

**MPN** RESEARCH  
FOUNDATION

**CHANGE YOUR PROGNOSIS**

# **Patient Information Kit**

Essential Thrombocythemia

Polycythemia Vera

Myelofibrosis

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# + Welcome

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The MPN Research Foundation would like to extend a warm welcome and a “thank you” for connecting with us. There is strength in numbers, and, even though an MPN diagnosis is not in anyone’s life plan, we have a welcoming community to help guide you.

Since its birth in 1999, it has been the mission of MPN Research Foundation to raise funds for original research in pursuit of new treatments, and eventually a cure, for the blood cancers polycythemia vera, essential thrombocythemia, and myelofibrosis, known collectively as myeloproliferative neoplasms (MPNs). As an organization that was founded by patients for patients, we also work every day to educate and empower patients, family members, doctors and researchers across the world.

In your Patient Information Kit you will find valuable resources. The kit includes handouts relating to specific disease information, caregiver resources, myMPN, the MPN Patients’ Bill of Rights and more. We encourage both patients and caregivers, to take a few minutes to review all of the materials in the kit and acquaint yourself with the information.

In the future, please continue to use The MPN Research Foundation as a resource during your MPN journey!



# + About The MPN Research Foundation

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## + Our Mission

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The mission of MPNRF is to stimulate original research in pursuit of new treatments - and eventually a cure - for the blood cancers polycythemia vera, essential thrombocythemia, and myelofibrosis, known collectively as myeloproliferative neoplasms (MPN).

Through a combination of MPN cancer research, advocacy and education, we bring together patients, researchers and clinicians around the common goal of realizing new treatment options and a cure for MPNs.

## + Our Research Impact

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With nearly \$15 million in funding and over 75 funded research projects, we have made a significant difference in advancing our understanding of the causes of MPNs, the development of new drug therapies and in cutting edge research that has been published in leading scientific journals. Some examples of our research impact include:

- MPN Research Foundation funding enabled researchers to perform preclinical testing of compounds to inhibit the JAK2 mutation.
- Support for genomic research helped lead to the discovery of Calreticulin (CALR), a mutation found in MPN patients without JAK2.
- Supported the establishment of the MPD Research Consortium, an international, multi institutional alliance of scientists at the forefront of MPN research.
- Funded and will continue to fund new mechanisms of action, including ALOX5 inhibitor and TGFβ inhibitor.
- Funded first large-scale tissue bank and associated data bank at the Mayo Clinic, enabling rapid testing of new JAK2 inhibiting drugs.
- Encourage researchers to examine strategies to harness a patient's immune system as a therapy.
- Launch of patient registry, myMPN – an online tool for patients to record their symptoms, demographic information, experiences with different therapies and, if interested, share their data with researchers.
- Assisted in the development of the SCT Spectrum Timing Tool to guide patient and physician discussions around timing for a stem cell transplant.

## + Trusted Resource for Patients

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Founded by patients for patients, the MPN Research Foundation works every day to educate and empower patients, caregivers, doctors and researchers throughout the world. MPNRF strives to provide the MPN community with the latest news in MPN research, treatments, drug discovery, community events, support groups and educational resources.

**[www.MPNRF.org](http://www.MPNRF.org)**

# +10 Steps to Take

## After an MPN Diagnosis



### Learn how MPN Research Foundation can help you.

MPNRF works every day to provide a welcoming community that educates and empowers MPN patients. We encourage you to visit our website at [www.mpnrf.org](http://www.mpnrf.org) so you can acquaint yourself with our available resources.



### Find a specialist.

If you aren't already under the care of a hematologist specializing in MPNs, we encourage you to seek one out. Visit the MPNRF website to find a doctor or treatment facility in your area that understands the particular needs of MPN patients.



### Become informed about your disease.

It's important to become knowledgeable about your disease so that you can successfully advocate for yourself during your MPN journey. Ask your doctor for help, use MPN Research Foundation as a resource and sign up on our website to get the latest MPN news.



### Research your financial options.

Economic information is an important part of advocating for yourself. Read about Drug reimbursements and financial assistance programs for the treatments you need to manage your diagnosis on MPNRF's Website.



