

FRANKLY
SPEAKING
ABOUT CANCER

Myelofibrosis



Table of Contents

PROLOGUE 1

CHAPTER 1 / EMPOWER YOURSELF 2

CHAPTER 2 / UNDERSTANDING MYELOFIBROSIS 6

CHAPTER 3 / MYELOFIBROSIS SYMPTOMS & COMPLICATIONS 10

CHAPTER 4 / DIAGNOSIS & TREATMENT OF MYELOFIBROSIS 12

CHAPTER 5 / MANAGING SIDE EFFECTS 20

CHAPTER 6 / COPING WITH THE EMOTIONS OF MYELOFIBROSIS 24

CHAPTER 7 / MOVING FORWARD 27

CHAPTER 8 / RESOURCES 30

Prologue

This booklet is designed to help you take more control over your situation and your treatment decisions. It will give you a better understanding of what **myelofibrosis** is and how it is diagnosed, what treatments are available, and what you may need to manage the emotional impact of **cancer**. It also gives information about reliable organizations and resources that can help you find support, feel less alone, and enable you to develop a renewed sense of hope. Consider your health care team to be your partner throughout this journey.



I went to a doctor who treats MF patients. She gave me information and then I did my research. I am very proactive when it comes to that and I feel that you need to be. You have to have faith in your doctor but you definitely need to be proactive in continually researching what they give you.

— Olivia, myelofibrosis patient

1

Empower Yourself

THE IMPACT OF CANCER

Hearing the words “you have cancer” can be devastating to a person and their loved ones. Studies by the Cancer Support Community have identified three common emotional stressors that impact most people with cancer. These are an unwanted sense of loneliness, a loss of control, and a loss of hope. Emotional distress is common for people with cancer. It can include feelings of vulnerability, anger, sadness, depression, and anxiety.

Having cancer can also disrupt practical elements of your life, which can be stressful. These can include changes in family roles, a strain on finances, and a decrease in self-esteem.

Fortunately you can take steps to learn about your disease, seek support, and learn how to overcome emotional distress to improve your quality of life.

THE EMPOWERMENT APPROACH

The Cancer Support Community uses the concept of empowerment to help people affected by cancer to feel a greater sense of control over the disease. This Empowerment Approach states that:

People with cancer who actively participate in their recovery along with their health care team will improve the quality of their lives and may enhance the change of their recovery.

This approach helps people who adopt this philosophy:

- Make active choices in their treatment
- Make changes in their lives that they think are important
- Communicate with their doctor
- Use resources and sources of support

Everyone's journey through cancer is unique. There is no right or wrong way to do it. Different people need different things. You decide what is best for you.



In a sense, slowing down is a positive thing. It's not all negative. I'm always aware of the gift of being able to appreciate what I do have and what I experience. You take less for granted.

— Jason, myelofibrosis patient

TEN ACTIONS YOU CAN TAKE TO IMPROVE YOUR QUALITY OF LIFE

1. **Take one day and make one decision at a time.**

Try to focus on resolving only today's problems. Avoid projecting worst-case scenarios for the future. Taking one small step at a time can help you feel less vulnerable. It will give you a greater level of control.

2. **Ask for support.** Be open with your family and friends about how you feel and how they can support you. Offer specific examples, such as driving you to appointments, researching sources for financial support, or just listening when you want to talk. Take someone with you to medical appointments to take notes and help you remember instructions. Ask your nurse or oncology social worker for more ideas.

3. **Communicate with your health care team.** **Prepare a list of questions for each appointment.**

If you don't understand something, ask what it means. Ask to see X-rays or scans to get a better picture of your status. If you do not develop a good relationship with your doctor, consider finding another. It is useful to get a second opinion on your diagnosis and treatment to feel more confident about next steps.

4. **Retain as much control of your life as you can.**

Having cancer can make it difficult for you to feel in charge of your life and your care. Work with your doctor, nurse, and caregiver to develop a plan that gives you as much control over your life as you want and can comfortably handle.

5. **Acknowledge and express your feelings.** A diagnosis of cancer can trigger many strong emotions. Take time to listen to yourself. Find helpful ways to express your feelings through writing, talking, physical activity, or being creative. Consider professional support if you feel that depression or anxiety is preventing you from functioning well.

