Caregiving for MPNs

FRANKLY SPEAKING ABOUT CANCER
A PROGRAM OF THE CANCER SUPPORT COMMUNITY

A caregiver is someone who provides physical and emotional care for a loved one. They may be a friend or family member. Caregivers can assist with a variety of tasks. This may include help with transportation, cooking, bathing, dressing, managing medications, attending doctor's visits, navigating insurance, watching for symptoms and side effects, etc.

You may also hear the term "care partner." In this resource, the term caregiver is used to describe anyone who provides or arranges care for a person. The term "loved one" is used in this resource to describe the person diagnosed with cancer. This could be someone that you have any type of relationship with that you care about.

This worksheet is for those caring for someone with a myeloproliferative neoplasm (MPN) diagnosis. This tool provides information about symptoms, treatment options, side effects, and support. Use this resource to navigate your loved one's care and assist them throughout their treatment process.

WHAT ARE MPNS?

MPNs are blood cancers that occur when the body makes too many white or red blood cells, or platelets. This can damage the bone marrow and create problems with blood flow.

White blood cells – also called leukocytes, are made in the bone marrow, and help fight infection and disease.

Red blood cells – also called erythrocytes, are made in the bone marrow, and carry oxygen from the lungs to the rest of the body.

Platelets – help to form clots that slow or stop bleeding and help wounds to heal.

Bone marrow – the soft, spongy tissue inside of most bones. Bone marrow stores stem cells that can become red blood cells, white blood cells, or platelets.

THERE ARE 3 CLASSIC TYPES OF MPNS:

1. **Polycythemia vera (PV)** – occurs when there are too many red blood cells
2. **Essential thrombocythemia (ET)** – occurs when there are too many platelets
3. **Myelofibrosis (MF)** – a rare type of blood cancer that leads to a buildup of scar tissue. This scar tissue is called “fibrosis” and collects in the bone marrow. This prevents the bone marrow from making enough healthy blood cells. At times, both PV and ET can progress and become MF.

There are also “unclassifiable MPNs (MPN-Us).” These are types of MPNs that do not fit into the other categories. They may involve an underproduction of various blood cell types, including white blood cells, red blood cells or platelets. Certain leukemias may be considered MPNs. Chronic myeloid leukemia (CML) and chronic neutrophilic leukemia (CNL) are MPNs. Other leukemias, like acute myeloid leukemia (AML) can be “secondary” to MPNs. This means they occur after or because of an MPN. Although MPNs can pose health risks, people with these conditions often live for many years after diagnosis. Treatment depends on the type of MPN.

ASK YOUR LOVED ONE:

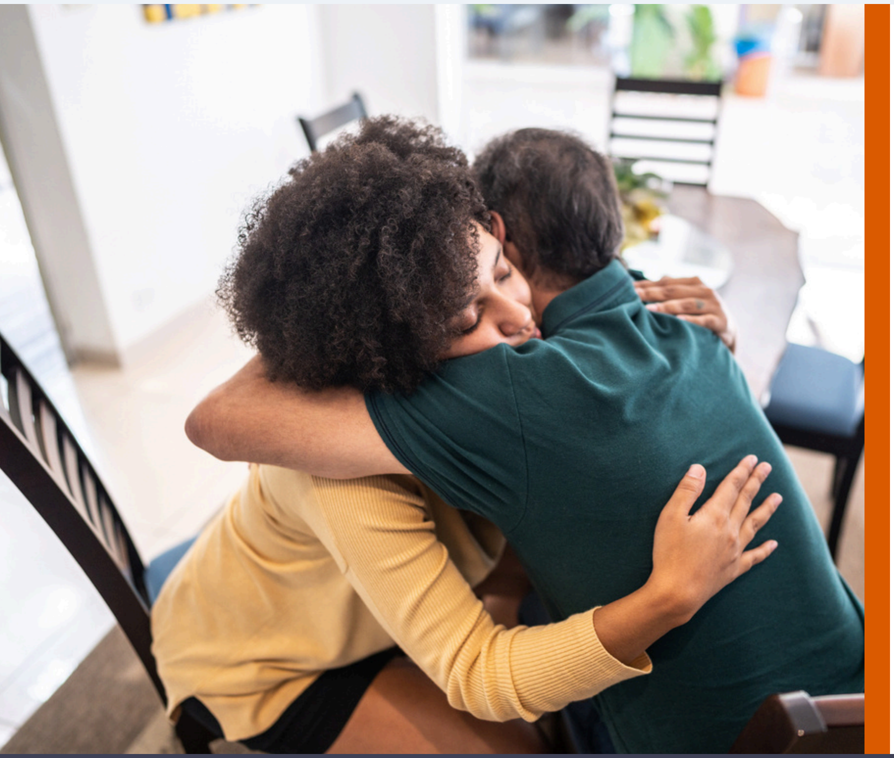
What type of MPN have you been diagnosed with?

What symptoms or side effects have you experienced?

What types of treatment have you tried?

Have you considered a clinical trial?

What can I do to support you?



Keep asking questions to understand your loved one's needs. Try to learn as much information as you can. Details of their diagnosis are important. Take time and patience to avoid overwhelming yourself or your loved one. Remember their needs may change over time. Your loved one may not have any needs when you first ask. Recognize this is an overwhelming time for them and ensure they know they can reach out to you at any time.

