

Polycythemia Vera



What is polycythemia vera?

Polycythemia vera (PV) is a rare blood disorder in which there is an increase in all blood cells, particularly red blood cells. The increase in blood cells makes your blood thicker and can cause problems with blood flow (circulation). This can lead to blood clots forming in blood vessels. This can cause strokes or tissue and organ damage.

What causes polycythemia vera?

Polycythemia vera is caused by a genetic change (mutation) that develops during your lifetime. It's not an inherited genetic disorder. In most cases, it's not known why this happens.

What are the symptoms of polycythemia vera?

When you have more blood and it's thicker than normal, problems can occur. Each person's symptoms may vary. Symptoms may include:

- Lack of energy (fatigue) or weakness
- Headache
- Dizziness
- Shortness of breath and trouble breathing while lying down
- Vision problems, such as double vision, blurred vision, and blind spots
- Inability to concentrate
- Night sweats
- Face becomes red and warm (flushed)
- Nosebleeds
- Bleeding gums
- Heavy menstrual bleeding
- Coughing up blood
- Bruising
- Itchy skin (often after a hot bath)
- Gout
- Numbness
- High blood pressure

These symptoms may look like other blood disorders or health problems. Always see your healthcare provider for a diagnosis.

How is polycythemia vera diagnosed?

Your healthcare provider will take your health history and give you a physical exam. Your provider may also do blood tests. These tests will check the increased number of red blood cells in your body. They will also check if there are other conditions that could cause your higher red blood cell count. Your healthcare provider will also likely do a bone marrow biopsy to look for abnormal cells.

How is polycythemia vera treated?

Treatment will depend on your symptoms, age, and general health. It will also depend on how severe the condition is.

Treatment may include:

- **Phlebotomy.** This procedure removes blood from your body. At first, this must be done often, such as every week. Once enough blood has been removed to reduce your body's iron stores (needed to make blood quickly), you will not need this done as often.
- **Certain medicines, including chemotherapy.** The medicines help stop your bone marrow from making too many blood cells. They also keep your blood flow and blood thickness closer to normal.

What are possible complications of polycythemia vera?

Polycythemia vera can be fatal if not diagnosed and treated. It can cause blood clots resulting in a heart attack, stroke, or pulmonary embolism. Liver and spleen enlargement are other possible complications. In some cases, it can transform into a condition resulting in bone marrow scarring (fibrosis) or leukemia.

Living with polycythemia vera

There is no cure for polycythemia vera. But correct treatment can help to reduce or delay any problems. Work with your healthcare provider to create a treatment plan that fits your needs. You should also be physically active to increase your heart rate and improve your blood flow.

Other ways to improve your blood flow include:

- Stretching your legs and ankles
- Staying away from extreme heat
- Drinking plenty of water

This condition can cause circulation problems. So, take care of your hands and feet. Protect them from injuries from cold and heat. For example, always wear shoes, even in your home. Wear warm gloves and socks during cold weather.

Key points about polycythemia vera

- Polycythemia vera is a rare blood disorder in which there is an increase in all blood cells, particularly red blood cells.
- The increase in blood cells makes the blood thicker.
- Thick blood can lead blood clots forming in blood vessels. This can cause strokes or tissue and organ damage.
- Symptoms include lack of energy (fatigue) or weakness, headaches, dizziness, shortness of breath, visual disturbances, nose bleeds, bleeding gums, heavy menstrual periods, and bruising.
- Treatment may include medicines and phlebotomy, a procedure that removes extra blood from your body.
- Sticking to your treatment plan, exercise, enough fluid intake, and staying away from extreme heat can help prevent or decrease symptoms

Next steps

Tips to help you get the most from a visit to your healthcare provider:

- Know the reason for your visit and what you want to happen.
- Before your visit, write down questions you want answered.
- Bring someone with you to help you ask questions and remember what your provider tells you.
- At the visit, write down the name of a new diagnosis, and any new medicines, treatments, or tests. Also write down any new instructions your provider gives you.
- Know why a new medicine or treatment is prescribed, and how it will help you. Also know what the side effects are.
- Ask if your condition can be treated in other ways.
- Know why a test or procedure is recommended and what the results could mean.
- Know what to expect if you do not take the medicine or have the test or procedure.
- If you have a follow-up appointment, write down the date, time, and purpose for that visit.
- Know how you can contact your healthcare provider if you have questions.

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