6. **Seek support from other cancer survivors.**

Often, people find a sense of comfort when they communicate with others affected by cancer. Ask your doctor, nurse, or social worker for local support groups. You can also contact the Cancer Support Community for ways to connect one-on-one, in groups, or online with others.

7. **Learn relaxation techniques.** Consider music that makes you happy, reading a book, or taking a walk. Yoga, tai-chi, or meditation programs are also helpful. Take time to enjoy the moment.

- 8. Do what you enjoy.** Try to find humor in the unexpected moments of each day. Consider activities that you can do comfortably. Spend time alone if you need to.
- 9. Make healthy lifestyle choices.** Improving your diet, exercising, and maintaining intimacy are all ways of feeling better both physically and emotionally.
- 10. Maintain a spirit of hope.** There are millions of people who have fought cancer. Even if your cancer recovery is complicated, you can set small goals and enjoy daily pleasures. It can help to focus on your spiritual beliefs, cultural customs, and family connections.

HELPING YOU PREPARE FOR CANCER TREATMENT DECISIONS



Open to Options® is a free program designed to help:

- **Create** the list of questions you have for your doctor or health care team
- **Organize** your questions to bring with you to your appointment
- **Communicate** your questions and concerns clearly

IT WORKS! Patients who participated in the program:

- Were less anxious about their doctor appointment
- Felt that their appointment went more smoothly
- Felt better about the care decision made

It is easy and FREE to participate!

1-888-793-9355

www.CancerSupportCommunity.org/

Open2Options

2

Understanding Myelofibrosis

UNDERSTANDING MYELOFIBROSIS

The Bone Marrow

In order to better understand myelofibrosis (MF), it helps to know about the **bone marrow** and its many functions. The bone marrow is the spongy tissue inside the bones that houses red blood cells, white blood cells, and **platelets**. **Stem cells** are immature cells in the bone marrow that become these blood cells. Each of these cell types serves a critical function in the body:

- Red blood cells carry oxygen to tissues
- White blood cells fight infections
- Platelets help in clotting

Myeloproliferative Neoplasms

Myelofibrosis is one of the three most common diseases known as a **myeloproliferative neoplasm** (MPN). MPNs are blood cancers that overproduce blood cells in the bone marrow. They are caused by genetic mutations in the blood stem cells. There are three main MPNs. The type a person has depends on which of the blood cells are affected. Other myeloproliferative neoplasms include polycythemia vera (PV) and essential thrombocythemia (ET). Ten to fifteen percent of myelofibrosis cases begin as either ET or PV.

Myelofibrosis

Myelofibrosis occurs in about 1 out of every 100,000 people in the United States annually. The disease affects both men and women. It is usually diagnosed in people over the age of 50, but the disease can occur at any age. Myelofibrosis is a type of chronic leukemia (cancer of the blood). It can occur on its own (**primary myelofibrosis**) or as a result of another bone marrow disorder (**secondary myelofibrosis**). In primary myelofibrosis, a genetic mutation in a single blood-forming stem cell disrupts the body's production of normal blood cells, including the red blood cells, white blood cells, and platelets. The abnormal cells begin to take over the normal cells. This leads to a disruption in the function of those cells. It also leads to extensive scarring in the bone marrow, known as fibrosis.

In people who have no symptoms, MF may be suspected when a routine medical checkup reveals an enlarged **spleen** and abnormal blood test results. The results of a blood test (a **complete blood count**, or CBC) that may indicate MF often include:

- A decrease in the number of **red blood cells** (**anemia**) below the normal range
- An increase or decrease in the number of **white blood cells**
- An increase in platelets above the normal range (occurs in about one-third of MF patients)
- A mild to moderate decrease in platelets below the normal range (occurs in about one-third of MF patients)