### Stay on Track.

It is critical to maintain your important medical information so that you stay on top of your treatment routine. MPNRF's online patient registry, myMPN, can help you keep track of questions/answers for your physician, test results, blood cell counts, medications, dosing schedules, prescription refills, etc.



### Read other patients' stories.

The MPN community is a place where patients learn from each other. Read the stories of patients who are coping with an MPN and share your story with others by visiting the Patient Stories page on our website.



### Find support groups.

If you've been diagnosed with an MPN it's important to know that you're not alone. Visit the Find Support section on MPNRF's website to learn more about the many online and in-person support groups that offer a platform for you to connect with fellow MPN patients.



### Find a mentor.

Peer-to-peer matching programs like Imerman Angels can be valuable for identifying a mentor who can help you walk through the initial stages of an MPN diagnosis. Visit Imerman Angel's website at [www.imermanangels.org](http://www.imermanangels.org) to learn more about their service.



### Learn about clinical trials.

By participating in clinical trials, you can help uncover opportunities that will advance MPN treatments and possibly benefit your personal prognosis. Visit our Find a Trial page to learn more and consult your physician to discover if clinical trials are an advisable course of action for you.



### Get involved.

Are you looking for a way to join MPN Research Foundation in the fight against MPN? Visit the Make an Impact tab on MPNRF's homepage to learn more about starting a support group, enrolling in a clinical trial, making a donation, hosting a fundraising event, sharing your story and more.

# + Polycythemia Vera

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## + What is PV?

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Polycythemia Vera (PV) is a chronic myeloproliferative neoplasm (MPN) primarily characterized by an abnormal elevation of the red blood cells. Patients suffering from this disease may also experience an elevated leukocyte (white blood cell) count, an elevated platelet count, and/or an enlarged spleen. In 2005, it was discovered that 95% of patients with PV have a mutation in the JAK2 gene. This gene plays a significant role in the production of red blood cells (in addition to white blood cells and platelets). When this gene is mutated, there is a loss of normal regulation resulting in an overproduction of red blood cells, and at times, white blood cells and platelets. The discovery of this mutation has propelled a broad range of scientific projects which will hopefully result in new and effective treatments for PV and the other myeloproliferative neoplasms.

## + Possible Causes

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No one knows exactly what triggers the start of PV or other myeloproliferative neoplasms (MPNs). Recently, researchers discovered that these diseases may be caused by mutations (changes in DNA). These mutations affect proteins that work in signaling pathways in your cells, which can be thought of as a chain of signals that your cells use to communicate messages in order to know what to do. Almost all people with PV have a mutation called "JAK2V617F" (found in the JAK2 gene) within their blood-forming cells. This mutation is one way that JAK (Janus Kinase) pathway signaling can become deregulated and cause disease. The end result is that the body produces too many blood cells. Researchers now know that Polycythemia Vera is complex and may have many contributing factors, and mutations in other genes or pathways are being investigated. Epidemiologic factors associated with PV may also include:

- Gender: Men may be slightly more likely than women to develop the condition.
- Age: People older than 60 are most likely to develop PV, though it may occur at any age.
- Environment: Exposure to intense radiation may increase the risk for the condition.

## + Symptoms

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PV patients may present with a variety of symptoms, or may be relatively asymptomatic, discovered incidentally during a routine doctor's visit. Symptoms can include:

- Headaches
- Sweating
- Ringing in the ears
- Blurred vision or blind spots
- Dizziness or vertigo
- Reddish or purplish skin
- Unexpected weight loss
- Bleeding or clotting
- Early feeling of fullness (satiety)
- Itching (pruritus), especially after showering
- Burning and redness of the hands or feet
- Tiredness (fatigue)
- Night sweats
- Bone pain

# + Polycythemia Vera

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## + Prognosis

Polycythemia Vera patients have an excellent chance of living a normal life span if properly monitored and treated as necessary. The most common cause of morbidity and mortality is the predisposition of PV patients to develop life threatening arterial thrombosis (heart attacks, strokes, intestinal gangrene), venous thrombosis (of the portal and/or hepatic veins), or pulmonary embolism. Important strategies for care can include aspirin and control of the blood counts in those at high risk. For others, life expectancy can be compromised as the disease evolves to Myelofibrosis, or rarely, acute leukemia.

