



## LIVING WITH POLYCYTHEMIA VERA (PV)

Information, resources, and support for wherever you are on your journey with PV.



For more information, visit [VoicesOfMPN.com/living](https://VoicesOfMPN.com/living) today.



## Moving Through the Polycythemia Vera (PV) Journey

### — UNDERSTANDING — **POLYCYTHEMIA VERA** (polly-sigh-THEE-me-ah-VAIR-ah)

This brochure provides an overview of **polycythemia vera**, or PV, including important information about:

- PV symptoms
- Blood counts
- Tracking your condition
- Taking an active role in your care

This resource may be used as a guide to help educate family, friends, and loved ones about your PV. Additional tools, information, and resources are available on [VoicesOfMPN.com/living](https://VoicesOfMPN.com/living).

PV is a rare, chronic blood cancer in which a person's body makes too many red blood cells, white blood cells, and platelets. PV is part of a group of diseases called "myeloproliferative neoplasms," or MPNs. Although every PV experience is unique, there are several important milestones that many PV patients may encounter as they move throughout their own PV journeys.

### 1 Suspecting That Something May Be Wrong

For some people, the PV journey may begin with a suspicion that something is wrong. It could be persistent, unexplained symptoms, such as severe fatigue, that affects a person's daily life and routines. However, some people may not experience any PV symptoms and may unexpectedly learn that they have elevated blood counts after a routine check-up.

Every PV journey is unique, but it's important for all individuals affected by PV to take an active role in their own care by learning to recognize how their health may be changing over time and sharing this information with a Healthcare Professional.

## 2 Seeking an Evaluation

A PV evaluation is an important step in the PV journey and may be performed by a *hematologist* (a specialist in blood diseases) or an *oncologist* (a cancer specialist). An evaluation may also include an *MPN specialist*, which is a Healthcare Professional who specializes in diagnosing and caring for individuals with MPNs, including PV. This may be a hematologist, an oncologist, or someone with expertise in treating both blood diseases *and* cancer.

Seeking input from an MPN specialist (such as for a second opinion) may provide you with access to different medical resources and facilities, as these are Healthcare Professionals who have extensive experience with blood cancers like MPNs.

Some reasons to consider an evaluation from an MPN specialist might be:

- You want another opinion about your diagnosis or care management plan.
- You want to explore specialized care management options.
- Your current doctor has limited experience with your condition.






It's important to remember that an **MPN specialist can collaborate and partner with your local Healthcare Professional(s)** to help provide you with more comprehensive care.

## 3 Testing and Diagnosis

PV may remain unrecognized for years. In fact, it is often diagnosed by chance during a blood test following a routine exam or some other medical reason by a Healthcare Professional. For example, approximately 30% of cases are diagnosed during testing after a cardiovascular event, such as a heart attack or stroke.

Certain signs and symptoms may also suggest a PV diagnosis, such as:

-  Abnormal blood tests (increased hematocrit or hemoglobin)
-  An enlarged spleen (an organ under your ribs and near the stomach on your left side)
-  Symptoms like fatigue (tiredness), itching, or sweating

Before confirming a PV diagnosis, your Healthcare Professional(s) may want you to undergo a number of medical tests, such as blood tests and/or bone marrow tests, genetic tests, and possibly even imaging studies (eg, ultrasound) to check your spleen size.

## 4 Exploring Care Management Options

PV can often be effectively managed for a long period of time with ongoing medical supervision and an individualized management plan. Your management plan may include low-dose aspirin and phlebotomy, a procedure that helps lower blood cell counts by removing blood from the body. If you have difficulty with phlebotomy, an enlarged spleen, experience severe PV-related symptoms, or continue to have elevated blood counts, you may also discuss other care management approaches with your Healthcare Professional.

## Living With Polycythemia Vera (PV)

After a PV diagnosis, it may take some time to adjust and learn about your disease. Know that it's okay—and normal—to feel overwhelmed at first. Just remember that *you are not alone on your journey*.

Taking an active role in learning about your PV can make a big difference and may help you feel more in control of your PV. Here's how you can get started:



**Partner with your healthcare team** to gather as much knowledge as you can so that you are able to participate in the ongoing discussions and decisions about your care.



**Be your own advocate.** Know that it's okay to speak up for yourself if you have any questions about your condition or your care. And don't be afraid to ask for clarification about anything you don't understand. Remember, this is *your* PV journey.



**Supplement your knowledge.** In addition to the information provided to you by your healthcare team, you may also want to supplement your knowledge by doing your own research. You may also want to ask your healthcare team about how to connect with advocacy groups for more information.