MYELOFIBROSIS FAST FACTS

- Myelofibrosis (MF) is a rare bone marrow cancer. It is one of a related group of blood cancers known as myeloproliferative neoplasms (MPNs) in which bone marrow cells that produce the blood cells develop and function abnormally. The resulting scar tissue formation leads to severe anemia, weakness, **fatigue**, and an enlarged spleen and liver.
- MF is a type of chronic leukemia. It can occur on its own (primary myelofibrosis) or as a result of another bone marrow disorder. Other MPNs that can progress to myelofibrosis include polycythemia vera and essential thrombocythemia.
- MF develops when a genetic mutation occurs in blood stem cells. The cause of the gene mutation is unknown. Between 50 and 60 percent of people with MF have a mutation of the Janus kinase 2 gene (*JAK2*). Researchers are investigating other possible gene mutations responsible for MF.
- MF usually develops slowly and some people may live symptom-free for years. Others, however, may get progressively worse, requiring treatment. In both cases, patients need to be monitored regularly.
- The treatment goal for most patients with MF is to relieve symptoms and reduce the risk of complications. Treatments include blood **transfusions**, **chemotherapy**, radiation, removal of the spleen, drugs to treat anemia, and **allogeneic** stem cell transplantation. Drugs targeted at JAK1 and/or JAK2 are some of the newest treatments for MF. **JAK Inhibitors**, such as ruxolitinib (Jakafi®) and fedratinib (Inrebic®), reduce symptoms of MF, including an enlarged spleen.
- Allogeneic stem cell transplantation (ASCT) is the only potential cure for MF. This treatment has a considerable risk of life-threatening side effects. ASCT is not a good option for most people with MF because of age, the course of their disease, or other health problems.

Excerpt from The Leukemia & Lymphoma Society's *Myelofibrosis Facts*

3

Myelofibrosis Symptoms & Complications

Myelofibrosis typically develops very slowly. Symptoms do not commonly develop early in the disease. However, as the abnormal cells increase, increasingly disrupt the functioning of the normal blood cells.

SYMPTOMS OF MYELOFIBROSIS

- Fatigue, weakness, or shortness of breath. These symptoms are associated with a decrease in the red blood cells (anemia)
- Pain or fullness below the ribs on the left side, as a result of an enlarged spleen
- Enlarged liver
- Pale skin
- Easy bruising or bleeding, due to a decrease in the platelet count
- Flat, red, pinpoint spots under the skin caused by bleeding
- Excessive **night sweats**
- Fever
- Frequent infections, due to a low white blood cell count
- Bone or joint pain
- Weight loss
- Itching

MYELOFIBROSIS COMPLICATIONS

Portal hypertension

This is an increase in the blood pressure of the portal vein, which carries blood from the spleen to the liver. When the volume of blood in the spleen increases, so does the pressure in the portal vein. This may force excess blood into smaller veins in the stomach and esophagus, which can cause the veins to rupture and bleed.

Extramedullary hematopoiesis

This is when a formation of blood cells outside the bone marrow creates clumps, or tumors, of developing blood cells in other areas of the body. These tumors may lead to bleeding in the gastrointestinal system, coughing or spitting up of blood, compression of the spinal cord, or seizures.

Hardening and inflammation of bone tissue

Myelofibrosis can cause hardening of the bone marrow and inflammation of the connective tissue that surrounds the bones. This results in severe bone and joint pain and tenderness.

Gout

This is a condition caused when the body produces too much uric acid. Needle-like deposits develop in the joints, causing joint pain and inflammation.

Acute leukemia

Some people with myelofibrosis eventually develop acute myeloid leukemia, a type of blood and bone marrow cancer that progresses rapidly.

Just trying to get the diagnosis of myelofibrosis for my wife was a challenge. She underwent so many tests, and didn't understand at first if it was even cancer. However, once we finally got the right diagnosis, we could form a plan and start treatment.

— Myelofibrosis Caregiver

4

Diagnosis & Treatment of Myelofibrosis

Most people diagnosed with myelofibrosis do not have obvious symptoms. Your doctor may suspect MF if a routine checkup reveals an enlarged spleen or an abnormal blood count. At that point, your doctor will likely refer you to a hematologist/oncologist (a doctor who specializes in blood cancers). Your **hematologist/oncologist** will coordinate your treatment plan, so it is important that you find someone you feel comfortable working with. For more information about choosing a doctor or a treatment center, see the free publication *Frankly Speaking About Cancer: Making Treatment Decisions* published by Cancer Support Community.



