A Discussion Guide for Patients and Their Healthcare Teams

Polycythemia vera, or PV, is a rare, chronic, blood cancer in which the body makes too many blood cells. PV is also a progressive disease. That means it may get worse over time. It’s important to keep your PV under control to reduce the risk of complications and help you feel better.

As you work with your healthcare team to manage your disease, it is important to be aware of your blood counts, how you feel, and how PV affects your daily life.

Complete the questions on the following pages. They may help guide conversations with your healthcare team.
Questions to Ask Your Healthcare Team

What is my care management plan to keep my PV under control?

What are my blood count targets?

Hematocrit (red blood cell volume): ________________

White blood cell count: ________________

Platelet count: ________________

Other: ________________

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Hematocrit (red blood cell volume): ________________

White blood cell count: ________________

Platelet count: ________________

Other: ________________

What types of tests and procedures will I need, and how often will I need them?

☐ Ultrasound: ____________________

☐ CT scan: ____________________

☐ MRI: ____________________

☐ Other: ____________________

How often should I schedule appointments with you and/or other members of my healthcare team?

What symptoms or changes should I let you and/or other members of my healthcare team know about right away?

________________________________________

________________________________________

________________________________________

________________________________________
Be Sure to Tell Your Healthcare Team If You Experience:

**Common PV symptoms:**
- Tiredness or fatigue
- Itching, especially after a warm shower
- Night sweats
- Bone pain
- Concentration problems
- Any other symptoms

**Symptoms related to an enlarged spleen in PV:**
- Pain or discomfort under your left ribs
- Feeling full when you haven’t eaten or have eaten very little
- General abdominal discomfort

**Other considerations:**
- Symptoms limit your activities
- You cannot do things now you could do three months ago
- Symptoms have worsened over the last three months
- There has been an increase in your need for phlebotomy

Take an active role in managing your PV.
If you have answered **YES** to any of the questions, it is important to talk with your healthcare team to understand if your PV is under control.