

PNH and you

A personal guide for making
the most of your doctor appointments



Walk in prepared. Walk out empowered.

Living your best life with PNH is possible, and it starts with you. Partner with your doctor by talking about your symptoms, challenges, and concerns with PNH. By reflecting on the bigger picture of your disease, you and your doctor can make informed decisions together.

Use this guide to help you prepare for your doctor’s appointments.

Before your appointment



Bring a loved one with you

Whether its a friend or family memeber, the prescence of a caregiver can be a source of strength during your appointments. They can also help you take notes and ask important questions



Talk openly

Having an honest conversation can help your doctor better understand what you’re experiencing. Don’t be afraid to ask questions or seek more information if you need it.



Share the details

Provide details on the challenges that you experience, what your day-to-day life looks like, and what you want to achieve with treatment.



Know what’s next

At the end of your appointment, make sure you understand what the next steps are so that you can plan ahead.

Guideposts: Talking about your PNH

Your symptoms

- What symptoms have you experienced over the past week? How frequently did they occur?
- How have your symptoms changed from when you were intially diagnosed?
- Which symptoms concern you the most and why?

Everyday impact of PNH

- What symptoms have affected your daily life the most? What was the impact?
- What adjustments have you made to your daily routine, if any?

Treatment

- Are you satisified with your current treatment? Identify what has been working and what hasnt.
- Were you able to reach your treatment goals?
- If you have any new treatment goals, what are they?

Use the next section to record your thoughts, feelings, and symptoms so that you can easily talk about them in your next appointment!

Preparing for appointment

Use this space to reflect on your thoughts, feelings, and any questions you may have for your doctor.

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Symptom diary

Date: _____

Symptoms	How would you rate your symptoms? (0=none; 1=Little; 5=severe)	How frequently does this happen? (E.g. 2-3 times a week)
Tiredness (fatigue)	0 1 2 3 4 5	
Shortness of breath	0 1 2 3 4 5	
Headache	0 1 2 3 4 5	
Difficulty exercising	0 1 2 3 4 5	
Loss of appetite	0 1 2 3 4 5	
Trouble swallowing	0 1 2 3 4 5	
Abdominal or chest pain	0 1 2 3 4 5	
Dark urine (hemoglobinuria)	0 1 2 3 4 5	
Other (please specify):	0 1 2 3 4 5	

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Notes

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When is your next appointment?

Date	Time	Clinic/hospital	Notes