The spectrum of treatment for myelofibrosis can be overwhelming at first. Although there are a variety of treatment approaches, you and your doctor will need to have ongoing discussions about how your disease can best be managed over time.

— Ross Levine, MD, Memorial Sloan Kettering Cancer Center

WHEN TO GET A SECOND OPINION

It is always a good idea to consider a second opinion. Getting a second opinion can give you more information, treatment options, or access to a different medical facility. It may also give you confidence that you are already on the right course. Some insurance companies require a second opinion and others will cover the cost if you request one.

Other reasons to consider a second opinion:

- If you feel uncertain about your diagnosis or treatment options
- If you were diagnosed by someone who has limited experience in treating myelofibrosis and would like to speak with someone who has more experience
- If you are interested in a clinical trial

People should know about other doctors offering other treatments. Get more opinions; make your own treatment plan. I haven't found a doctor to lead my treatment. I lead my treatment.

— *Myelofibrosis Patient*

FINDING AN EXPERIENCED DOCTOR

It is very important to find a doctor who is experienced in treating myelofibrosis, who answers your questions, and makes you feel comfortable.

Never be afraid to ask your doctor important questions such as:

- How much experience do you have in treating myelofibrosis?
- Are you board-certified in this specialty?
- Do you stay up-to-date with the latest treatments for myelofibrosis? If so, how?
- Do the doctors at your clinic/hospital participate in clinical trials?
- Do you accept my insurance?
- Will you refer me to an oncology nurse and/or social worker to help me with education, resources, and support?
- What other support services are available to me and my family?
- How often and when can I contact my treatment team with questions? (Can I use email, phone or a patient portal, or do you prefer only office visits?)

WHAT DIAGNOSTIC TESTS SHOULD YOU EXPECT?

The doctor will use a combination of tests that examine the blood and bone marrow to decide your treatment.

In addition to a physical exam and history, these diagnostic tests may be used:

A **complete blood count (CBC)**. One or more of these results may suggest a myelofibrosis diagnosis:

- Decreased red blood cell count (anemia)
- Increased white blood cell count
- Either an increased OR decreased platelet count

Changes in the shape, size, or maturity of the cells that could indicate a problem. There may also be certain levels in the blood that are either high or low, which could lead to more testing.

- **Ultrasound** takes a picture called a sonogram. It is created by bouncing sound waves off organs in the abdominal cavity. This is used to see if there are any problems in the spleen or liver.

- **Magnetic Resonance Imaging (MRI)** can provide a detailed picture of the organs and bones in the body. It is created by using a magnet, radio waves, and a computer. This is used to identify changes in the bones that indicate myelofibrosis.
- **Bone Marrow Examination** can confirm a myelofibrosis diagnosis. The doctor removes a small amount of your bone and bone marrow, which is studied under a microscope to look for genetic components that can help in both diagnosis and treatment decisions.
 - The aspiration removes the liquid portion of bone marrow.
 - The biopsy and aspiration are usually done at the same time as an outpatient procedure.
- **Genetic tests** may also be done by analyzing a sample of your blood or bone marrow tissue. Certain genetic mutations, such as the *JAK2* mutation, are seen in the majority of myelofibrosis patients.

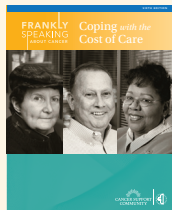
TREATMENT OF MYELOFIBROSIS

Who is involved in the treatment of myelofibrosis?

There may be several doctors involved in your care. In addition to your hematologist/oncologist you might also have a surgeon, radiation oncologist, and/or a stem cell transplant specialist.

Other key players on your medical team may include an oncology nurse, nurse navigator, oncology social worker, and pharmacist. Each of these professionals can provide information and resources that may help you both during and after your treatment. If you do not meet these professionals upfront, ask your doctor how you can arrange an appointment with them.

In addition, you may want to contact your insurance carrier to ask for a case manager, who can help you manage your treatment coverage options.



www.CancerSupportCommunity.org/Cost.

