through an injection. Each of the drugs may have side effects. These can include a fast heartbeat, headaches, dizziness, shortness of breath, and fatigue. The doctor can lower the dose of certain drugs to help lessen side effects. If you think you are having any side effects, tell your doctor.

Some of the drugs your doctor may recommend include:

INTERFERON, which is given as an injection in some people with ET and PV. It acts like a protein your body naturally makes, by boosting your immune system to fight cancer cells.

HYDROXYUREA, which is a pill given to people with MPN. It stops the growth of cancer cells and may reduce the chance of blood clots, like strokes, heart attacks, or lung clots.

ANAGRELIDE, which is a pill that lowers the number of platelets that your body makes.

JAK INHIBITORS, targeted therapies such as ruxolitinib (Jakafi®) and fedratinib (Inrebic®), reduce symptoms of myelofibrosis, including an enlarged spleen.

Living With MPN: A Long-term View

If you've been diagnosed with MPN, your doctor may tell you that your disease may change from one type of MPN to another. It even may transform into an acute leukemia. It is possible for ET or PV to change into myelofibrosis, and for any MPN to change into an acute leukemia

over time. It is also possible that your diagnosis may fall between two types. It is important that you understand the different symptoms of the disease so that you can work with your doctor to manage your care. Research is rapidly growing in the understanding of MPN and leading to new treatments. By working with your health care team, you can take charge and maintain your quality of life with this chronic disease.



SEYMOUR

Seymour, 73, credits the rapid pace of medical research with the fact that he's alive today. Two years ago, he was diagnosed with myelofibrosis, which is a type of MPN.

After Seymour was diagnosed, his doctors recommended that he enroll in a clinical trial that was testing new drug combinations to treat his disease. A chemical engineering major and a science lover, Seymour readily agreed to enroll in a trial. He has already completed two clinical trials and is currently looking to enroll in a third. "I was fortunate that I was diagnosed when new treatments were available," said Seymour. Since beginning his second trial, his disease has remained stable and Seymour has not had to have a blood transfusion in a year. "If I was diagnosed with this disease even five years ago, I wouldn't have had access to the trials that I participated in," he said. "I feel lucky to be where I am at this point in time."

Living with myelofibrosis is challenging, Seymour admits. He still suffers from fatigue and needs to rest often. He copes with his limitations by managing his expectations and being able to accept help from others. An Orthodox Jew, Seymour says his religion also helps him cope. He knows his cancer is incurable and understands his health may decline. He added that if a clinical study is available, people should talk to their oncologist to learn if it may be the right option for them.



“But knowing about the available treatment options is one of the big things that patients can do.”

—Seymour

Your Support Team

MPN is a chronic disease. This means you will need to build a support system that can help you cope with your disease for the rest of your life. Connect with other MPN patients who can share ideas and advice in living with the disease. Talking with others who can relate may help

Talk to your doctor about clinical trials

Ask about clinical trials. These are research studies to test new treatments or learn how to use existing treatments better. Today's clinical trials may become tomorrow's newest treatments.

KEY THINGS TO KNOW:

- A clinical trial may be the only way to get some of the newest, most promising treatments.
- The U.S. Food and Drug Administration and local review boards oversee all U.S. clinical trials to keep patients safe.
- If you join a clinical trial, you can leave at any time.
- Every doctor does not have the same trials.
- Most often, the trial pays the costs of the drug being studied and your health insurance only has to pay for "standard" treatment costs. However, your health insurance may not pay for everything. Be sure to ask.

Learn more about Clinical Trials by visiting www.CancerSupportCommunity.org/ClinicalTrials.

provide an important sense of comfort and community since they can understand what you are going through. Your family and friends are a very important part of your support team. They can help you cope with and manage the disease. A friend or family member can also act as an advocate, talking to members of your health care team or asking them questions. You may find it helpful if someone goes with you on visits to the doctor, to act as a second set of ears or to take notes.

Living with MPN also takes a team approach in your medical care. The members of your health care team will include your oncologist, primary care doctor, nurse, social worker, nutritionist, as well as other specialists, such as neurologists and cardiologists. It is important that everyone works together and stays informed of your care and treatments to help you have the best quality of life.

Coping With MPN

Being diagnosed with cancer can feel very isolating and depressing. "Since MPNs are a rare disease, it is easy to feel alone and misunderstood," says Sara Goldberger, LCSW-R. "If you mention breast cancer, everyone knows what you have, but if you mention MPN, most people have never heard of it."

There are also social and emotional factors related to a cancer diagnosis. These include feeling out of control, loss of hope, loneliness, and anxiety in living with uncertainty. Because MPN tends to progress slowly, people who have decided to watch and wait before beginning treatment may hear comments from friends or family, such as, "You have cancer but you're not being treated for it?" Talk about your concerns with your doctor, especially if you have symptoms that limit your quality of life.

Being able to express your feelings with others is an important part of coping. You can find a support group and talk with other people who share similar experiences. Or you can speak with a counselor or social worker about the challenges of living with cancer. A counselor or social worker can provide tips on making changes to improve your quality of life, learning to live with uncertainty, managing expectations, and taking a proactive approach to treatment and symptom management.

Keep a Treatment Journal

As you live with MPN, it's important to remember that you can take charge of your own care. One way to do this is by keeping a treatment journal. This a daily diary about your treatment and any side effects. Writing down notes, including the dosage of any drugs or treatments that you've taken that day, can help you and your doctor review your treatment history over time. The more you can talk with your health care team in detail about living with MPN, the better they will be able to help you cope with symptoms to improve your quality of life.

BELOW ARE SPECIFIC DETAILS YOU MAY WANT TO INCLUDE:

- Your current medicines, and daily dosage
- Frequency of your doctor visits or blood draws
- Any pain or discomfort, including the level and length of time of the pain and discomfort
- New symptoms/side effects or worsening of symptoms/side effects
- Impact on your quality of life
- Your feelings about living with MPN
- Questions and concerns you may have for your health care team

QUESTIONS TO ASK YOUR HEALTH CARE TEAM:

- What is my diagnosis?
- What treatment do you recommend?
- How often will I be given treatment and for how long?
- What is the plan if my disease progresses?
- What does disease progression look like?
- How often will I need to come in for follow-up care?
- How will treatment affect my quality of life?
- What side effects of treatment should I expect?
- Am I able to join a clinical trial?
- Will my MPN change to an acute leukemia?
- What other resources (support groups, educational materials, organizations) are available to learn more about my disease and treatment options?

MPN Information, Survivorship & Support

Cancer Support Community • 888-793-9355 • www.CancerSupportCommunity.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

MPN Research Foundation • 312-683-7249 • www.mpnresearchfoundation.org

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[®]—Preparing for your next appointment? Call CSC's toll-free Cancer Support Helpline (888-793-9355), available in 200 languages Mon–Fri, 9 am–9 pm ET.

Open to Options[®]—Need help making a cancer treatment decision? 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.

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.

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

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.

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.

THIS PROGRAM WAS MADE POSSIBLE WITH GENEROUS SUPPORT 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.

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