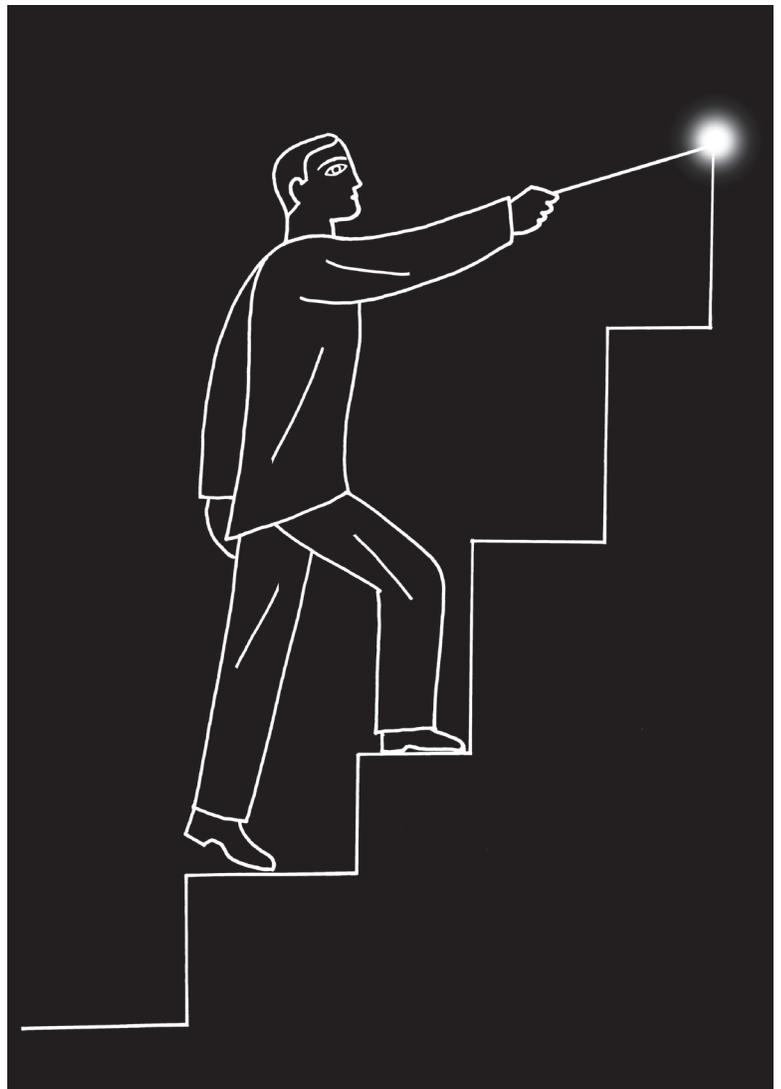


Understanding Myeloproliferative Neoplasms

If you or a loved one has recently been diagnosed with a myeloproliferative neoplasm (MPN), you may have many 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 and cope 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.



**CANCER SUPPORT
COMMUNITY**

SUPPORT FOR FINDING INFORMATION ABOUT MPN

Cancer Support Community 1-888-793-9355

www.cancersupportcommunity.org

MPN Education Foundation www.mpninfo.org

MPN Research Foundation www.mpnresearchfoundation.org

About Myeloproliferative Neoplasms

Myeloproliferative Neoplasms are a group of blood cancers caused by a mutation in the blood's stem cells, which 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.