For more information on the cost of care, please refer to CSC's ***Frankly Speaking About Cancer: Coping with the Cost of Care*** at 1-888-793-9355 or

APPROACHES TO TREATMENT

Watch and Wait

Patients who are symptom free and do not have signs of anemia, an enlarged spleen, or other complications are generally not treated when they are first diagnosed. Some people remain stable and symptom free for many years. It is very important that these patients be closely monitored through regular medical checkups to detect any signs or symptoms of disease progression.

Drug Therapies

There are various drugs used in the treatment of myelofibrosis. Many of them have very different ways of slowing the disease and/or controlling its effects. Side effects are likely with any drugs. Your doctor or nurse should review these with you before starting.

- **Chemotherapy** — These are drugs that kill cancer cells that divide rapidly. These agents also attack other fast-growing cells in the body, such as nails and hair. They may cause other more serious side effects. These drugs may be given by mouth (orally) or into the vein (intravenously).

- **Janus-associated kinase (JAK) inhibitor** – These drugs target “JAK1” and/or “JAK2,” which are genes involved in regulating blood. JAK inhibitors work in people with or without a JAK mutation. They treat some of the symptoms of MF, including an enlarged spleen, night sweats, itching, and bone or muscle pain. Side effects include an increased risk of bleeding and infection, bruising, dizziness and headaches. Some patients may have nausea, vomiting, or diarrhea.
- **Immunomodulators (IMiDs)** – These drugs work against cancer cells by affecting the immune system. Certain immunomodulators are used to treat MF patients for anemia. Another has been used to treat an enlarged spleen, bone pain, and high platelet count in some MF patients. Others are under study in clinical trials.
- **Androgen therapy** – These drugs are synthetic forms of male hormones. They can promote red blood cell production. They are used to relieve the symptoms of severe anemia in MF patients. These drugs can be toxic to the liver. They require close monitoring of liver functions through blood tests and ultrasound. They may also cause facial hair growth and other masculinizing effects in women.
- **Recombinant erythropoietin** – This treatment helps regulate red blood cell production. It is given by injection into the muscle or under the skin. However, the response of anemia-related symptoms in MF patients has been limited.
- **Glucocorticoids** – Also known as “steroids,” these drugs are used in MF patients to treat significant anemia. They may cause a number of side effects but are usually manageable with short-term use.
- **Bisphosphonates** – These drugs are used to prevent bone loss in cancer patients. They may relieve bone pain and increase blood counts in MF patients. These drugs are given intravenously. Short-term use may cause upset stomach.
- **Anagrelide hydrochloride** – This drug, given orally, may be used in MF patients who have an extremely high platelet count, especially following removal of the spleen. It may cause headache, diarrhea, weakness, nausea, and dizziness.

Radiation Therapy

Radiation uses high-powered beams, such as X-rays, to kill cells. **Radiation therapy** can help reduce the size of the spleen when surgical removal isn't possible. It is also used to treat bone pain and tumors outside the bone marrow.

Surgical Removal of the Spleen (Splenectomy)

If your spleen is enlarged and causing harmful complications and pain, and other treatments have not been successful, you may benefit from having your spleen surgically removed. Your doctor will consider the risks and benefits of your particular situation and tell you if this may be a good option for you. If you have surgery, you should be closely monitored for complications.

Stem Cell Transplantation

This is the only type of treatment that has the potential to cure myelofibrosis. However, it is a very high risk treatment. It can only be considered for certain people, and is dependent on whether a suitable donor is available.

- **Allogeneic stem cell transplant** – In this procedure, the patient receives high doses of chemotherapy or radiation to destroy the diseased bone marrow. The donor stem cells (from someone other than the patient) are then infused into the patient.
- **Non-myeloblastic stem cell transplant** – This transplant uses lower doses of chemotherapy or radiation before donor cells are infused. This type of transplant can be used in older and sicker patients, who may not be eligible for an allogeneic transplant.

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*](http://www.CancerSupportCommunity.org/ClinicalTrials).