SUPPORT AT MEDICAL APPOINTMENTS

One of the key roles often assumed by caregivers is attending medical appointments with their loved one. If you are invited to join someone at their medical appointment, be prepared to support them. This is still their medical appointment – allow them to be in control and assist when needed. Try offering these supportive services:

PREPARATION: Help your loved one prepare for appointments by making a list of questions and concerns. Bring along a notebook to jot down important information and instructions from the provider.

ACTIVE PARTICIPATION: Encourage the patient to take an active role in discussions with the doctor. Offer to take notes or ask questions if your loved one feels overwhelmed.

FOLLOW-UP: Help your loved one follow through with any recommended tests, treatments, or lifestyle changes. Keep track of appointments and medications to ensure consistency in care. Ask for a copy of test results and a current list of medications.

Below are some of the symptoms people with MPNs may experience. Think about how often these may impact your loved one. Talk openly with your loved one and, with their permission, their healthcare team about how to manage them.

	Rarely	Sometimes	All the time
Fatigue/weakness			
Headache			
Difficulty concentrating			
Excessive sweating			
Fever			
Blurred vision			
Dizziness/lightheadedness			
Itchiness/Burning sensation			
Red, Pale, or purple skin			
Bloating or feeling full after only a few bites			
Changes to appetite			
Bone or Joint pain			
Unintentional weight loss			
Feelings of Sadness/Depression			
Feelings of Fear and/or Anxiety			
Others:			

RECOGNIZE THE SIGNS AND SYMPTOMS OF:

ANEMIA: Low red blood cells. Symptoms include: fatigue, shortness of breath, pale skin tone, unusual food or flavor cravings (e.g., ice, metallic flavors, soil/sand), changes to the skin and nails, cold hands and feet, and dizziness.

THROMBOCYTOPENIA: Low number of platelets. Symptoms include: easy bruising, bleeding and difficulty clotting from wounds or mucous membranes like those in the nose and mouth, headache, rashes, blood in the urine, changes to menstruation, fatigue, and weakness. It is vital that people with low platelets know that any falls that result in hitting their head need to be receive imaging tests to rule out bleeding.

THROMBOCYTHEMIA: Too many abnormal platelets. This can lead to blood clots and stroke. There may be no symptoms, or your loved one may only notice symptoms after a blood clot has developed. Some symptoms that may happen include: headache, dizziness, chest pain, fainting, numbness, nosebleeds, bruising, blood in the stool, or bleeding gums.

NEUTROPENIA: Not enough healthy white blood cells. This can make it difficult for the body to fight infections. The main symptoms of neutropenia are often related to the symptoms of an infection. It is important to regularly check temperature and report to healthcare team. If your loved one has a fever above 100.4 degrees Fahrenheit (38 degrees Celsius), chills, of flu-like symptoms, they should speak with their doctor to see if they need a full infection workup.

ENLARGED SPLEEN: the bone marrow may become unable to make blood cells in people with MPNs. The spleen works as a backup to bone marrow to make blood cells in this case. When the spleen supplies the body with blood cells it gets bigger. When the spleen enlarges it presses against other body parts. Symptoms can include: feeling full quickly when eating, shortness of breath, cough, abdominal pain, and a decrease in activity.

UNINTENTIONAL WEIGHT LOSS: many people believe that weight loss is just a part of having and treating cancer. Weight loss and loss of muscle mass can be severe and should be reported even if there is only a minimal change on the scale. Your loved one's healthcare team can provide them and you with resources and may refer them to specialists, like a dietitian or nutritionist, who can ensure your loved one continues to get the nutrients they need.

WHAT CAREGIVERS NEED TO KNOW ABOUT MPN DIAGNOSIS AND TREATMENT

There are several ways you can further prepare yourself as a caregiver for your loved one. It is important to familiarize yourself with certain tests, symptoms, treatments, and side effects.

One common test your loved one may need to diagnose MPNs is a bone marrow biopsy. This is a procedure that removes a small amount of bone marrow to test for signs of disease. The bone marrow is located inside the hollow center of larger bones. It is a soft, sponge-like tissue, and some liquid. The marrow creates new red and white blood cells as well as platelets. The liquid in bone marrow contains stem cells and vitamins.

If your loved one needs a bone marrow biopsy, their healthcare provider will likely perform it in their office or ask that they go to a hospital. The entire procedure lasts about 30 minutes. Your loved one will be awake the whole time but will be numbed wherever the biopsy is taking place to reduce pain.

Depending on where the biopsy is coming from, your loved one may lie on their side or stomach. Most biopsies come from the back of the hip bone. A small cut is made and then a needle is inserted into the bone. This needle will remove some of the liquid from the marrow. Another needle is then inserted to collect a small piece of the sponge-like tissue. This is called a “core biopsy.” After the needles are removed, the healthcare team will bandage the area and send the samples for testing.

During the biopsy, your loved one may feel a sharp sting at first and then a brief, dull pain at the end. While the skin can be numbed, the bone cannot. Your loved one may feel pressure, pushing, or pulling that is unpleasant. This feeling may radiate or feel like it is spreading down the leg. This is normal.

Speaking with your loved one’s healthcare team about their concerns for pain is important. Their care team may be able to offer additional advice for before and after the procedure to help with pain.

Problems after a biopsy are unlikely. If any, your loved one may have pain, some bleeding at the site, and could get an infection. Discuss these with the healthcare team and determine if any additional steps need to be taken to prevent infection.