**Seek the support you need.** Sometimes connecting with others who may share your experience can provide valuable insight—and much needed support. Consider finding a PV support group, either in person or through social media.



**Keep track of your PV over time.** Talk with your healthcare team about how you can work together to regularly track your PV. This may include keeping copies of your lab reports, as well as documenting any changes in your PV symptoms, blood counts, and the frequency of medical procedures (such as phlebotomies).



**Stay positive.** Although living with PV can be stressful at times, it's still important to focus on the positives in your life and make time for things that bring you joy.

**Your experience with PV is unique to you.** No matter which milestones you may pass along the way, don't forget that this is *your* journey. **You have a voice in the decisions being made about your care.** Always work closely with your healthcare team to manage your PV. Be open and honest when talking about how PV affects your daily life. And be empowered to take an active role in your care.



**Really document your journey to see where you've been and where you're going.**

—Karen, MPN Community Member

## Learning About Polycythemia Vera (PV)

### What Is PV?

PV is a rare, chronic blood cancer where the bone marrow produces too many red blood cells. You may also have too many white blood cells and platelets (blood clotting cells) in your blood, but having too many red blood cells causes most of the problems associated with this condition. PV is part of a group of diseases called myeloproliferative neoplasms, or MPNs.

Too many red blood cells can cause the blood to thicken. Thicker blood doesn't flow normally through arteries and veins. Increased blood thickness and decreased blood flow, as well as abnormalities in your platelets and white blood cells, may increase your risk of blood clots. Blood clots can cause a stroke, heart attack, or blockage of an artery in your lungs or in a vein deep within a muscle in your arms or legs.



**“When you’ve been told that you have cancer, it is a challenge. With time, things become clearer.”**

—Matt, MPN Community Member

### What Causes PV?

Scientists think that PV may be related to changes in certain genes. These changes are called *mutations*. In PV, mutations may cause the bone marrow to make an abnormal number of red blood cells. This imbalance of blood cells may cause some of the symptoms associated with PV.

About 95% of people with PV have a specific mutation, or change, in the *JAK2* (Janus-associated kinase 2) gene. Genetic tests can show whether or not you have this mutation or other less common mutations found in people with this condition.

### Who Gets PV?

PV can occur at any age, but it is more common in people over 60 years of age. PV affects slightly more men than women. It is considered a rare disease, with about 100,000 cases in the United States.

### How Serious Is PV?

PV is a chronic, progressive disease, which means that it never goes away and may change or get worse over time. While PV can often be managed effectively for some time, it can lead to other blood diseases, such as myelofibrosis (MF) or leukemia, in a small number of people.

PV affects each individual differently. Some people have no symptoms, while others have severe symptoms that interfere with their daily lives. Recognizing how PV is affecting you gives your Healthcare Professional important information that can help you have informed discussions about your care.

## Identifying the Symptoms of PV

### What Are the Signs and Symptoms of PV?

Because PV is a progressive condition, it may change or get worse over time. That means that some of your symptoms may change as well. This is why it's important to take an active role in your care by tracking your condition on a regular basis and understanding what "normal" means for you. Whether you use a notebook, diary, or online tracker tool, it's important to keep track of how your PV symptoms may be changing over time.

Be sure to **inform your care team about all the symptoms you may be experiencing**, even if you're not sure they are related to your PV. This includes new symptoms or symptoms that may have changed (worsened or decreased) and how your symptoms may be impacting your activity levels and daily routines. This information may offer valuable insights that can impact your ongoing care management plan.



Remember, regularly evaluating your PV symptoms may help you recognize when something isn't right. And that can help you more effectively partner with your care team in managing your condition.

### Common PV Symptoms



Tiredness  
(fatigue)



Itching  
(especially after  
a warm shower)



Headache



Night sweats



Blurred vision  
or blind spots



Painful burning  
or numbness of  
the hands or feet



Problems  
concentrating



Bone pain



Shortness  
of breath



Bleeding  
from the gums  
and heavy bleeding  
from small cuts



Insomnia



Dizziness,  
vertigo or  
lightheadedness



Reddening  
of the face or  
a burning feeling  
on the skin



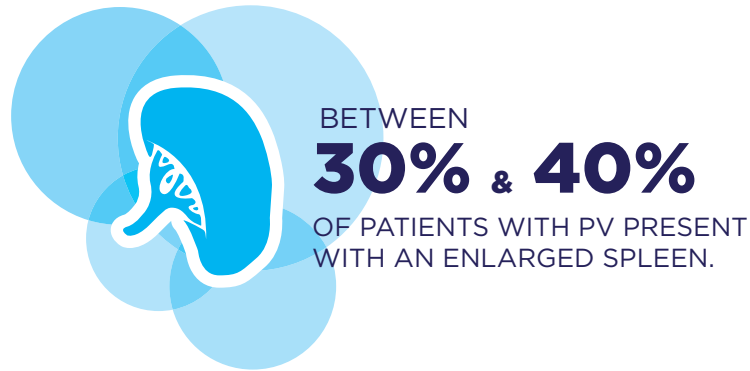
Angina  
(chest pain)