TYPES OF CLINICAL TRIALS	
TYPE OF TRIAL	STUDY GOALS
Prevention trials	What can prevent cancer from developing?
Screening and early detection trials	What new screening and detection methods can be used to identify cancer in people, before it spreads and before symptoms appear?
Diagnostic trials	How can new tests identify a cancer earlier and more accurately?
Treatment (or therapeutic) trials	What new treatments can be used to stop or cure cancer?
Quality of life and supportive care trials	What can be done to improve the overall well-being of people who have cancer? What can be done to make people who have cancer more comfortable?

5 *Managing Side Effects*

Just as each person's treatment plan is individualized, the side effects that each person experiences might be very different. For this reason, we provide only general information here. We encourage you to work closely with your health care team to manage side effects.

The side effects of cancer treatment are due to the specific type of treatment(s) that you receive. They can be mild to severe. It helps to learn about potential side effects before you begin so you can work with your health care team to manage your quality of life during and after treatment. Fortunately, there are very effective medications to address traditional side effects (such as nausea, diarrhea, constipation, fatigue, low blood counts, and mouth sores), as well as side effects from targeted treatments.

MANAGING ANEMIA

Everyone responds differently to treatment. Many factors a person's response including:

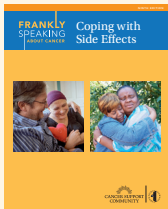
- type of treatment and dosage
- the age of the patient
- coexisting medical conditions

While no one can predict with certainty how you will respond to a particular treatment, your health care team will help manage your side effects. That is why it is so important to tell your health care team how you're feeling and any concerns you may have.

Anemia is a very common effect of myelofibrosis. As mentioned in the treatment section of this booklet, there are many drug therapies to treat anemia. Blood transfusions are also an option for patients when their red blood cell count is very low.

There are also non-drug therapies that can help manage your anemia. Because anemia may cause fatigue and shortness of breath, there are a number of things you can do to conserve energy. These include pacing your activities, taking frequent breaks, getting plenty of rest, and maintaining good nutrition.

LEARN MORE ABOUT COPING WITH SIDE EFFECTS



An educational booklet and personal planner combination designed to help people learn about cancer treatments and manage the potential physical side effects from treatment, as well as the emotional burden. Find ***Frankly Speaking About Cancer: Coping with Side Effects*** at www.CancerSupportCommunity.org/SideEffects.

SIDE EFFECTS OF SURGERY (SPLENECTOMY)

Your body will need time to recover from surgery. You will have pain or discomfort at first. You will receive medication to control the pain after surgery. You will be asked to rate your pain on a scale of 0 (no pain) to 10 (very painful). Be sure to tell your nurse or doctor if your pain is not well controlled.

Because painkillers can slow the movement of the bowel, your health care team will monitor this closely. You may need to take medications temporarily to help return your bowel function to normal.

- The incision from your surgery will take time to heal. Your nurse or a homecare nurse will teach you how to take care of the incision when you return home. If you notice any redness or pus at the surgical site or if you develop a fever, contact your doctor right away. After a splenectomy, people have increased risk of severe infections, especially during the first two years after surgery.
- You may feel tired or weak after surgery. Take short naps (20-30 minutes). Do only the things that are most important to you, and let family or friends do the rest.

SIDE EFFECTS OF DRUG THERAPIES

Every drug causes a unique set of side effects. Your oncology nurse will discuss the side effects you can expect based on your treatment plan. If you are taking a drug as part of a clinical trial, the research nurse will discuss any side effects you should expect. Ask for written information about the drugs you are taking and the best way to manage those side effects.

SIDE EFFECTS OF STEM CELL TRANSPLANT

Once a donor's stem cells are infused, there is a risk that the new stem cells will react against your body's healthy tissues. This can cause potentially fatal damage, called graft-versus-host disease. Other risks include organ or blood vessel damage, cataracts, and developing a different cancer later on.

SIDE EFFECTS OF RADIATION THERAPY

If you receive external radiation therapy, you may have nausea, vomiting, or diarrhea. Radiation also causes fatigue and can reduce your blood count.

This can lead to:

- Low white blood cells, which increases your risk for infection
- Low platelets, which increases your risk for bleeding
- Low red blood cells, which may make you feel tired or short of breath

Radiation therapy can also cause skin changes. These include redness, dry or peeling skin, itching, blisters, and swelling.

