PIECETOGETHERPV

Your guide to more EMPOWERED CONVERSATIONS WITH YOUR DOCTOR

Living with polycythemia vera (PV) and making sense of your condition doesn't have to feel overwhelming. This guide is designed to help you piece together the important parts of your PV journey, so you can have more productive and empowering conversations with your doctor.

Bring this guide with you to your next appointment to help you speak up about how you're feeling, understand your options, and set treatment goals that matter to you.

What's inside this guide:

- **Preparing for your appointment**
  Before your next appointment, take some time to fill out the treatment goals checklist and symptom tracker to help inform your care plan.

- **Talking to your doctor**
  When you're ready to meet with your care team, this guide includes questions to help you self-advocate with confidence to get the answers you need.

My PV treatment goals

Check any treatment goals that are important to you and use the list to help guide the conversation with your doctor.

- ☐ Targeting the underlying disease
- ☐ Having treatment work for the long term
- ☐ Avoiding chemotherapy
- ☐ Minimizing the number of phlebotomies
- ☐ Reducing my symptoms
- ☐ Finding a treatment that doesn't interfere with my life
- ☐ Normalizing all 3 blood cell counts (red blood cells, white blood cells, and platelets)

Are there any other treatment goals or details you'd like to share with your doctor?

_____

_____

_____

_____

_____

_____

Self-advocacy tip

PV treatment is about more than just hitting the right numbers. How you feel and what you want out of life are also important pieces of the treatment puzzle. So be sure to be honest about your goals to help your doctor understand your priorities.

Symptom tracker

Use this tracker to let your doctor know how you're feeling. That way, they can see all the pieces of your PV story—not just the ones that show up in lab results. Please be specific in your answers and feel free to print this tracker out as many times as you need.

Symptom	How often have you experienced it in the past 30 days?	How does it affect your daily life? Be as specific as possible.
Headache	☐ Not at all ☐ Several days ☐ More than half the days ☐ Almost every day	
Dizziness	☐ Not at all ☐ Several days ☐ More than half the days ☐ Almost every day	
Blurry vision	☐ Not at all ☐ Several days ☐ More than half the days ☐ Almost every day	
Unusual bleeding or bruising	☐ Not at all ☐ Several days ☐ More than half the days ☐ Almost every day	
Itchy skin (especially after a hot bath or shower)	☐ Not at all ☐ Several days ☐ More than half the days ☐ Almost every day	

Symptom tracker (CONTINUED)

Symptom	How often have you experienced it in the past 30 days?	How does it affect your daily life? Be as specific as possible.
Red or purplish skin rash	☐ Not at all ☐ Several days ☐ More than half the days ☐ Almost every day	
Feeling full soon after eating	☐ Not at all ☐ Several days ☐ More than half the days ☐ Almost every day	
Bloating/pain in upper left abdomen	☐ Not at all ☐ Several days ☐ More than half the days ☐ Almost every day	
Fatigue/low energy	☐ Not at all ☐ Several days ☐ More than half the days ☐ Almost every day	
Shortness of breath/difficulty breathing when lying down	☐ Not at all ☐ Several days ☐ More than half the days ☐ Almost every day	
Painful swelling of one joint (often the big toe)	☐ Not at all ☐ Several days ☐ More than half the days ☐ Almost every day	

Symptom tracker (CONTINUED)

Symptom	How often have you experienced it in the past 30 days?	How does it affect your daily life? Be as specific as possible.
Numbness, tingling, or a burning sensation in the hands, feet, arms, or legs	☐ Not at all ☐ Several days ☐ More than half the days ☐ Almost every day	

Any other symptoms your doctor should know about?

Self-advocacy tip

Your doctor needs to know how you *really* feel. Even if you're not sure if something is related to your PV, be honest about the changes you notice. Small details can help your doctor create a care plan that addresses every piece of your PV.

Questions for your care team

Understanding PV

- What is PV, and what does it mean for my daily life?

- What is a *JAK2* mutation? Do I need to get tested for it?

Symptoms

- What symptoms or changes in how I'm feeling should I tell you about right away?

Testing and monitoring

- How will you monitor my PV, and what should I be watching for at home?

- How often should I see you? How often will I need to get complete blood counts (CBCs)?

Questions for your care team (CONTINUED)

Can you explain my current blood counts and what my target numbers are?

	Test date	Current	Target
Red blood cells (RBC)	__/__/____		
White blood cells (WBC)	__/__/____		
Platelets	__/__/____		
Hematocrit (HCT)/ red blood cell volume	__/__/____		
Hemoglobin (HB or HGB)	__/__/____		

- Will you track my complete hematologic response (CHR)? Why is this important?

  _____

  _____

  _____

- What other tests or scans will I need, and how often?

  _____

  _____

  _____

Questions for your care team (CONTINUED)

Treatment and management

- What treatment options are available beyond phlebotomies, aspirin, and chemotherapy?

_____

_____

_____

- What can I do to stay on top of my PV and feel more in control?

_____

_____

- What potential complications should I know about? How can we lower my risks for the long term?

_____

_____

_____

- What can I do to proactively manage my PV for the long term?

_____

_____

Other

Use the space below to note any other missing pieces.

_____

_____

_____

> **"Ask a lot of questions to make sure that you understand exactly what's going on and what treatment options are available to you."**
>
> **– Person with PV**

PharmaEssentia

© 2025 PharmaEssentia Corporation. All rights reserved.
PharmaEssentia is a registered trademark of PharmaEssentia Corporation,
and the PharmaEssentia logo is a trademark of PharmaEssentia Corporation.
US-PV-2500054 (v2.0) 12/2025