Ringing in  
the ears

## What Should I Know About PV and the Spleen?

Your spleen is a small organ located near the stomach under your left rib cage. It has a number of important jobs, including filtering the blood, storing blood cells, and helping fight infection.



In some people with PV, the spleen may become enlarged—a condition called *splenomegaly* (splee-nuh-MEG-uh-lee). This may be a sign that your spleen is working harder than usual. However, it can also be a sign that your PV may be changing or getting worse.



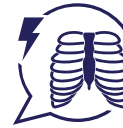
**I can tell when my spleen is enlarged because my appetite is gone.**

-Karen, MPN Community Member

### Symptoms of an enlarged spleen may include:



Abdominal discomfort

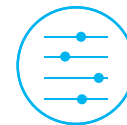


Pain under the left ribs



An early feeling of fullness when eating (early satiety)—even if you haven't eaten much food

You can take an active role in your care by helping identify the signs and symptoms of spleen enlargement. Be sure to ask your Healthcare Professional to check your spleen size on a regular basis throughout your PV journey.



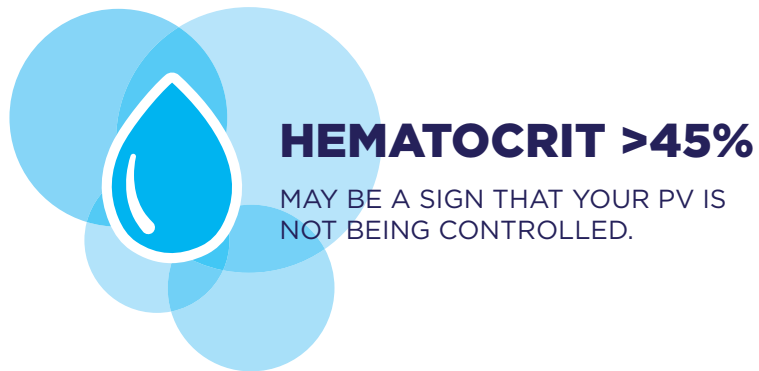
### Keep track of your PV with the PV Tracker Tool

Track symptoms, blood counts, and phlebotomies related to PV. To learn more, visit [MPNSymptomTracker.com](https://MPNSymptomTracker.com).

## Understanding the Importance of Controlling Blood Counts in PV

### Why Is It Important to Keep Track of Blood Counts?

Keeping your blood counts—particularly your hematocrit—at the right levels is an important goal in managing PV. It's important to work with your Healthcare Professional to determine the individual blood count targets that are right for you.



Hematocrit is a measure of the volume of red blood cells in the blood and is stated as a percentage.

Medical research suggests that an elevated hematocrit level can increase the risk of serious health problems, such as blood clots leading to heart attack or stroke. Study findings have also shown that, for some patients, stabilizing blood counts can help lessen the chance of serious complications.

In addition to hematocrit, your Healthcare Professional may also monitor your:

- red blood cell count (hemoglobin)
- white blood cell count
- and platelet count

He or she may periodically order blood tests to monitor your condition.



**“Every three weeks I’ve been getting a phlebotomy to keep my hematocrit under 45.**

—Dave, MPN Community Member



Keeping track of your blood counts is important, so consider asking for copies of lab reports to keep for your own records.

Whether you keep a folder with copies of your lab results or use a notebook, journal, or online tracker tool, it's important to keep ongoing records of how your PV is affecting you over time.



## Taking an Active Role in Your PV

### Why Is It Important to Be an Advocate for Your Own Care?

Every PV journey is unique, and how it may change over time can vary from person to person. However, it's important to take an active role in your care no matter where you are on your journey with PV. Some of the ways you can advocate for your own care include:

- Continue to learn about your condition
- Schedule—and keep—regular PV care appointments
- Partner with your care team to keep track of your disease
- Maintain a healthy lifestyle
- Get additional support when and if you need it



**“One of the first things I would tell someone... is to be your own advocate.**

—Aimee, MPN Community Member

### Why Is “Ongoing Education” an Important Part of Managing PV?

Scientists and researchers continue to explore new solutions for diagnosing and managing disease. That's why it's important to stay up to date with the latest information about PV—and how this information may impact the decisions you make in partnership with your healthcare team.