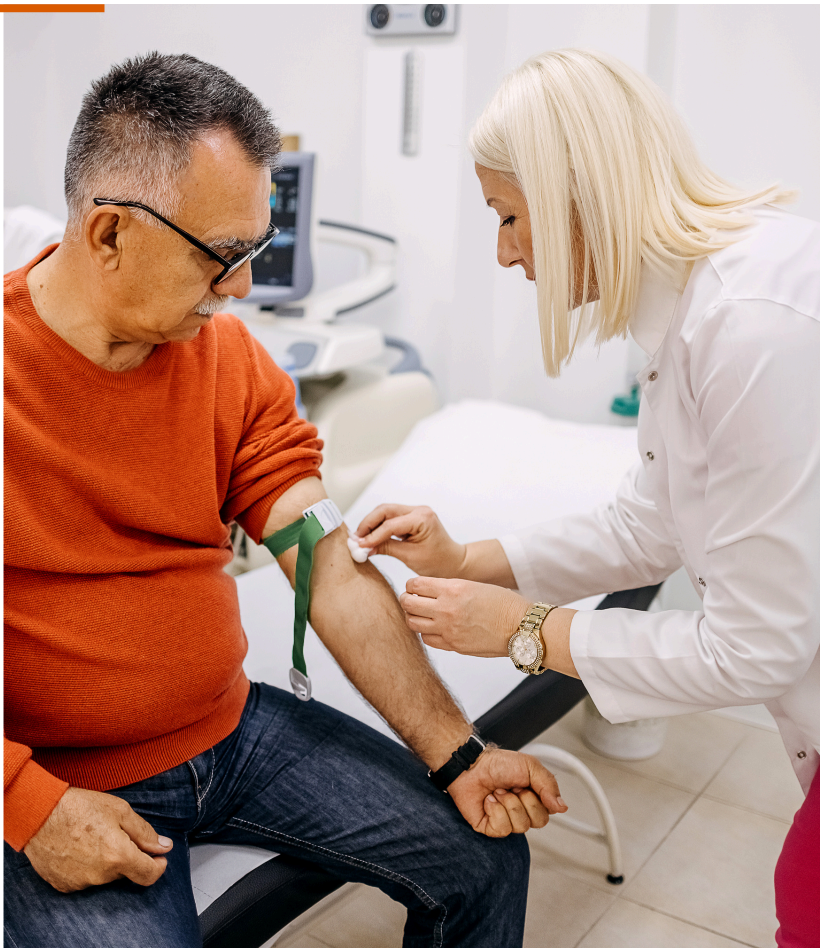
RISK FACTORS

Risk factors are things that can increase a persons chance of developing a disease or having problems with treatment. Some risk factors can affect which treatments may work for your loved one. Cardiovascular risk factors, those affecting the heart, lungs, and blood vessels, are of specific concern. Family or personal history of cardiac issues, diabetes, smoking, obesity, physical activity, and others can impact treatment plans. As a caregiver, you may be able to help support your loved one's cardiovascular health through assistance with nutrition and exercise. Be sure to discuss these risk factors with your loved one and their care team. Treatments for MPNs may include:

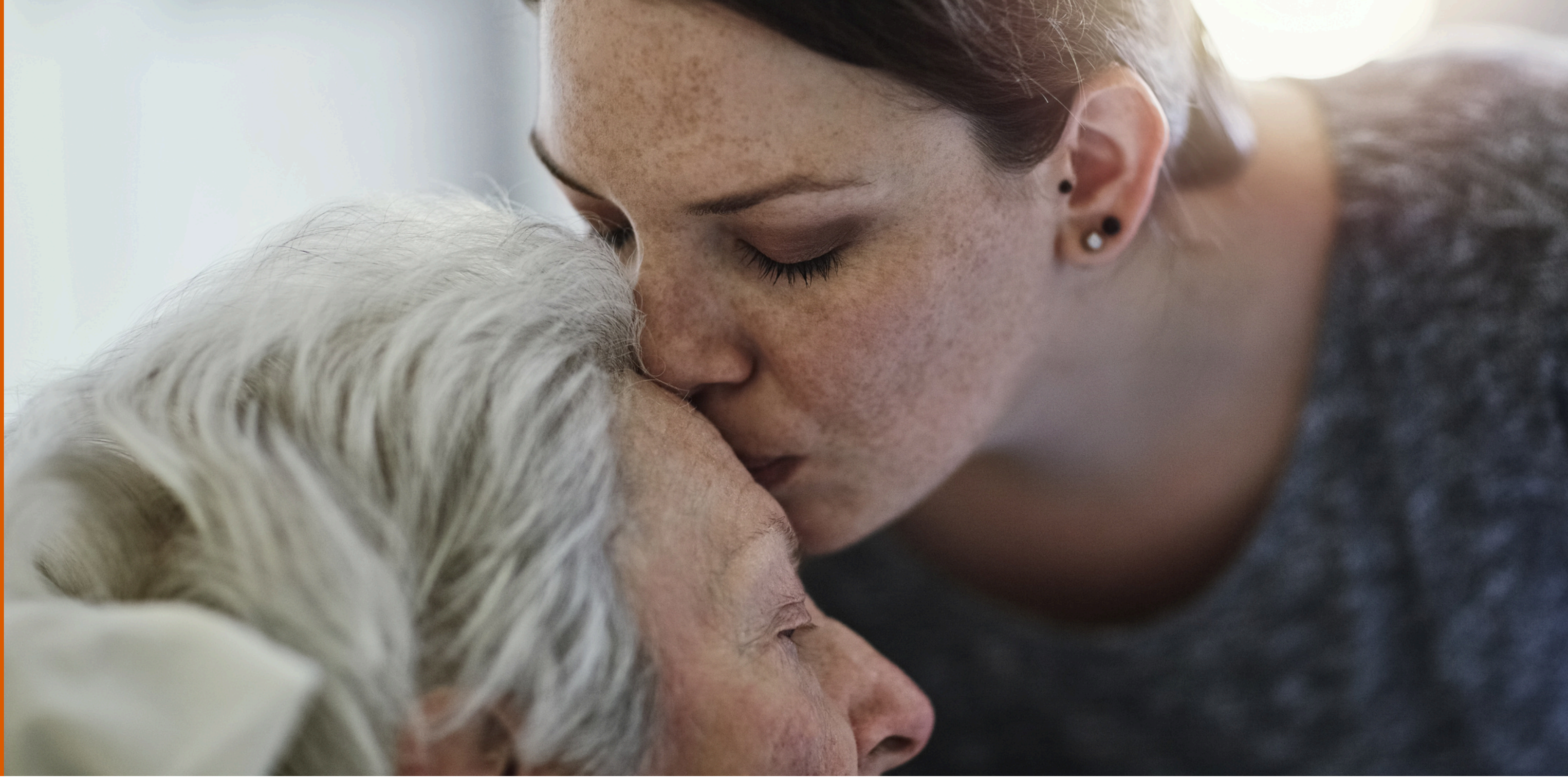
TREATMENT OPTIONS FOR MPNS

Blood Transfusion is a procedure in which whole blood or certain blood cells are put into your loved one's blood stream through a vein. The blood may be donated by another person or can be taken from your loved one and stored until needed. It is important for caregivers to be aware of the time and support commitment needed for a blood transfusion. Transfusions can boost blood counts and reduce symptoms. They can happen as often as twice per week and take up to several hours.

Therapeutic Phlebotomy is a procedure that removes blood from a vein in order to lower the number of red blood cells in the body. This is often the first treatment for Polycythemia Vera. Blood is removed over several sessions. Often this begins as a daily or weekly process until blood counts are normal. Once normalized, the blood is tested every 4-8 weeks to determine if further phlebotomy is needed.



Bone Marrow and Stem Cell Transplants put blood-forming cells into the body. Doctors will determine on a case-by-case basis whether your loved one is a good candidate for a transplant. Not everyone is eligible for a transplant. Bone marrow transplant is a type of stem cell transplant. These procedures typically include two parts. First, a high dose of chemotherapy is administered. This destroys blood cells. Next, transplant cells are introduced into the bloodstream to replace the blood cells. A separate donor will provide cells for your loved one. This is an allogenic stem cell transplant. If you are related to your loved one, you can get tested to see if you may be eligible to donate to them. The same is true for any biological children or siblings.



For the donor, there are specific commitments. Being a donor often takes 20-30 hours over 4-6 weeks from screening to donation. If you donate bone marrow, you will have surgery. You will be put to sleep using anesthesia. A needle is inserted into the hip bones to collect bone marrow. After the surgery, you may experience pain where the needle was inserted when you bend or walk. The pain often decreases within 6-12 weeks. If you donate stem cells using blood instead of bone marrow, the process is less invasive. Blood will be collected from a vein through a needle. The stem cells are then separated from the blood for use. Your loved one's doctor will determine which, if any, type of transplant would be best for your loved one.

