



CANCERcare®

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# fact sheet

## COPING WITH POLYCYTHEMIA VERA (PV)

**Polycythemia vera (PV) is a rare, chronic (long-term) disease in which the bone marrow overproduces red blood cells and, in many cases, white blood cells and platelets as well.**

**Red blood cells carry oxygen throughout the body, white blood cells fight infection and platelets are involved in clotting the blood to stop or slow bleeding and help heal wounds. When too many red blood cells circulate, the blood thickens and may not flow properly through the blood vessels. This raises the risk of blood clots in major arteries and veins, which can lead to a stroke or heart attack, and can affect other vital organs as well.**

**Because PV is characterized by uncontrolled cell growth, it is considered a blood cancer.**

### HOW IS PV DIAGNOSED?

Doctors diagnose PV by examining the blood and bone marrow to count the numbers of different blood cells and determine the level of erythropoietin, a hormone that stimulates the production of new red blood cells.

A blood test also is used to determine whether certain gene mutations (changes) are present. About 95 percent of people with PV have a gene mutation called JAK2 V617F. Up to four percent of patients have a different type of JAK2 mutation (JAK2 exon 12). A JAK2 mutation is a kind of switch that turns on and stays on, sending a constant signal to the bone marrow to produce blood cells.

PV must be carefully and routinely monitored by a hematologist/oncologist. These doctors specialize in diagnosing and treating blood disorders and blood cancers. Ask your doctor to refer you to a hematologist/oncologist, or visit [www.hematology.org](http://www.hematology.org) to search for a specialist in your own community.

### LEARN ABOUT TREATMENTS AND SYMPTOMS

**A number of treatments are used to control PV symptoms:**

**Low-dose aspirin.** Not only is low-dose aspirin beneficial for heart disease, it also can help people with PV. Taking low-dose aspirin is one of the first steps doctors advise when creating a treatment plan for people with PV.

**Hydroxyurea (Hydrea and others) and busulfan (Myleran).**

These medicines are often used to treat cancer. They can reduce the number of red blood cells, white blood cells and platelets, which helps improve blood flow and reduce the thickness of the blood.

**Interferon alfa (Intron A, Roferon-A).**

Interferon alfa prompts the immune system to lower the red blood cell count and keeps the blood thickness and blood flow closer to normal.

**Phlebotomy (fle-BOT-o-me).**

This procedure removes some blood from the body to reduce the volume of circulating blood cells so that blood can flow and function

(over)

correctly. A needle is inserted into a vein in a process similar to donating blood. Some people with PV need to have phlebotomy done every few months. For many people, it is the only treatment they will need for years to come.

## ON THE HORIZON

**Here are some of the treatments being studied in clinical trials now:**

**JAK inhibitors.** The U.S. Food and Drug Administration has approved ruxolitinib (Jakafi) for treating myelofibrosis. This oral medication and other JAK inhibitors such as momelotinib and NS-018 are being studied in clinical trials for people who have advanced PV.

**HDAC inhibitors.** This relatively new class of drugs has been shown to slow down the overproduction of red blood cells and PV symptoms. Two HDAC inhibitors currently being studied in patients with PV are givinostat and panobinostat.

**Peginterferon alfa (Pegasys).** In one clinical trial, this long-acting form of interferon is being compared with hydroxyurea in people with newly diagnosed PV to see which is the better treatment to use first. In another clinical trial, researchers are trying to learn whether peginterferon alfa can benefit people whose PV was previously treated but did not respond well.

## MANAGING SYMPTOMS

Ask your doctor or oncology social worker about the kinds of symptoms you might experience. Your health care team can help you develop a routine for managing each symptom and keep

track of your progress. If you're prescribed any medications to manage symptoms, remember to keep your dosing consistent and timely. Often, changing your diet, exercising regularly, taking pain-relieving medications, and getting plenty of rest are helpful ways of coping with the effects of cancer and its treatment. To learn more, read CancerCare's fact sheet, "Managing Symptoms of Polycythemia Vera."

## SEEK 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.** 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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