## + Available Treatments

Your doctor can describe available treatments that may be appropriate for you. PV is different in every person. If you don't have a lot of symptoms your doctor may decide that you don't need treatment yet. Instead, your doctor will observe and monitor your condition. Treatment to return hematocrit to normal values is the foundation of management. Treatment options include:

- **Phlebotomies** reduce the number of blood cells by removing blood from your body. With fewer blood cells, the blood is thinner and flows more easily. Better blood flow improves symptoms. At present, your physician targets your blood count goals depending on sex (45% or less in men, and 42% or less in women is often recommended), though researchers are evaluating the optimal target in the future.
- **Low-dose aspirin** is usually given to reduce the risk of blood clotting. Aspirin may also help relieve the burning sensation that some people get in their hands and feet

Maintaining a hematocrit below 45% and 42%\* for men and women respectively, along with low dose aspirin, is currently accepted as first choice treatment in newly diagnosed low risk PV patients. If phlebotomy and low-dose aspirin are not sufficient or appropriate, your doctor may prescribe medicine to lower your red blood count and relieve symptoms. In 2014 Jakafi became the first drug approved to treat Hydroxyurea resistant/intolerant PV patients. In addition, some medicines approved for other diseases are used to treat the signs and symptoms of this condition. A physician will prescribe one of these options based on a variety of risk factors including age (over 60), history of thrombotic events and drug tolerance, or if certain disease related symptoms cannot otherwise be controlled. Current options include:

- **Jakafi or Jakavi outside of the US** (Ruxolitinib) is the first FDA approved treatment intended for PV patients who have an inadequate response to or cannot tolerate hydroxyurea. You do not need to be JAK2 positive to take Jakafi. The drug helps to decrease the occurrence of an enlarged spleen (splenomegaly) and the need for phlebotomy.
- **Hydroxyurea** is often considered for those at high risk for blood clots, based on age and prior history of blood clotting.
- **Pegylated Interferon** is often prescribed to younger patients and women of childbearing age because it has not been shown to cause birth defects.
- **Ropeginterferon Alpha-2b** is a new formulation of Interferon that, as of publication, is available for use in Europe and the middle east.

\*Please do not rely on these counts as absolute certainty. Always consult with your physician about your test results.

# + Essential Thrombocythemia

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## + What is ET?

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Essential Thrombocythemia (ET) is a chronic myeloproliferative neoplasm characterized by an increased number of platelets in the circulating blood. ET is characterized by a proliferation of platelet precursors in the bone marrow, and its most common complications include tendencies toward blood clotting and/or bleeding; later but more rare consequences include a transformation to myelofibrosis (marrow scarring) or acute leukemia.

## + Possible Causes

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No one knows exactly what triggers the start of essential thrombocythemia (ET) or other myeloproliferative neoplasms (MPNs). Recently, researchers discovered mutations that alter the activity of proteins that control signaling pathways in many patients with MPN. Signaling pathways are important regulators of cell growth and development.

About half of all people with essential thrombocythemia have a mutation called “JAK2V617F” (found in the JAK2 gene) within their blood-forming cells. This mutation leads to hyperactive JAK (Janus kinase) signaling and leads to many of the characteristic features of the disease. The end result is that the body makes the wrong number of blood cells. Recently, clusters of families with MPN have been described, suggesting a familial predisposition in some patients. About 23.5% of people with ET have a mutation called Calreticulin, or CALR. This genetic marker was discovered in 2013 by two independent laboratories, including one funded by MPN Research Foundation. Research is still ongoing, but there are potential implications for prognosis and treatments for those with the CALR mutation. Epidemiologic factors associated with ET may also include:

- Gender: Women are 1.5 times more likely than men to develop the condition
- Age: People older than 60 are most likely to develop the condition, although 20% of those with this condition are under 40
- Environment: Exposure to chemicals or to electrical wiring may increase an individual's risk

## + Prognosis

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Essential thrombocythemia patients have an excellent chance of living out a normal life span if properly monitored and treated as necessary. ET is a chronic hematologic malignancy and it is prudent to be monitored regularly by a hematologist. It is important to report any symptoms such as visual disturbances, unexplained pain, numbness, tingling or bruising to your physician. For those with symptoms from their ET, treatment will be required.