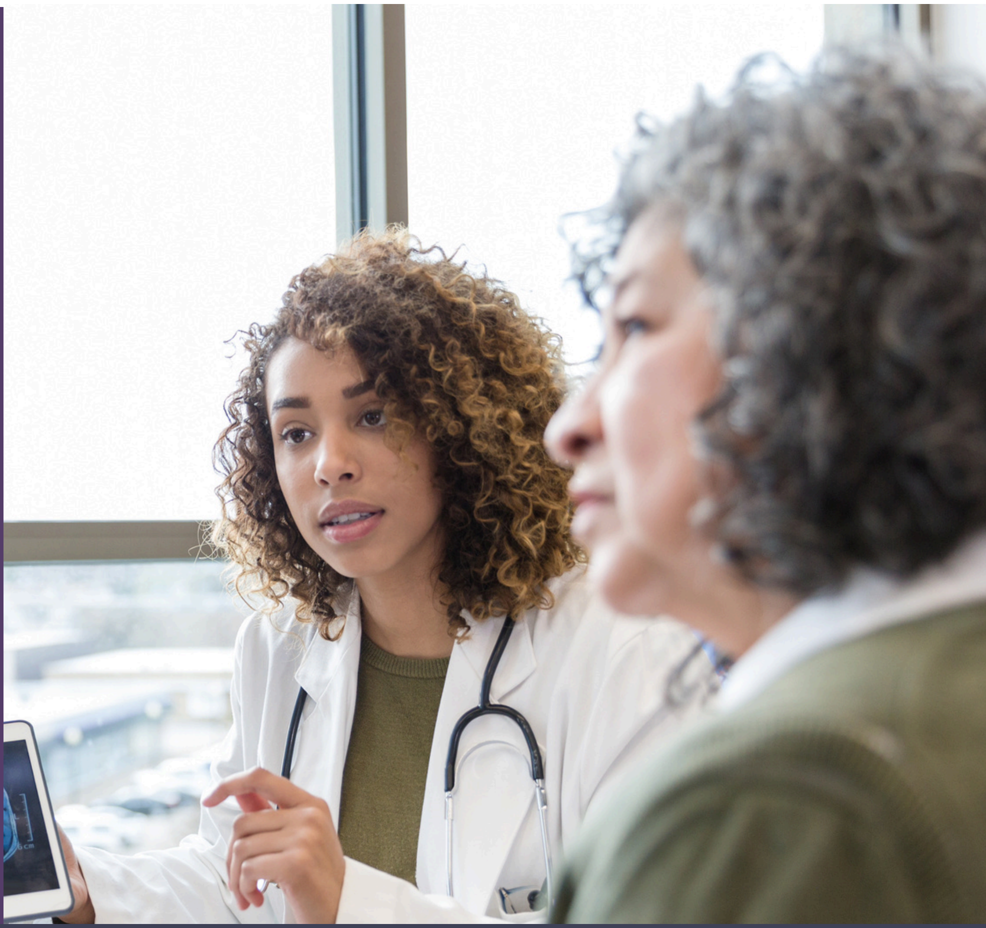
The process takes about 4 months after initial consultation for the procedure to take place. Cells are then collected for later use. Once infused, your loved one will be monitored for potential complications. They will have continued follow ups to manage any complications or side effects. When using donor cells, it is also important to monitor for graft-versus-host-disease (GVHD). This can occur when the recipient's body identifies new cells as foreign and attacks them. This can cause damage to your loved one's body, especially in the skin, liver, and gastrointestinal system. Watch for symptoms of this side effect which include nausea, vomiting, diarrhea, and rash or redness on the neck, shoulders, ears, palms of the hands, and soles of the feet.

The transplant takes about 20-30 minutes to complete. It can take several weeks to recover from. Weakness and fatigue may continue for six months to a year. This treatment often requires a hospital stay for about 1 month. This is followed by daily follow ups for about 1 week. Then your loved one will need weekly follow ups for a few months (approximately 100 days). Overall, it takes about a year to fully recover from transplant procedures.

Cytoreductive Therapies reduce the blood counts and are usually given by mouth (orally) or by injection. Some examples of these treatments include:

1. **Hydroxyurea** – a chemotherapy drug. It can cause some side effects such as numbness, tingling, burning sensation, skin ulcers/sores, chest pain, wheezing, cough, and shortness of breath. It can also cause blood counts to decrease too much. Therefore, your loved one will be asked to check their labs periodically to monitor blood counts.
2. **Interferons** – proteins that the body produces as a defense response to infections. It is called this because it can "interfere" with some cancers, viruses, and other germs. This prevents them from multiplying. They can cause some side effects such as pain, headache, dry mouth, diarrhea, nausea, and flu-like symptoms. Interferons can put your loved one at risk of depression and some cardiac events such as heart attacks and strokes. It is very important to report any history of depression or anxiety as this treatment may not be the best option due to these side effects.
3. **Aspirin** – a medication that reduces things in the body that cause blood clotting, pain, fever, and inflammation. Some side effects of this drug include nausea, heart burn, drowsiness, and headache.
4. **Anagrelide** – a medication that treats thrombocythemia. Side effects may include fast heartbeat, chest pain, breathing problems, numbness/tingling, headache, fatigue, dizziness, nausea, vomiting, diarrhea, fever, pain, and rashes/itching.

Targeted Therapies target changes in the genes or proteins of cancer cells. These therapies stop or slow the growth, division, and spread of cancer cells. Doing this causes less harm to normal cells. Your loved one may get targeted therapy alone or with other types of treatment. The most common type of targeted therapy used for MPNs is a JAK inhibitor. These stop or slow Janus kinases (JAKs) which can cause growth of certain cancer cells.



Clinical Trials are research studies to test new treatments or learn how to use existing treatments better. It is important to know that:

Your loved one will always receive the best available treatment during a cancer clinical trial. Even if they do not receive the experimental medication, they will still receive the standard of care treatment.

Clinical trials test new treatments, new combinations of treatments, or better ways of using existing treatments.

The U.S. Food and Drug Administration (FDA) and local review boards oversee all U.S. clinical trials to keep patients safe. Doctors can apply to the FDA and create their own studies if research supports their idea.

If your loved one joins a clinical trial, they can leave at any time.

Not every doctor has access to the same trials. However, they can recommend a different location that may have clinical trials appropriate for your loved one.

Often, the trial pays the costs of the drug being studied. Then, your loved one's health insurance and copay covers "standard" treatment costs. Be sure to ask about the costs to your loved one.

There are phase 1, phase 2, and phase 3 clinical trials; make sure you understand the goals before joining a clinical trial.

Some clinical trials may make your loved one ineligible for a future trial or treatment, so make sure to ask questions about this. See the resources below for help finding clinical trials that might be right for them.