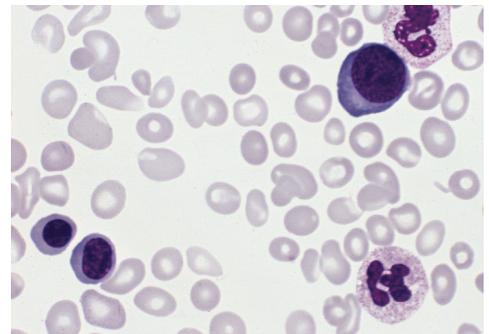
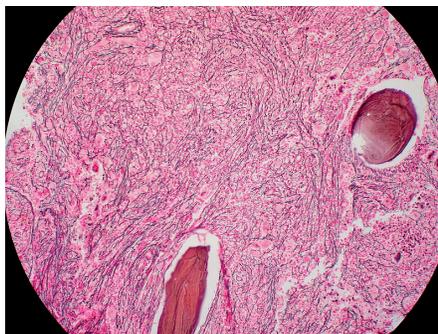
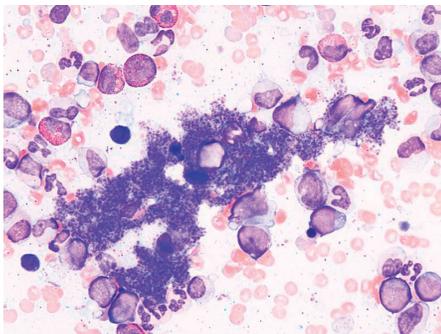
■ **ESSENTIAL THROMBOCYTHEMIA (ET)**, a type of blood cancer that leads your bone marrow to make too many platelets. ET is typically diagnosed through a blood test, and with a bone marrow biopsy, which is the removal of soft tissue from within your bone. People are also tested for the genetic mutation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

■ **MYELOFIBROSIS**, a type of blood cancer that is the result of a mutation in the blood-forming stem cells, leading 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. Talk to your doctor about the tests that are being done to confirm your type of MPN. It is important to understand how your MPN is being diagnosed.

SOME PEOPLE HAVE NO SYMPTOMS OF THEIR DISEASE, BUT OTHERS DO NOTICE SYMPTOMS, INCLUDING:

- HEADACHE
- LIGHTEADEDNESS 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

Depending on your age, your type of MPN, your symptoms and stage of your disease, your doctor may recommend a variety of possible treatments. 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 at the time of diagnosis. 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, it is very important to tell your doctor and discuss your treatment options.

If your doctor recommends treatment right away, he or she may begin with phlebotomy, which removes

blood to reduce the number of red blood cells in your body. You may also be told to take a low-dose aspirin daily to help reduce your risk of clotting.

There are also many different drugs to treat the symptoms of MPN and also reduce the number of platelets in your body. 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, ranging from a fast heartbeat, headaches, dizziness, shortness of breath, fatigue in some people, and other issues that may affect your quality of life. Doctors can lower the dose of certain drugs to help lessen side effects. Talk with your doctor about side effects you think you might be having so that you stay on a treatment and not skip any treatments.

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 similar to a protein your body naturally makes, by boosting your immune system to fight cancer cells.

HYDROXYUREA, which is a pill that is given to people with MPN, to stop 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 is given to people whose platelets cannot otherwise be controlled. This drug lowers the number of platelets that your body makes.

RUXOLITINIB (Jakafi®), which is the first FDA-approved drug to treat myelofibrosis. It is a pill that inhibits a protein known as JAK1 and targets a mutated gene known as JAK2. The drug reduces symptoms of myelofibrosis, including an enlarged spleen, and has been shown to prolong survival. The drug is also being tested in people with other MPNs at this time.

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, or even 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. While it is important to know the type of MPN that you have, it is also possible that your diagnosis may fall between two types. In order to be as involved

and knowledgeable as possible, 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 talking and working with your health care team, you can take charge and maintain your quality of life with this chronic disease.

Profile: Seymour Perlowitz



Seymour Perlowitz, 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 Perlowitz 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 Perlowitz. Since beginning his second trial, his disease has remained stable and Perlowitz 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, Perlowitz 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, Perlowitz 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 Perlowitz

Your Support Team

MPN is a chronic disease, which 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 provide an important sense of comfort and community since they can understand and relate to what you are going through. Your family and friends are a very important part of your support team, and can help you cope with and manage the disease. A friend or family member can also act as an advocate, someone who talks to members of your health care team or who asks questions for you when talking to members

of your health care team. You may find it helpful if someone goes with you on visits to the doctor, to act as a second set of ears in listening to information or for taking down notes.