- Your radiation oncologist and nurse will talk to you about skin care. Be gentle with your skin. Don't use any lotions or creams unless the radiation treatment team recommends them.
- Don't put anything hot, like a heating pad, or cold, like an ice pack, on the area being treated.
- Wear soft clothes and use soft sheets made of fabrics like cotton.

Call your nurse or doctor if your skin blisters or swells, you have diarrhea for more than 24 hours, or you are too nauseated to drink liquids after receiving external radiation therapy. Let your health care team know if you have a fever, any signs of infection, bleeding, or shortness of breath.

6 *Coping with the Emotions of Myelofibrosis*

Your myelofibrosis diagnosis affects the way that you feel, think, and act. Just as you need to take care of your body, you need to take care of your emotions.

Common emotions you may experience:

- Anxiety
- Depression
- Anger
- Irritability
- Grief and loss for your old life (“loss of normal”)
- Helplessness
- Frustration
- Fear

One thing I have found is that it helps me to talk about my diagnosis, especially when family and friends take the time to ask and try to understand this disease. Knowing that people care and want to know what I am going through gives me strength and hope.

— Dorothy, myelofibrosis patient

Every person finds different ways to manage stress, depression, worry about what the future holds, or other emotions. Learn how to effectively manage your emotions. This can help improve many aspects of your life – eating, sleeping, working, relationships with others, and enjoying leisure activities. There are many resources available to assist you in managing your emotions. We encourage you to contact the *Cancer Support Community Helpline* at 888-793-9355 for more information and help in finding resources to help you cope with your diagnosis or the diagnosis of a loved one.

CANCER SUPPORT COMMUNITY HELPLINE: 1-888-793-9355

CSC's Helpline is staffed Monday through Friday from 9 am to 9 pm EST by licensed mental health professionals. All services are at no cost to callers. Counselors can provide information, resource referral, psychosocial support, access to Open to Options treatment decision support, referrals to CSC programs, affiliates, and online groups.

TIPS TO HELP YOU MANAGE FEAR AND ANXIETY

- Educate yourself. Learn what physical and mental signs or symptoms you should be aware of.
- Keep up with any medical tests or appointments your doctor recommends.
- Express your feelings with others either in a support group, with family and friends, or a counselor.
- Meditate or do deep breathing and relaxation exercises.
- Keep a journal and write down your thoughts.
- Take control of what you can, make a plan, and know what you cannot control.
- When you have health-related questions or concerns write them down and bring them your appointments. Call your health care team if you have immediate concerns.

GENERAL STRATEGIES FOR WELLNESS

Take good care of yourself while you are undergoing cancer treatment:

- Eat healthy foods. Good nutrition maintains energy, strengthens the immune system, can decrease side effects, and provides comfort.
- Drink enough fluids to avoid dehydration, prevents constipation, and decreases fatigue.
- Try to get some physical activity every day. Exercise combats fatigue, helps maintain physical function, promotes restful sleep, and can elevate your mood.
- Stay clean. Good personal hygiene decreases the risk of infection, keeps your skin healthy, and improves your feelings of wellness.
- Get enough sleep. If you are having trouble sleeping tell your health care team.
- Participate in mind-body activities such as yoga, meditation, and guided imagery to reduce stress and increase energy.
- Participate in a support group to help you understand and manage your feelings and connect with others facing cancer.
- If you have questions about activities you may or may not participate in, ask your health care team.

7 *Moving Forward*

LIFE WITH A CHRONIC ILLNESS

Myelofibrosis is not always curable. For this reason, it is necessary to consider that the changes that lie ahead may not be temporary, but possibly lifelong.

When you have a chronic illness, it becomes a part of who you are and how you live your life. It may require changes in your routine or in how you care for yourself. It may also change what you need from others in your life. It does not, however, define you. You are not your disease.

You will need to be monitored on a regular basis. Your health care team will likely become people who you value as key players in the management of your illness. How often you see your health care team will depend on many factors, and will need to be an ongoing discussion between you and your doctor.



A diagnosis of myelofibrosis can feel overwhelming at first, but there is hope, you can regain some control in your life and you can find that 'new normal' as you realize you are not alone.

