



DOCTOR DISCUSSION GUIDE

Managing Polycythemia Vera

Being diagnosed with polycythemia vera can feel intimidating, but you and your doctor will work together to help take control of your symptoms. Asking the right questions during your conversation will help you know what to expect and how to better navigate your condition. Familiarize yourself with these common terms before your appointment to help facilitate your discussion.

Vocabulary to Know

Your doctor might mention these common terms. Here's what they mean.

JAK2 (Janus Kinase 2) Gene	Nearly all cases of polycythemia vera are caused by mutations to this gene. The gene's function is to give instructions for the production of blood cells. When a mutation is present, the gene is perpetually operating and the body, therefore, produces too many blood cells. It is not yet known what causes these mutations.
Myeloproliferative Neoplasms	The name for a group of blood cancers under which polycythemia vera falls.
Hematocrit	The main measure of the concentration of red blood cells in the blood that's used to diagnose polycythemia vera. Essentially, it is the ratio of the volume of red blood cells to the total volume of blood.
Hematologist	A doctor that specializes in diagnosing and treating blood diseases.
Phlebotomy	The removal of blood from the body through a vein to reduce the hematocrit concentration. It's usually the first (and sometimes the only) course of treatment for polycythemia vera patients. The process is basically like blood donation. Long-term, phlebotomy leads to iron deficiency.
Myelosuppressive Drugs	Drugs that suppress the bone marrow's ability to produce blood cells and platelets. It's used for patients on whom phlebotomies alone aren't effective enough.
Hydroxyurea	The most commonly used myelosuppressive drug used to treat polycythemia vera. It helps to reduce hematocrit concentration as well as platelet count. It can cause mild to moderate side effects.



Questions to Ask

These questions will help you start a conversation with your doctor about how to best manage polycythemia vera.

About Symptoms

- Should I expect to develop blood clots?
- I understand that my clots can cause serious conditions like strokes and heart attacks. How do I prevent them?
- Am I likely to develop leukemia or myelofibrosis as a result of my polycythemia vera?

About Causes & Risk Factors

- Is polycythemia vera inherited? Can I pass this on to my children?

About Diagnosis

- Can you run me through the figures of my hematocrit concentration, hemoglobin concentration, and red blood cell count?
- Will I have to undergo a bone marrow analysis?

About Treatment

- What treatment do you recommend based on the severity of my condition?
- I understand that constant phlebotomies can cause iron deficiency. Is there any way to prevent that?
- Will I be referred to a hematologist or oncologist?
- Has my hematocrit concentration changed since my last test?
- Are my phlebotomies working or will I have to switch to myelosuppressive drugs?
- Will I have to take drugs to prevent blood clots?

About Living with Polycythemia Vera

- Will I have to make any changes to my diet?
- I understand that polycythemia vera cannot be cured. However, how close to a normal life can I expect to live?