Living with MPN takes a team approach, even 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. There may be many different members of your overall support team. But it is important that everyone work together and be informed of your care and treatments in order to help you live the best quality of life.

Talk to Your Doctor About Clinical Trials

You or your doctor may be interested in looking into a clinical trial to help manage your MPN, since it is a very active area of research. Clinical trials offer patients the opportunity to benefit from new combinations of therapies, while also advancing the pace of knowledge about the disease and treatment options.

If your doctor has not mentioned a clinical trial as an option, be proactive and ask if it is right for you. Although there is much information about clinical trials on the internet, it is important to talk with your doctor so you can find the right trial for you. Each trial has specific guidelines and eligibility criteria, including age, limits based on previous treatments and stage of your disease. Your doctor or nurse will also be able to explain to you what joining in a clinical trial will require and how it may affect your care and daily 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, Senior Director of Programs at the Cancer Support Community. “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, including 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?” This can be confusing, so be sure to bring up these 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. People with a MPN can find a support group and talk with other people who share similar experiences or speak with

a counselor or social worker about the challenges of living with cancer. A counselor or social worker can help you cope by providing 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 empower yourself and take charge of your own care. One way to do this is by keeping a treatment journal to let your health care team know of how you are coping with the disease. The more you can talk with them in detail about living with MPN, the better they will be able to help you cope with symptoms to improve your quality of life. You may also find it helpful to write in 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 also help you and your doctor review your treatment history over time.

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
- Affect to 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?*

Resources for Information & Support

CancerCare 800-813-4673 www.cancer.org

Clinicaltrials.gov

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

MPN Education Foundation www.mpninfo.org

MPN Research Foundation www.mpnresearchfoundation.org

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 1-888-793-9355 or visit www.cancersupportcommunity.org

CANCER SUPPORT HELPLINE ®

Whether you are newly diagnosed with cancer, a long-time cancer survivor, caring for someone with cancer, or a health care professional looking for resources, CSC's toll-free Cancer Support Helpline (1-888-793-9355) is staffed by licensed CSC Helpline Counselors available to assist you Mon-Fri 9 am- 8pm ET.

OPEN TO OPTIONS ®

If you are facing a cancer treatment decision, Open to Options® is a research-proven program that can help you prepare a list of questions to share with your doctor. In less than an hour, our Open to Options specialists can help you create a written list of specific questions about your concerns for your doctor. Appointments can be made by calling the Helpline or by visiting the CSC website to locate a CSC affiliate offering this service near you.

FRANKLY SPEAKING ABOUT CANCER ®

CSC's landmark cancer education series, which provides sound medical and psychological information for cancer patients and their loved ones. Information is available through books, online, and in-person programs.

AFFILIATE NETWORK SERVICES

Almost 60 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.

THE LIVING ROOM, ONLINE

CSC's "The Living Room" offers much of the same programming available at each CSC affiliate. On CSC's website you will find online support groups, discussion boards and social networking, "build your own website."

A special thanks to our contributors and reviewers: Laura C. Michaelis, MD, Linda Zignego, RN, BSN, Froedert Hospital and Medical College of Wisconsin; Sara Goldberger, LCSW-R, Cancer Support Community; Seymour Perlowitz, patient representative.

The Cancer Support Community and its partners provide this information as a service. This publication is not intended to take the place of medical care or the advice of your doctor. We strongly suggest consulting your doctor or other health care professionals to answer questions and learn more.

THIS PROGRAM WAS MADE POSSIBLE THROUGH AN UNRESTRICTED EDUCATIONAL GRANT FROM:



© July 2014 Cancer Support Community. All rights reserved.

Design by Yolanda Cuomo Design, NYC; Cover Illustration © Anthony Russo

Photographs of Seymour Perlowitz © Bonnie Briant and Jonno Rattman