



CANCERcare®

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# fact sheet

## COPING WITH MYELOFIBROSIS

**Myelofibrosis is a type of chronic leukemia that causes blood cells to grow uncontrollably, creating scar tissue in a person's bone marrow. The scar tissue slows the production of blood cells, causing patients to develop anemia. The disease can lead to an enlarged spleen and liver. Other symptoms may include bone aches and pain, night sweats, low-grade fevers, itching, weight loss, fatigue, and shortness of breath.**

**The origins and risk factors for myelofibrosis are unknown. The condition is rare, affecting 3,000 to 4,000 people in the U.S. each year. Several academic institutions across the U.S. have established centers of excellence to help patients diagnosed with the disease.**

### TREATMENT OPTIONS AND MANAGING SYMPTOMS

The primary treatment approach for myelofibrosis is focused on managing symptoms, such as anemia or an enlarged spleen and liver, as well as addressing quality of life issues.

Current therapies involve radiation, oral chemotherapy, and medications including prednisone to boost red blood cell production. Blood transfusions and a bone marrow transplant may also be considered.

To address serious itching associated with myelofibrosis, antihistamines or UV light can provide relief. Some patients have also benefited from antidepressants that have anti-itching effects, such as paroxetine (Paxil) or sertraline (Zoloft).

A few years ago, researchers made a major breakthrough by identifying a gene called JAK2, which is mutated in half of all myelofibrosis patients. JAK2 inhibitors improve a patient's symptoms, relieving night sweats, weight loss, itching, and other difficult issues that patients experience. The first drug the U.S. Food and Drug Administration approved to treat myelofibrosis, called ruxolitinib (Jakafi), works as a JAK2 inhibitor.



Clinical trials are under way to test if similar drugs can produce comparable results in patients. Drugs that might improve scarring in bone marrow are also being studied, as well as combination therapies. If you have questions about clinical trials, talk with your doctor or health care provider.

### COMMUNICATING WITH YOUR HEALTH CARE TEAM

**Write down questions as they arise.** It is easy to get overwhelmed by treatment information from advertisements or websites. As questions come up, write them down. Then, at your next medical appointment, bring these questions with you so you can keep track of what you need to know.

**Take notes.** Ask a friend to accompany you to take notes at your appointments, or ask your doctor if you can record your visits

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to review them later. Write down the names of professionals and places you were referred to, and how to take any medications you were prescribed. The more information you have, the more empowered you will feel while meeting with your health care team.

**Find someone on your team who can serve as your advocate.** You should identify at least one person on your health care team you feel comfortable talking to. Your health care team includes nurses and social workers, as well as your primary care doctor and cancer specialist. Don't be afraid to ask them questions or bring up any concerns you have.

**Remember: you are a key member of the team.**

## EMOTIONAL SUPPORT

**Join a support group.** A support group connects you to other people coping with similar situations. CancerCare's face-to-face, telephone, and online support groups are led by professional oncology social workers who specialize in helping people facing cancer.

**Accept help.** It can be hard to ask for or accept help. People with cancer often worry that they will be a burden to family or friends, and overlook the fact that many family and friends often want to help. It may help if you break down your needs into categories, including practical ones that others can help you with. For example, do you need help with household chores, transportation to appointments or managing paperwork?

**Take time for yourself.** Take care of yourself by connecting with sources of strength, which can include activities like prayer, meditation or even taking a relaxing walk. Learn some deep-breathing and relaxation techniques to calm your mind and body. Take a long bath, or read a good book. Research shows that people with cancer who better manage stress and maintain a positive outlook often do better throughout their diagnosis and treatment.



## CancerCare® Can Help

Founded in 1944, CancerCare is the leading national organization providing free support services and information to help people manage the emotional, practical and financial challenges of cancer. Our comprehensive services include counseling and support groups over the phone, online and in-person, educational workshops, publications and financial and co-payment assistance. All CancerCare services are provided by professional oncology social workers and world-leading cancer experts.

To learn more, visit [www.cancercares.org](http://www.cancercares.org) or call **800-813-HOPE (4673)**.

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