GET READY FOR YOUR NEXT APPOINTMENT



"Being well prepared for your visit can really help you get the most out of your time with your healthcare professional."

—Lindsey Lyle, MS, PA-C

New or changing symptoms may be a sign of disease progression in polycythemia vera (PV). This is why it's important that you understand these symptoms and make sure you are communicating them to your healthcare professional.

When these symptoms are caught early on, they may be easier to manage.

Use the PV Symptom Assessment Form to help you have more productive conversations with your healthcare professional at your next appointment

Voices of MPN®

KEEP TRACK OF YOUR PV SYMPTOMS

The PV Symptom Assessment Form on the next page is an easy way to keep track of your symptoms. Below you will find useful information about commonly experienced PV-related symptoms that will help you answer the questions on the form.

After you print out the form, fill it out and bring it with you to your next office visit.

Cytokine symptoms

Fatigue and inactivity

73% of patients experience fatigue

Fatigue is the most common PV symptom. Feeling tired occasionally is normal, but this kind of tiredness may stop you from doing day-to-day activities and cause you to miss moments that matter.

Night sweats

45% of patients experience night sweats

It's normal to sweat at night if the room temperature is too hot, but if it's happening under normal conditions, it may be your PV.

Itching

55% of patients experience Itching

Itching is the second most common symptom. Occasional itching is normal, but if you experience frequent itchiness that cannot be controlled or that affects your daily routine, this could be related to PV.

Bone pain

23% of patients experience bone pain

Bone pain may feel like a deep ache throughout the body. It can be constant or occasional, but it's important to talk with your healthcare professional if it happens more than twice a week.

Unintentional weight loss

12% of patients experience unplanned weight loss

Track your weight to see if you are experiencing weight loss without trying.

Fever (>100°F)

5% of patients experience fever of over 100°F

A fever of over 100°F should always be reported to your healthcare professional.

"When you first notice a symptom, keep track of it using the PV Symptom Assessment Form. The more specific and detailed you are, the better."

—Lindsey Lyle, MS, PA-C



Hyperviscosity-related symptoms

Concentration problems

36% of patients experience concentration problems

If you are experiencing difficulty paying attention or have brain fog or memory lapses (such as problems remembering dates or names), you are not alone. Concentration problems affect 36% of people with PV.

Enlarged spleen–related symptoms

Reduced appetite

22% of patients experience reduced appetite

You may feel full quickly after your meals or you may not be able to finish an entire meal. If your appetite has changed, this may be a sign of worsening PV.

Abdominal swelling/Discomfort

35% of patients experience abdominal discomfort

Does your stomach seem bulgy or larger than normal? Do you experience discomfort in your abdomen after eating or when laying down? If you experience abdominal discomfort, it should be reported to your healthcare professional.

POLYCYTHEMIA VERA SYMPTOM ASSESSMENT FORM

A tool for tracking your polycythemia vera (PV) symptoms

Know your PV symptoms

There are 3 important words you need to know to identify your symptoms:

SYMPTOM: Which symptom are you experiencing?
SEVERITY: How severe is the symptom?
IMPACT on quality of life: How is it affecting your daily life?

Sharing this information with your healthcare professional will give them a better understanding of how your PV is making you feel and how to help you manage symptoms.



Click here to watch a video **and take a real-time assessment of your PV symptoms with a leading MPN expert.**

Dr John Mascarenhas

Cytokine symptoms

1 FATIGUE AND INACTIVITY

SEVERITY (Check one box)

☐ None ☐ Mild ☐ Moderate ☐ Severe

How much has your fatigue or inactivity influenced your daily life? Are there activities that you were able to do 3 months ago that you struggle with now?

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2 NIGHT SWEATS

SEVERITY (Check one box)

☐ None ☐ Mild ☐ Moderate ☐ Severe

How many times in the last week have you experienced night sweats that have woken you up or required you to change your sheets or clothing?

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3 ITCHING

SEVERITY (Check one box)

☐ None ☐ Mild ☐ Moderate ☐ Severe

Have you noticed changes in your skin, particularly itching? For example, when you shower, do you ever feel itchy afterwards? How often?

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4 BONE PAIN

SEVERITY (Check one box)

☐ None ☐ Mild ☐ Moderate ☐ Severe

Have you felt any deep achiness throughout your body that caused you to limit your activities?

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5 UNPLANNED WEIGHT LOSS

SEVERITY (Check one box)

☐ None ☐ Mild ☐ Moderate ☐ Severe

Have you been losing weight without trying? Do your regular clothes not fit you anymore?

POLYCYTHEMIA VERA SYMPTOM ASSESSMENT FORM

A tool for tracking your polycythemia vera (PV) symptoms

Cytokine symptoms (continued)

6 FEVER (>100°F)

SEVERITY (Check one box)

☐ None ☐ Mild ☐ Moderate ☐ Severe

Have you been experiencing fevers over 100°F? How often? For how long?

Report fevers over 100°F to your healthcare professional.

Hyperviscosity-related symptoms

1 CONCENTRATION PROBLEMS

SEVERITY (Check one box)

☐ None ☐ Mild ☐ Moderate ☐ Severe

How often have you felt brain fog (memory lapses, problems remembering) or inability to pay attention?

Enlarged spleen-related symptoms

1 ABDOMINAL SWELLING/ DISCOMFORT

SEVERITY (Check one box)

☐ None ☐ Mild ☐ Moderate ☐ Severe

Have you had abdominal discomfort, particularly after eating?

2 REDUCED APPETITE

SEVERITY (Check one box)

☐ None ☐ Mild ☐ Moderate ☐ Severe

Have you felt full quickly after meals? How much weight have you lost over the past 6 months?

After filling out this form, share your responses with your healthcare professional.

Glossary

CYTOKINE: A type of protein in the body that has an effect on the body's immune system. When your body has too many of these proteins, you may experience various symptoms related to PV. **HYPERVISCOSITY:** A condition where the overproduction of red blood cells in the body causes the blood to thicken, making it harder to flow through smaller blood vessels.

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TAKE AN ACTIVE ROLE IN YOUR CARE

Get the most out of every appointment by keeping track of how your PV symptoms are affecting you

When you routinely track your PV symptoms and share them with your healthcare professional at every appointment, you are taking an important step in being an active participant in your treatment journey.

That's why it's so important to **prepare for your appointments by writing down the symptoms that are affecting you**. That way you can have a productive discussion with your healthcare professional and they can find a treatment path that gets you back to doing what you love.

"PV is a dynamic disease and things change over time. That's why every symptom is important to bring up, no matter how small or big."

—Lindsey Lyle, MS, PA-C

Download the Voices of MPN Tracker App to track your symptoms

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