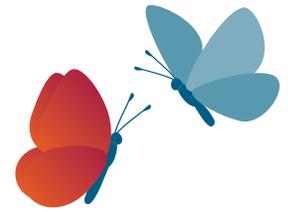


Asking for what you need from your healthcare team

This document was developed in partnership with the PNH community and Leslie Thorpe, a professional health and wellness coach.



Taking an active role

One of the most important parts of your PNH journey, whether you've just been diagnosed or have been living with PNH for decades, is taking an active role with your doctor. While doctors can assist you with their medical expertise, they rely on you to share how PNH is impacting your life.

An active role can mean many things: preparing for doctor's appointments, proactively planning ahead, or even expressing what you might want to change in your life.

By working with your doctor to create an action plan, you are taking an important step in speaking up for the life you want.

Five steps to being your own best advocate

1

Identify your "wish list"

Go to [PNHwellness.com](https://www.pnhwellness.com) for a tool to help explore how PNH affects your overall wellness: it helps you identify what's most important to you, how your symptoms might be impacting those areas of your life and the areas of focus for change.

Print out your results for a customized discussion guide you can use at your next doctor's appointment.

2

Make an appointment

Call your doctor's office to make an appointment to discuss your results and the elements you'd like to discuss changing. Be sure to let the office know the purpose of your visit so your doctor can plan ahead.

- Date _____
- Time _____
- Location _____

3

Practice what you want to say

It can feel daunting to ask an expert like your doctor for what you need. Practicing with a friend, family member or even a mirror can be helpful. Think about the top 3 things you'd like to convey and your specific "asks," then role play that conversation in advance.

- _____
- _____
- _____

4

Develop a joint action plan

At your appointment, talk with your doctor about how to make progress with your priorities by developing an action plan with joint responsibilities and next steps.

Examples of doctor responsibilities: medical test(s), treatment recommendations, specialist referrals, follow-up appointments. Examples of my responsibilities: lifestyle changes, making doctor's appointments, talking to family/friends for support

- Write down your action plan here: _____

5

Follow up

Ask your healthcare team about any remaining questions or concerns you have, and plan to provide progress updates on how the action plan is working for you.

- My remaining questions/concerns: _____

- My progress: _____

REMEMBER!

You are the expert on your life, and your doctors use their medical expertise to support you. By working together, you can better navigate the impacts of PNH and take steps toward the life you deserve.



Leslie Thorpe was compensated by Apellis for the time required to develop this worksheet. PNHwellness.com is a site developed and operated by Apellis.