# + Essential Thrombocythemia

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## + Symptoms

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Many patients are asymptomatic, diagnosed after blood counts as part of a routine check-up reveal a high platelet count. When symptoms are present, they may include fatigue, or may be related to small or large vessel disturbance or bleeding. Thrombotic complications can be quite serious.

- Small vessel disturbances
- Headaches
- Vision disturbances or silent migraines
- Dizziness or lightheadedness
- Coldness or blueness of fingers or toes
- Burning, redness, and pain in the hands & feet
- Stroke
- Transient ischemic attack (TIA)
- Heart attack
- Deep vein thrombosis or Pulmonary Embolus
- Easy bruising, nosebleeds or heavy periods
- Gastrointestinal bleeding or blood in the urine

## + Available Treatments

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You should consult your doctor about available treatments that may be appropriate for you. Essential thrombocythemia (ET) is different in every person. If you don't have a lot of symptoms, your doctor may decide that you don't need treatment yet. Instead, your doctor will observe and monitor your condition. Current treatments for ET patients who require treatment include the following:

- **Low-dose aspirin** is usually given to reduce the risk of blood clotting. Aspirin may also help relieve the burning sensation that some people get in their hands and feet (erythromelalgia, along with other vasomotor symptoms).
- **Hydroxyurea** is often used in essential thrombocythemia in people at high risk for clotting (age over 60 and those with a prior blood clot), and is usually considered the first line agent in those that require treatment.
- **Anagrelide** is another option to lower the platelet count, often chosen after a patient has intolerance or complications with Hydroxyurea.
- **Interferon** is sometimes prescribed for ET patients. Younger women of childbearing age are often treated with interferon because it hasn't been shown to cause birth defects. A pegylated version may be associated with less side effects and easier administration.

Potential new treatments for ET are currently being developed and tested as a result of the discovery of the link between the JAK2 mutation and incidence of ET. These drugs, referred to as JAK2 Inhibitors, are currently in early stages of testing for ET. Pegylated interferon is also being considered as a treatment in those with high risk disease.

# + Primary Myelofibrosis

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## + What is MF?

Myelofibrosis (MF) is a chronic blood cancer caused by abnormal blood stem cells in the bone marrow. The abnormal stem cells produce mature cells that take over the bone marrow, causing fibrosis (scar tissue formation) and chronic inflammation. As a result, it becomes more difficult for the bone marrow to create normal blood cells and blood cell production that may cause spleen enlargement. MF can arise on its own (primary myelofibrosis, PMF), or as a progression of polycythemia vera (post-PV-MF) or essential thrombocythemia (post-ET-MF). The manifestations of PMF, post-PV-MF and post-ET-MF are virtually identical and treatment is generally the same for all three.

## + Available Treatments

Each patient with MF may have a different set of symptoms & different treatment requirements. Your doctor can describe available treatments that may be appropriate for you, your symptoms & your specific circumstances. For those that require treatment, Jakafi (ruxolitinib) and Inrebic (Fedratinib) are approved by the FDA for treating MF patients. Additionally some medicines approved for other diseases can be used to treat the signs & symptoms of MF. These medicines may not be effective for everyone & some have potentially serious side effects. Therapies currently used include the following:

- Jakafi or Jakavi outside of the US (ruxolitinib) Jakafi is taken orally & inhibits the activity of JAK2 & the related protein JAK1. In clinical trials, Jakafi reduced spleen size, abdominal discomfort, early satiety, bone pain, night sweats & itching in MF patients. Jakafi also reduces the level of “pro-inflammatory cytokines” in the blood, which cause the symptoms of chronic inflammation.
- Inrebic (fedratinib) is an oral kinase inhibitor with activity against wild type and mutationally activated JAK2 and FMS-like tyrosine kinase 3 (FLT3) indicated for the treatment of patients with primary MF post-PV-MF and post-ET-MF. The end points focused on spleen size reduction and symptom relief.
- Allogenic Stem Cell Transplantation (ASCT) ASCT is the only known potential cure for MF, but is not suitable for many patients due to high risk of complications.