There are often more requirements of your loved one if they are involved in a clinical trial. They may need to complete more tests, symptom reporting, and physical exams.
In addition to talking with the healthcare team, you can look up clinical trials online if you know the type and stage of your loved one's cancer. Learn more here:
www.CancerSupportCommunity.org/Find-Clinical-Trial

GET TO KNOW THE CARE TEAM

There may be times when you are the person calling or advocating for your loved one. They may be meeting with many professionals who all play different roles. Together, you can work with this team to determine goals and better understand their care. Here is a list of people who may be on their care team. As you meet each person, ask about the best way to contact them.

Oncologist: These doctors have specialized training in cancer treatments and diagnosis.

Hematology oncologists (hematologists) are doctors who specialize in treating blood cancers like MPNs.
- Name:
- Phone Number:

Oncology Pharmacist (PharmD): Pharmacists have special training in preparing and giving prescription drugs. They know how drugs work, how to use them, and their side effects. Your pharmacist can help you prepare for any side effects.
- Name:
- Phone Number:

Physician Assistants/Physician Associates (PAs): These individuals are licensed to diagnose and treat certain conditions. You may meet PAs throughout your loved one's care with and without their oncologist.
- Name:
- Phone Number:

Nurses and Nurse Practitioners (NPs): You may talk to a nurse and nurse practitioners more than any other member of the care team. They can answer questions about your loved one's treatment, side effects, and care plan. Some have specialized training in providing treatment.
- Name:
- Phone Number:

Palliative Care Specialists: This team focuses on providing relief from the stresses and symptoms of a serious illness. A palliative care team can help manage the symptoms of cancer and side effects of treatment. Palliative care is different from hospice or end-of-life treatment. You can request palliative care to assist with comfort at any time.
- Name:
- Phone Number:

Registered Dietitians (RDs): Symptoms of MPNs and side effects of MPNs treatments can be eased through diet. A registered dietitian (RD) can recommend foods and meal plans to help your loved one eat comfortably, get the nutrients they need, and assist in their treatment.
- Name:
- Phone Number:

Social Workers: A social worker can provide support for both social and emotional concerns and help you find community resources. In some cancer centers, social workers may hold support groups or offer counseling services.
- Name:
- Phone Number:

Patient, Nurse, and Financial Navigators: Some cancer centers may have navigators to help patients and their caregivers throughout diagnosis, treatment, and survivorship. They may help with care coordination, working with insurance and finances, and other aspects of your loved one's care.
- Name:
- Phone Number:

CONTACTING YOUR HEALTHCARE FACILITY
- Main Phone Number:
- After Hours and Weekends Number:

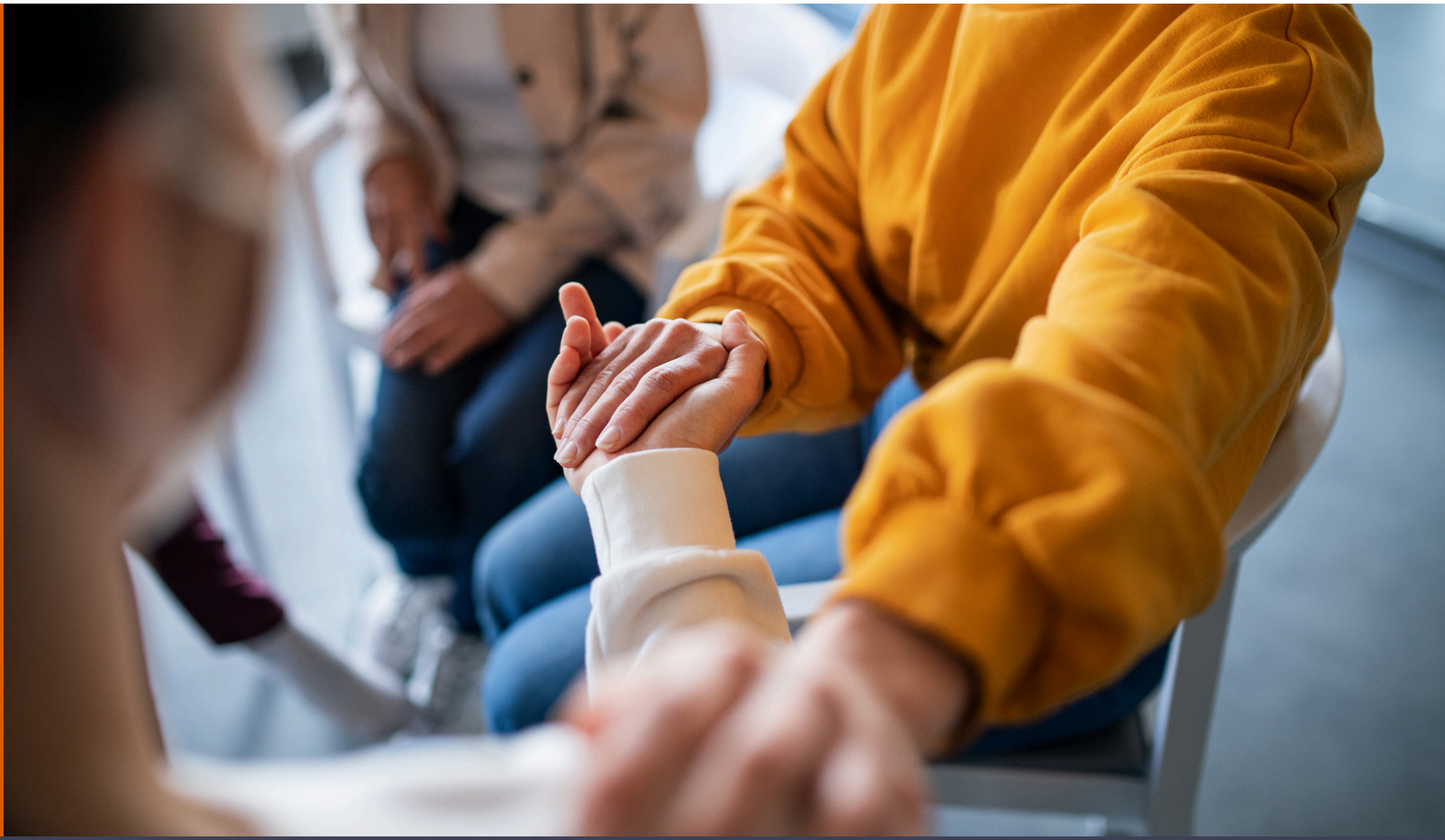
HELPING YOUR LOVED ONE COPE

Caregivers often provide social and emotional support for their loved ones. Be a source of emotional support for your loved one by listening to their concerns, fears, and goals without judgement. Encourage them to seek a professional who specializes in emotional wellbeing if you are unable to provide the support they need. This could be a therapist, social worker, or religious/spiritual leader.

Help your loved one stay connected with friends and family members for emotional support. Cancer Support Community's MyLifeLine® is a secure, online community that welcomes anyone impacted by cancer and allows them to easily connect with a supportive community. This can reduce stress, anxiety, and isolation. Your loved one can create a personal network site and invite friends and family to follow their journey. MyLifeLine® allows people with cancer to participate in discussion forums any time of the day to meet others with similar experiences. Learn more and join at www.MyLifeLine.org.

You may want to recommend that your loved one join a support group to connect with others in similar situations. There are also many support groups for caregivers who are caring for loved ones with cancer. These groups may take place in cancer centers, faith groups/religious institutions, or community centers.

Whether you are a friend, family member, or loved one, Cancer Support Community offers a variety of professionally led programs designed to empower you. We have over 190 locations worldwide offering programs and services at no cost. Find a location near you at www.CancerSupportCommunity.org/Find-Location-Near-You.



Learn about the resources local to you that can help. Social workers and your loved one's healthcare team can be great resources to assist you with many caregiving challenges. They may be able to help with:

Transportation

Financial & insurance assistance

Legal assistance

Nutrition assistance

Housing Assistance

Interpretation and language services

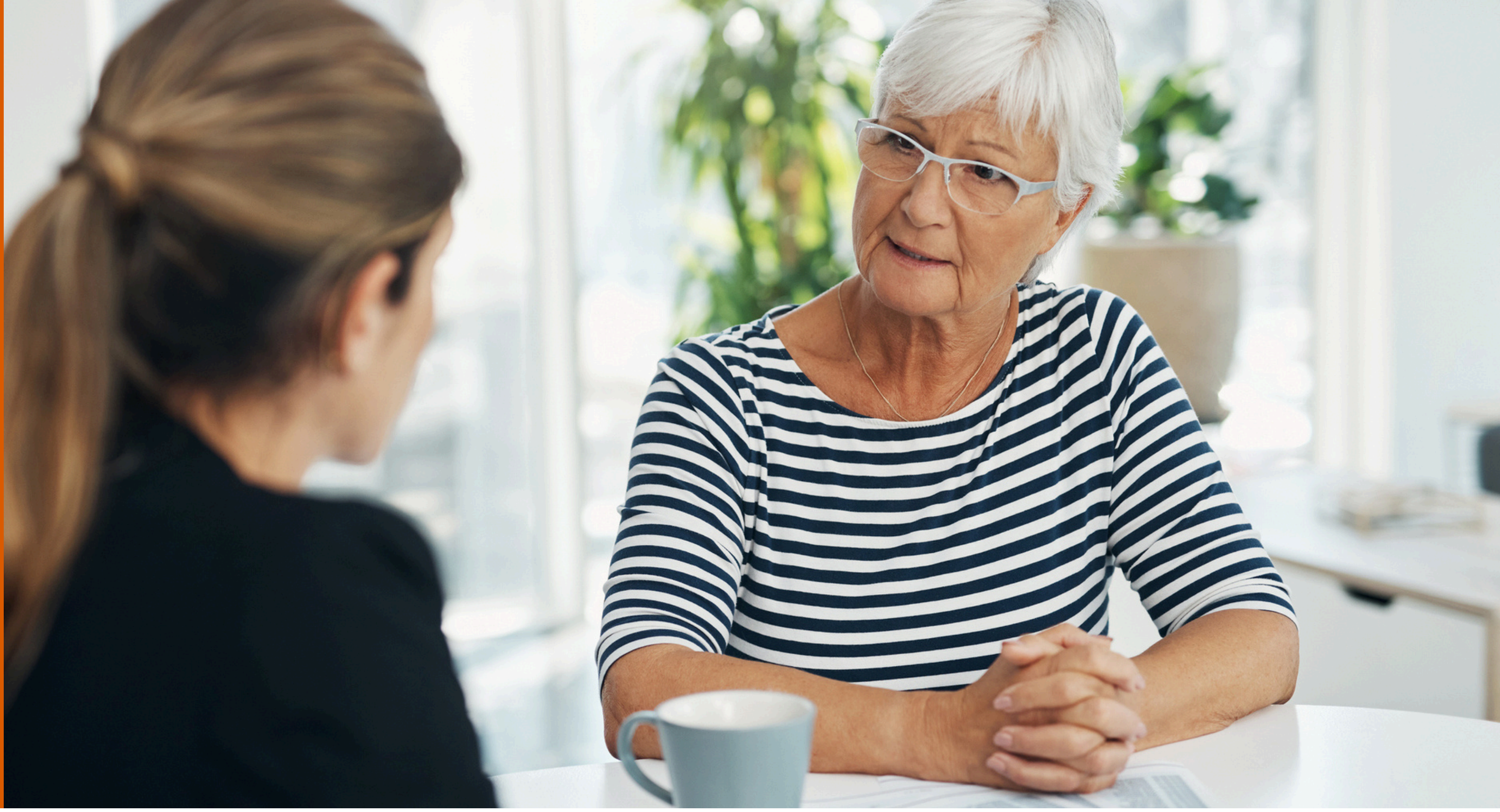
TAKING CARE OF YOURSELF

The role of a caregiver can be tiring and overwhelming. It is easy to prioritize the needs of your loved one at the cost of your own wellbeing. Just because you are caring for someone else does not mean your life or the things you need to get done for yourself stop. Self-care is necessary to ensure you can provide the best support for yourself and others.

It is important to take breaks when needed and prioritize your own physical, emotional, and social wellbeing. Just as you offer to help your loved one, reach out and seek support from friends, family, or community resources to prevent burnout. Set realistic expectations for yourself and delegate tasks to avoid feeling overwhelmed. Communicate openly with other caregivers and your own support system.

Maintain a healthy diet, exercise regularly, and get enough sleep to support you and the responsibilities you have. While you may not want to be in any more doctor's offices, it is important that you still attend medical appointments for yourself. Regular physical exams and preventive appointments (like dental and eye exams) can keep you healthy and empower you to support your loved one.

Practice stress-relief and coping techniques, such as meditation or yoga, to manage the stress brought on by being a caregiver. Allow yourself to feel every emotion and feel comfortable with seeking support from a mental health professional, social worker, or support group. You are not in this alone and your wellbeing is vital to the wellbeing of your loved one.



DOCUMENTS AND LAWS TO BE AWARE OF AS A CAREGIVER

While many people diagnosed with MPNs live many years after their diagnosis, now is a good time to discuss your loved one's wishes and ensure they are respected. A **"Living Will"** also called an **"Advanced Directive"** is a legal document that designates the future of their medical care if they are unable to speak for themselves. It is best to discuss your loved one's wishes and intentions and develop this legal document as soon as possible.

A **Medical Power of Attorney (POA)** is a document that allows your loved one to appoint a trusted person to make decisions about their medical care if they are unable to make decisions themselves. This is also called a **"healthcare agent"** or **"healthcare proxy."** In most places, the appointed person is authorized to speak on the patient's behalf anytime they cannot speak for themself, not only at the end of life. Your loved one may choose you or someone else for this role.

In the United States, the **Family Medical Leave Act (FMLA)** may entitle you to up to 12-weeks of unpaid, job-protected leave to care for a seriously ill family member. In Canada, you may qualify for up to 28-weeks of **Compassionate Care Leave** under the country's regulations. Other countries may have similar programs available for caregivers. Speak to your employer about the benefits available to help support you.

Caring for a loved one with MPNs can be challenging, but with the right support and resources, you can navigate this journey more effectively. Remember to prioritize your own wellbeing, seek support when needed, and communicate openly with your loved one, their healthcare team, and your own support network.

INFORMATION AND SUPPORT FOR MPN CAREGIVERS

Cancer Support Community
888-793-9355
www.CancerSupportCommunity.org/

Caregiver Action Network
855-227-3640
www.CaregiverAction.org

MPN Research Foundation
773-977-7216
www.MPNResearchFoundation.org

MPN Education Foundation
www.MPNInfo.org

MPN Connect
www.MPNConnect.com

National Alliance for Caregiving
202-918-1013
www.Caregiving.org

National Organization of Rare Disorders
www.RareDiseases.org

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

CancerCare
800-813-4673
www.CancerCare.org

American Cancer Society
800-227-2345
www.Cancer.org/Cancer/Caregivers.html

National Cancer Institute
800-422-6237
www.Cancer.gov/About-Cancer/Coping/Caregiver-Support

Patient Advocate Foundation
800-532-5274
www.PatientAdvocate.org

Cancer Support Community Resources

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.

Services at Local CSCs and Gilda's Clubs — With the help of nearly 200 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.

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

MyLifeLine® — CSC's secure, online community welcomes anyone impacted by cancer to easily connect with community to reduce stress, anxiety, and isolation. Create a personal network site and invite friends & family to follow your journey. And participate in our discussion forums any time of day to meet others like you who understand what you are experiencing. Join now 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**.

Photos are stock images posed by models.

This publication is available to download and print yourself at **www.CancerSupportCommunity.org/MPNs**.
For print copies of this publication or other information about coping with cancer, visit **www.Orders.CancerSupportCommunity.org**.

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Frankly Speaking About Cancer: MPN Program Partner: MPN Research Foundation

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