— Melissa Wright, LMSW, OSW-C, Gilda's Club Quad Cities

POSITIVE LIFE CHANGES

Instead of returning to normal, you will likely have to search for a “new normal.” Some cancer survivors talk about the “gifts of illness” – positive changes that occur as an outcome of a trauma or a life crisis.

Because cancer exposes you to the fragility of life, it gives you the chance to do things you have left undone. You may want to tell family members or friends that you love them, say thank you, tell someone that you forgive them, or ask for their forgiveness.

CANCER MAY:

- Let you feel a greater sense of self-esteem or mastery
- Help you recognize the importance of surviving, find new meanings for life, and gain stronger coping skills
- Enable you to better understand what is important to you
- Give you a desire to “give back”
- Make you want to live in the present to do things now rather than later
- Let you feel a greater appreciation for life

MAKING PLANS

It is a good idea for all adults, no matter their health situation, to prepare for the future by having their affairs in order. These legal documents help you:

- A **will** is a legal document that designates who will receive your money and belongings and who will be responsible for your children (in the absence of another parent). If there is no will in place, an agent of the state may become responsible for these decisions.
- A **living will** is a legal document to let your doctor know what kind of medical care you want at the end of your life if you can’t speak for yourself.
- A **durable power of attorney** is a person who will make health care decisions for you if you can’t make them yourself.
- A **do not resuscitate (DNR)** order is an order for your doctor if you decide that you would not like heroic measures to be taken in the event of cardiac or respiratory arrest.

Choose someone you feel very comfortable with to assist you in making plans like these. If you make these plans, you will help your family and loved ones by not leaving them with terribly difficult decisions. You will be reducing confusion and helping everyone around you feel more comfortable that the decisions made are yours.



Through the support groups, these are people that I would have never met if I didn't have this disease and joining these groups. I have met wonderful people who will be lifelong friends. We have this common bond. People think that support group meetings are so depressing, but it is not like that. Knowing that people care and want to know what I am going through gives me strength. I know people care and the support is what gives me strength.

— Oliva, myelofibrosis survivor

FINDING HOPE

People affected by cancer hope for many things: peace in relationships; good communication with doctors; a way to come to terms with cancer; and for the recovery of physical and emotional health.

By being empowered during cancer treatment and by having support, you can balance optimism and hope with a realistic understanding of your experiences. You can more effectively deal with information, regain a sense of control, and find hope that you are not alone.

Hope is found throughout the cancer experience in a variety of ways. Science is offering new hope for the best possible treatments available today and in the future.

8 *Resources*

MPN INFORMATION, SURVIVORSHIP & SUPPORT

Cancer Support Community

www.CancerSupportCommunity.org

HelpLine 888-793-9355

American Cancer Society

www.cancer.org

800-227-2345

Cancer Care

www.cancercare.org

800-813-4673

Good Days

www.mygooddays.org

877-968-7233

The Leukemia & Lymphoma Society

www.lls.org

800-955-4572

MPN Connect

www.mpnconnect.com

MPN Education Foundation

www.mpninfo.org

MPN Research Foundation

www.mpnresearchfoundation.org

312-683-7247

National Cancer Institute

www.cancer.gov

800-422-7237

National Organization of Rare Disorders

www.rarediseases.org

800-999-6673

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 1-888-793-9355 or visit [**www.CancerSupportCommunity.org**](http://www.CancerSupportCommunity.org).

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 – Fri, 9 am – 9 pm 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.
[**www.CancerSupportCommunity.org/FranklySpeakingAboutCancer**](http://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**](http://www.CancerSupportCommunity.org/FindLocation).

Cancer Experience Registry® — Help others by sharing your cancer patient or cancer caregiver experience via survey at [**www.CancerExperienceRegistry.org**](http://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**](http://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**](http://www.CancerSupportCommunity.org/become-advocate).

FRANKLY SPEAKING ABOUT CANCER: MYELOFIBROSIS PROGRAM PARTNERS:



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.

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 professionals to answer questions and learn more.

© June 2020 Cancer Support Community. All Rights Reserved. Photography by Jared Zagha.