In an effort to improve stem cell transplant outcomes for MF patients, MPNRF supported the creation of a **Myelofibrosis Assessment Graphic Internet Calculator**. MAGIC is a portable online tool based on a clinically validated scale. It provides a color signal in response to information entered by a patient, that indicates a risk level and median survival times without a SCT. A patient can then take what they’ve learned and use it to facilitate a meaningful dialogue between themselves and their physician about their treatment options. SCT Spectrum Transplant Timing tool is available for free on a mobile phone, tablet, and PC. ([www.MPN-MAGIC.com](http://www.MPN-MAGIC.com))

If a suitable donor can be found, hematopoietic (blood-forming) stem cells are transferred from the healthy donor to the MF recipient to replace their defective stem cells. Prior to the stem cell infusion, chemotherapy and/or radiation therapy are administered to eradicate the diseased marrow.

For many patients with MF, available treatment approaches may not be effective & experimental treatments (receiving a novel drug or treatment on a clinical trial) may be an appropriate option. Below is a list of specific symptoms of MF & available therapeutics used to treat these symptoms:

- Anemia may be treated with corticosteroids, androgens (danazol), thalidomide, lenalidomide, blood transfusions, or erythropoiesis stimulating agents (ESAs).
- Splenomegaly may be treated with Jakafi, Inrebic, hydroxyurea (HU), cladibrine, interferon, or, in some cases, radiation or splenectomy
- Risk of thrombosis may be managed with low-dose aspirin therapy or hydroxyurea.
- Extramedullary hematopoiesis may be treated with radiation therapy.
- Constitutional symptoms, such as night sweats, pruritus, & fever may be treated with Jakafi or Inrebic.

# + Primary Myelofibrosis

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## + Symptoms

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Many symptoms of MF are caused by insufficient numbers of normal blood cells or chronic inflammation. Symptoms may include the following:

- Tiredness, weakness, shortness of breath
- Fullness, discomfort or pain in the left upper area of the abdomen and early satiety
- Fever, caused by inflammation or infection
- Night sweats, caused by inflammation
- Weight loss or malnutrition, caused by an enlarged spleen pressing on the stomach & bowel
- Bone pain
- Itching (pruritus)
- Easy bleeding or bruising
- Susceptibility to infection
- Joint pain
- Portal hypertension
- Abnormal growth of blood forming cells outside of the bone marrow can occur in different parts of the body, including lymph nodes, lungs, & spinal cord.

## + Possible Causes

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No one knows exactly what triggers the start of MF or other MPNs. In most cases, myelofibrosis is not inherited—you can't pass it on to your children and you didn't get it from your parents (although some families do demonstrate a predisposition). Recently, researchers have discovered that these diseases may be caused by gene mutations (changes in DNA) that are acquired.

About 50%-60% of MF patients have a mutation called "JAK2V617F" within their blood-forming cells. JAK2 is a messenger inside blood cells and participates in a relay system that receives signals from the body. When the body needs more blood cells, it sends signals to JAK2, which then signals to the cell to start growing and dividing. The V617F mutation causes JAK2 to become constantly active, which means that JAK2 can no longer stop signaling. Between 5%-10% of patients will have a mutation in another gene named MPL, which also affects JAK signaling pathway and 30% of patients will have the CALR mutation.

- Age: Most often diagnosed in people ages 60 - 70
- Environment: Exposure to petrochemicals (benzene & toluene) and ionizing radiation may increase your risk

## + Prognosis

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The prognosis of MF is different for every patient. People in a good prognostic group can live for many years without having major symptoms; those with a poor prognosis may progress more quickly. In general, the most important factors that determine prognosis are age, white blood cell counts, number of "blasts" (immature blood cells) in the blood, "constitutional symptoms" (night sweats, weight loss, fever, pruritus), anemia (low red blood cells), transfusion dependence, low platelets and abnormal chromosome analysis.

For most patients, the most important symptoms to be managed in cooperation with a doctor are anemia enlarged spleen, extra medullary hematopoiesis (production of blood cells in organs outside the bone marrow), thrombosis and thrombohemorrhagic complications (blood clotting or bleeding complications), leukocytosis (too many white blood cells), thrombocytosis (too many platelets), "constitutional symptoms" (fatigue, night sweats, weight loss, pruritus, fever, bone and joint pain) & gout.

