

PNH APPOINTMENT GUIDE

This guide is meant to help you have more productive discussions with your health care team and get more support in managing your PNH.

This guide is divided into 2 sections:

1. Where you are right now
2. Where you want to be

USE THIS GUIDE TO:



REFLECT

On your PNH symptoms and how you're feeling



RECORD

Your fatigue, hemoglobin (Hb) levels, and more



DISCUSS

Your notes and next steps with your doctor

Bring this guide along to your next appointment to help you confidently advocate for yourself and your needs.

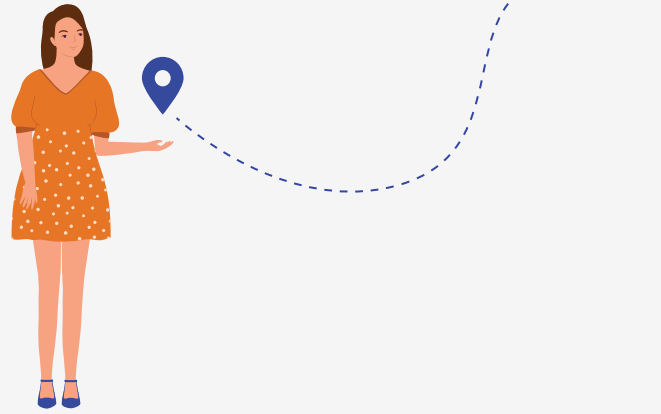


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RESOURCES AT: [EXPLOREP NH.COM/HELPFUL-RESOURCES](https://www.explorepnh.com/helpful-resources)

WHERE I AM NOW

Take a moment to think about how you've been feeling lately and how PNH has been impacting your life. Then, fill out this page and bring it to your next appointment. It will help you prepare for when your doctor asks how you've been doing.



Since my last doctor appointment, my PNH seems:

I would describe my PNH as:

| | | | | | |
|------------|-----------|---------------|-----------------|--------------|------------|
| a struggle | chaotic | relentless | well controlled | inconvenient | manageable |
| exhausting | tolerable | unpredictable | intimidating | low priority | |
| _____ | _____ | _____ | _____ | _____ | _____ |

Right now, the symptoms bothering me most are:

Fatigue: This is one of the most common symptoms of PNH. It can impact many aspects of life but can be difficult to describe.

| | | | | |
|---|-------|--------|---------|-------|
| <i>Fatigue negatively impacts my activities</i> | daily | weekly | monthly | never |
| <i>I require extra rest</i> | daily | weekly | monthly | never |

| | | |
|-----------------------------|--------------------------|--------------------|
| Anemia /Low hemoglobin (Hb) | Abdominal pain | Weakness |
| Shortness of breath | Bruising/bleeding easily | Dark-colored urine |
| Other symptoms: | Brain fog | Headaches |



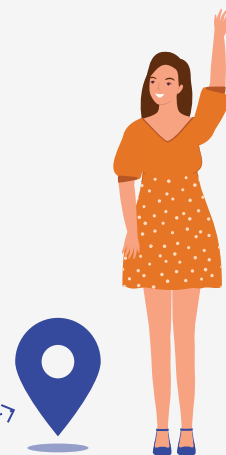
Remember, any symptoms, mild or severe, may be a sign that your PNH isn't well controlled. It's important to let your doctor know how you're feeling, so you can get the support you need.

THINKING ABOUT MY FUTURE

WHERE I WANT TO BE

Sometimes, it also helps to take a step back and look at the bigger picture. What would you be doing if your PNH was better controlled?

Jot down a few thoughts below, so you and your health care team can work together on a path forward.



When it comes to PNH, I really want to:

Raise my Hb level

Reduce my need for red blood cell transfusions

Other: _____

Find more relief from fatigue

Understand my hemoglobin levels: Hb levels of **at least 12 g/dL for women and 13 g/dL for men** are considered normal. Hb levels that are steady but below 12 or 13 might result in symptoms like fatigue and shortness of breath. Low Hb levels could mean your PNH is not well controlled.

My most recent Hb level: _____ g/dL

I want it to

Improve

Be normal

Stay steady

Other PNH goals:

So that I may:

Use the spaces below to write down what you might do or how you think you'd feel if your PNH was better controlled. Some examples might be: "Travel more with my family." "Schedule more date nights." "Feel more like myself."



Keep up the good work! Planning for appointments can lead to more productive conversations with your doctor. It may help to set a reminder to fill out this appointment guide a day or two before each office visit. Print or save a new copy of this guide to prepare for each appointment. Then, look back at them to track changes to your PNH over time.