

A Guide for Making Informed Treatment Decisions About Your Care for Polycythemia Vera

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Asking your healthcare provider questions at any phase of your treatment will help you take an active role in managing your care. If you do not understand any part of the information your healthcare provider gives you, ask him or her to explain it in another way.

Doctor's name _____

Date of appointment or call _____

1. What exactly is my diagnosis?

How long will I need to continue treatment? _____

Do I have JAK2 or any other mutation? _____

What are the chances it will cure me? _____

What is the significance of this or another mutation for my treatment and quality of life? _____

What are the expected side effects associated with standard treatment? _____

2. Are you the right doctor to treat my disease?

5. How well does the standard treatment work?

How many people with polycythemia vera have you treated? _____

Should I seek a second opinion? _____

6. What happens if I do not get treatment?

3. Is there a standard treatment for my disease?

7. How can I access clinical trials?

4. Is there more than one accepted standard treatment for polycythemia vera and, if so, how should I choose between them?

8. How do I get copies of my lab reports?

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9. What kind of testing will be done to monitor my disease and treatment? How often will testing be needed?

10. If I am treated at an out-patient clinic or at the doctor's office, will I be able to drive/get myself home after treatments or will I need someone to assist me?

11. How will I know if the treatment is effective? What options are available if the treatment is not effective?

12. Are there risks of second cancers?

13. How do I find out if my insurance will cover the costs of my treatment or the study treatment? Who can help answer any medical questions my insurance company or health plan asks?

14. If I'm getting a study treatment, will I be responsible for paying any treatment-related costs, such as tests, travel or the clinical trial drug(s)?

15. I have headaches and vision changes. When should I be calling you about these types of symptoms?

16. What types of symptoms do you consider urgent?

17. Can you work with my family doctor so that I can be followed closer to home?

18. I am currently taking baby aspirin. Should I continue to take it?