For a small number of patients, MF can transform to acute myeloid leukemia (AML), a serious blood and bone marrow cancer which progresses quickly, is often difficult to treat & can be rapidly fatal.

# +Caregiver Information

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Caregiving often involves different types of support and tasks. There are several ways to help manage all the duties of a caregiver to help you provide effective support and care.

## **You may find the following tips can help you become a successful caregiver:**

Remember that caregiving is a team effort. A caregiver is a member of an important team of family members, friends, volunteers, & the health care team. Each member of the team offers different skills & strengths to provide effective care. If you are the main caregiver, help each team member express concerns, opinions, & emotions. Also, make sure that the person with an MPN has a central role in all of the decisions. It is very important for the person with cancer to feel like an active member in their care.

Create a list of tasks. Caregiving, like any responsibility, involves tasks of varying importance. Start by making a list of all of your caregiving tasks. Then, use it to decide how to divide the tasks between friends, family, professionals, & other volunteers. Create schedules that list which volunteer is available when & for what tasks. Make sure that all of the caregivers involved have some time to be away without feeling guilty or concerned.

Be a problem solver. Identify problems, find out what is needed & follow through. Do not be afraid to seek advice & help from others. Look for creative solutions that work for your & the person you care for.

Stay positive. Having a positive attitude can help set the tone for all that you do. You may not have control of what happens to you, but you can change how you react. To help you cope, talk with other members of the caregiving team. You may also wish to talk with friends, religious or spiritual advisors, counselors, & health care professionals.

Know yourself & your limits. Recognize your own strengths & weaknesses as a caregiver. This allows you to set boundaries & know when to ask for help. Setting limits can help you & the person you care for. The person you care for can exercise some independence while you get a break. It is important to recognize when you need a break!

Consider professional & volunteer services. Some community agencies have volunteers who can help with transportation or advocate for health insurance or other benefits. A local hospital or community social worker is a great source for referrals to programs in your community.

## **Caring for the emotional well-being of the person with cancer**

It's important to help the person you care for maintain a sense of control. A cancer diagnosis may make him or her feel little control over life. A simple step would be to ask if you can help with a specific task or decision instead of doing it on your own.

Communicate. One of the caregiver's most important jobs is to communicate openly with the person who has cancer. Choose a time that is convenient for both of you to talk. Provide assurance that he or she will be a central part of all discussions & decisions. Be open to the person's feelings & opinions & allow enough time to fully explain your feelings.

Accept the limitations of a patient. A person who just received chemotherapy may not be able to taste a meal you worked hard to prepare. Or, a person on pain medication may not notice all of the small things you do. Also, be aware that caregiving tasks may change as the person's health changes.

Be inclusive. Include your loved one in activities that provide meaning or pleasure. Even if the person with an MPN is no longer able to actively participate in activities he or she enjoys, look for other ways to encourage involvement. It is important to help the person stay connected to the world beyond the diagnosis & to maintain a sense of normalcy.

## **Participating in medical & physical care**

Gather details about the patient's diagnosis, treatment, & prognosis. As a caregiver, learn more about the MPN, including the patient's type of MPN. Many patient advocacy groups also can provide information related to specific cancers. Ask the doctor about other trusted resources. In addition, you may want to keep a record of medical appointments, test results, medications & dosages, symptoms & side effects, questions, & names & numbers for resources.

Be an advocate. Take an active role in the patient's medical care. If possible, go with the patient to all medical appointments. It is helpful to write down questions for the doctor beforehand & to write down answers. In addition, give the doctor any new information that helps them make informed decisions.

