

Starting a conversation around a sub-optimal treatment response

If you think you are experiencing a sub-optimal treatment response, starting that conversation with your doctor can be challenging. If you're unsure where to start, use these questions as a guide to discuss important aspects of your PNH and why you may be having a sub-optimal treatment response.

01 Share how you've been feeling (symptoms)

What symptoms have you been experiencing since your last appointment (e.g., fatigue, abdominal pain, etc.)? Are they better or worse since you last saw your doctor?

Have your symptoms changed since you last saw your doctor? ☐ Yes ☐ No

Do you experience significant fatigue that interferes with your daily life? ☐ Yes ☐ No

Select all the following symptoms you have experienced since your last doctor's visit.

- | | | |
|--|--|--|
| <input type="checkbox"/> Fatigue | <input type="checkbox"/> Rapid heartbeat | <input type="checkbox"/> Trouble concentrating (brain fog) |
| <input type="checkbox"/> ____ transfusions per month | <input type="checkbox"/> Loss of appetite | <input type="checkbox"/> Trouble breathing |
| <input type="checkbox"/> Abdominal or chest pain | <input type="checkbox"/> Difficulty exercising | |
| <input type="checkbox"/> Difficulty swallowing | <input type="checkbox"/> Headaches | |

What kind of adjustments did you make, if any, to your regular activities?

02 Restate your treatment experience

What do you want to accomplish with treatment?

Be open about your treatment experience

List treatments you have been prescribed.

How well do you believe these medications have worked for you?

Have you had a red blood cell transfusion in the past 6 months?

What kind of tests does your doctor conduct to assess how well your treatment is working?

What aspects of your treatment do you feel have gone well, and which ones could be improved?

Have you discussed other medication options with your doctor? If so, which ones?

Use this section to write down any notes, questions or concerns that you want to talk about during your appointment.