Don't be afraid to do your own ongoing research—and be sure to discuss your findings with your Healthcare Professional(s).

### How Can PV Patients and Healthcare Professional(s) Work Together?

When you have a chronic condition like PV, regular healthcare visits are an important part of managing your disease.



**If you have an appointment, be sure to keep it.**

And if you don't have one scheduled, talk to your healthcare team about how often you need to be seen. Also keep in mind that you have options in how those PV care visits take place. In addition to in-person appointments, many healthcare practices may also offer telehealth (virtual) appointments, which enable you to meet with your healthcare team via telephone, tablet, or computer.

No matter which type of appointment you schedule, it is important to think of your Healthcare Professional as a partner in managing your care. Know that talking to your Healthcare Professional about your PV helps you both:

- Understand how PV is affecting you
- Follow how your PV is changing over time
- Discuss your ongoing care management options

Finally, remember to be open and honest in your discussions about your PV. Know that it's okay to ask questions or seek clarification if there is something you don't understand. And don't be afraid to speak up about your symptoms and any other concerns you may have.

Finally, don't be afraid to seek out a second opinion or the support of an MPN specialist. Not every hematologist or oncologist specializes in treating blood disorders or blood cancers, so it's okay to seek out expert advice.



All of your Healthcare Professionals can work *together* to help ensure that you are getting the comprehensive care that you need.

## Why Is Tracking a Valuable Tool in Managing PV?

Because PV is a progressive condition, it may change or get worse over time. That means that some of the signs and symptoms may change as well. You can take an active role in your care by regularly monitoring various aspects of your PV, such as blood counts, symptoms, and the frequency of certain medical procedures (eg, phlebotomy).

Take note of how your daily routines and activity levels are affected by your PV. For example, are there certain things you could do before that you are no longer able to do? Also, do not assume that any symptom is too minor or not worth recording. After all, it could be related to your PV.



It is important to **keep track of *any* changes in your condition, even if you are not sure they are related to your PV.**

Whether you use a notebook, a diary, or an online tracker tool, careful and consistent tracking provides a number of valuable insights. Not only can it help identify trends within your health, but it may also help you have more informed discussions with your healthcare team.

## How Can People With PV Maintain a Healthy Lifestyle?

Maintaining a healthy lifestyle is an important part of managing your PV. Taking small steps can add up to big changes over time. You can:

- Work toward a healthier diet by adding a fruit or vegetable to each meal
- Start walking or doing other physical activities, even for a few minutes a day at first. Be sure to consult your Healthcare Professional first!
- Get a full night's sleep as often as you can
- Get help breaking unhealthy habits (eg, cigarette smoking)
- Consider yoga or meditation to relax and help relieve stress

# Where Can People With PV Find Additional Support?

When you're living with a rare disease like PV, it's important to know that you are not alone. [VoicesOfMPN.com](https://www.voicesofmpn.com) connects people with PV to an entire community of patients and caregivers affected by PV.



To help support your PV journey, the Voices of MPN website offers a comprehensive variety of information, tools, and resources, such as:

- Disease education materials
- Real patient stories and videos
- Expert videos
- Blog articles written by and for the PV community
- Community support programs
- Podcasts
- Frequently asked questions
- Glossary of terms
- PV Tracker Tool
- Advocacy events and activities

With an emphasis on self-awareness and education, Voices of MPN encourages patients and caregivers to regularly evaluate their condition and raise their voice via informed, proactive discussions with their Healthcare Professional(s).



Visit [VoicesOfMPN.com](https://www.voicesofmpn.com) today!

Open your camera app and point it here to see more resources on our website.





# Know That You Are Not Alone

## Share Your Story. Connect With a Peer.

When you're living with PV, it's not always easy to find someone who knows what you're going through. Connecting with a peer is a way to remember that you are part of a greater community—and are not alone.

### Become a Member of CHAMPN Connections

As part of the larger **CHAMPN** Program, **CHAMPN Connections** provides patients and caregivers with an opportunity to connect one-on-one via telephone with a peer who may share a similar PV experience. Members can find a mentor or become a mentor for someone who needs one!



If you'd like to share your story or get connected with a peer from the MPN community, you can learn more at [VoicesOfMPN.com/Connect](https://VoicesOfMPN.com/Connect).



“One of the best experiences I've had so far with PV is being able to talk to somebody else who has it.

—Josh, MPN Community Member



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