# + Additional MPN Resources

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## Caregiver Resources

### National Family Caregivers Association (NFCA)

Toll-free number: 1-800-896-3650

Website: [www.thefamilycaregiver.org](http://www.thefamilycaregiver.org)

### National Alliance for Caregiving (NAC)

Website: [www.caregiving.org](http://www.caregiving.org)

### Well Spouse Association (WSA)

Toll-free number: 1-800-838-0879

Website: [www.wellspouse.org](http://www.wellspouse.org)

### Caregiver Action Network

Telephone: 202-772-5050

Website: [www.caregiveraction.org](http://www.caregiveraction.org)

### Medicare: Caregiving

Website: [www.medicare.gov/campaigns/caregiver/caregiver](http://www.medicare.gov/campaigns/caregiver/caregiver)

### National Respite Locator Service

Website: [www.respitelocator.org](http://www.respitelocator.org)

### Cancer Legal Resource Center

Toll-free number: 1-866-843-2572 (1-866-THE-CLRC)

TTY: 213-736-8310

Website: [www.cancerlegalresourcecenter.org](http://www.cancerlegalresourcecenter.org)

### Cancer Hope Network

Toll-free number: 1-877-467-3638 (1-877-HOPENET)

Website: [www.cancerhopenetwork.org](http://www.cancerhopenetwork.org)

### Cancer Support Community (formerly Gilda's Club)

Toll-free number: 1-888-793-9355

Website: [www.cancersupportcommunity.org](http://www.cancersupportcommunity.org)

### CancerCare

Toll-free number: 1-800-813-4673

(1-800-813-HOPE)

Website: [www.cancercare.org](http://www.cancercare.org)

### National Cancer Institute

Toll-free number: 1-800-422-6237 (1-800-4-CANCER)

TTY: 1-800-332-8615

Website: [www.cancer.gov](http://www.cancer.gov)

## Partner Organizations

### Aplastic Anemia & MDS International Foundation

Telephone: 800-747-2820

Website: [www.aamds.org](http://www.aamds.org)

### Cancer Research & Treatment Fund, Inc.

Telephone: 212-288-6604

Website: [www.crt.org](http://www.crt.org)

### Imerman Angels

Telephone: 212-288-6604

Website: [www.imermanangels.org/](http://www.imermanangels.org/)

### Leukemia & Lymphoma Society

Telephone: 800-955-4572

Website: [www.lls.org](http://www.lls.org)

### MPD Chat

Email: [yourfriendbeverly@gmail.com](mailto:yourfriendbeverly@gmail.com)

Website: [www.mpdchat.com](http://www.mpdchat.com)

### MPN Advocacy & Education International

Telephone: 517-899-6889

Website: [www.mpnadvocacy.com](http://www.mpnadvocacy.com)

### MPN Advocates Network

Email: [mpnadvocatesnetwork@gmail.com](mailto:mpnadvocatesnetwork@gmail.com)

Website: [www.mpn-advocates.net](http://www.mpn-advocates.net)

### MPN Alliance Australia (Australia)

Telephone: 1800 620 420

Website: [www.mpnallianceaustralia.org.au](http://www.mpnallianceaustralia.org.au)

### MPN Cancer Connection

Website: [www.mpnconnection.org](http://www.mpnconnection.org)

### MPN Education Foundation

Website: [www.mpninfo.org](http://www.mpninfo.org)

### MPN Forum

Telephone: 07934 689 354

Website: [www.mpnforum.com](http://www.mpnforum.com)

### MPN Stichting (The Netherlands)

Email: [info@mpn-stichting.nl](mailto:info@mpn-stichting.nl)

Website: [www.mpn-stichting.nl](http://www.mpn-stichting.nl)

### MPN Voice (UK)

Telephone: 07934 689 354

Website: [www.mpnvoice.org.uk](http://www.mpnvoice.org.uk)

### National Organization for Rare Disorders (NORD)

Website: [www.rarediseases.org](http://www.rarediseases.org)

### Patient Power

Website: [www.patientpower.info](http://www.patientpower.info)

### PV Reporter

Website: [www.pvreporter.com](http://www.pvreporter.com)

### Ruby Red Foundation (Australia)

Email: [patientadvocate@rubyred.org.au](mailto:patientadvocate@rubyred.org.au)

Website: [www.rubyred.org.au](http://www.rubyred.org.au)

## **Address**

180 N Michigan Ave, Suite 1870  
Chicago, IL 60601

## **Online**

[www.mpnresearchfoundation.org](http://www.mpnresearchfoundation.org)  
[communications@mpnrf.org](mailto:communications@mpnrf.org)