

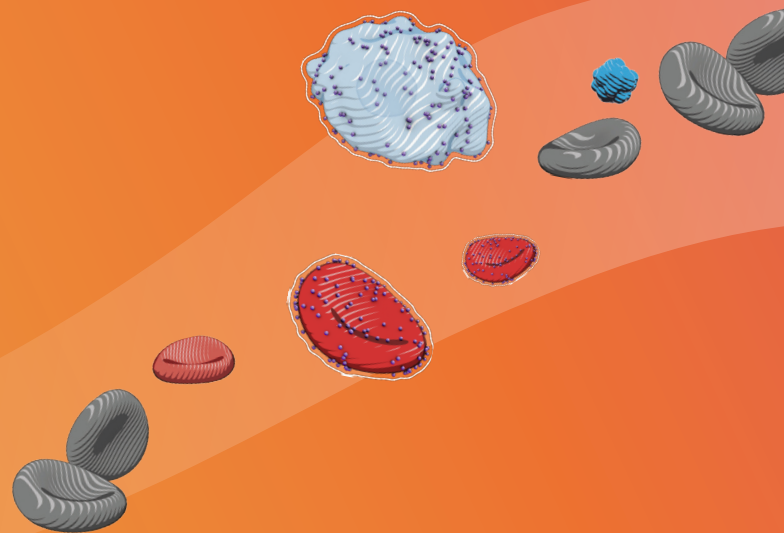


## Talking With Your Healthcare Provider

Collaborative, two-way conversations with your healthcare provider are vital to both understanding and managing your paroxysmal nocturnal hemoglobinuria (PNH). This discussion guide is designed to help encourage informative interactions with your healthcare team.

This guide will provide:

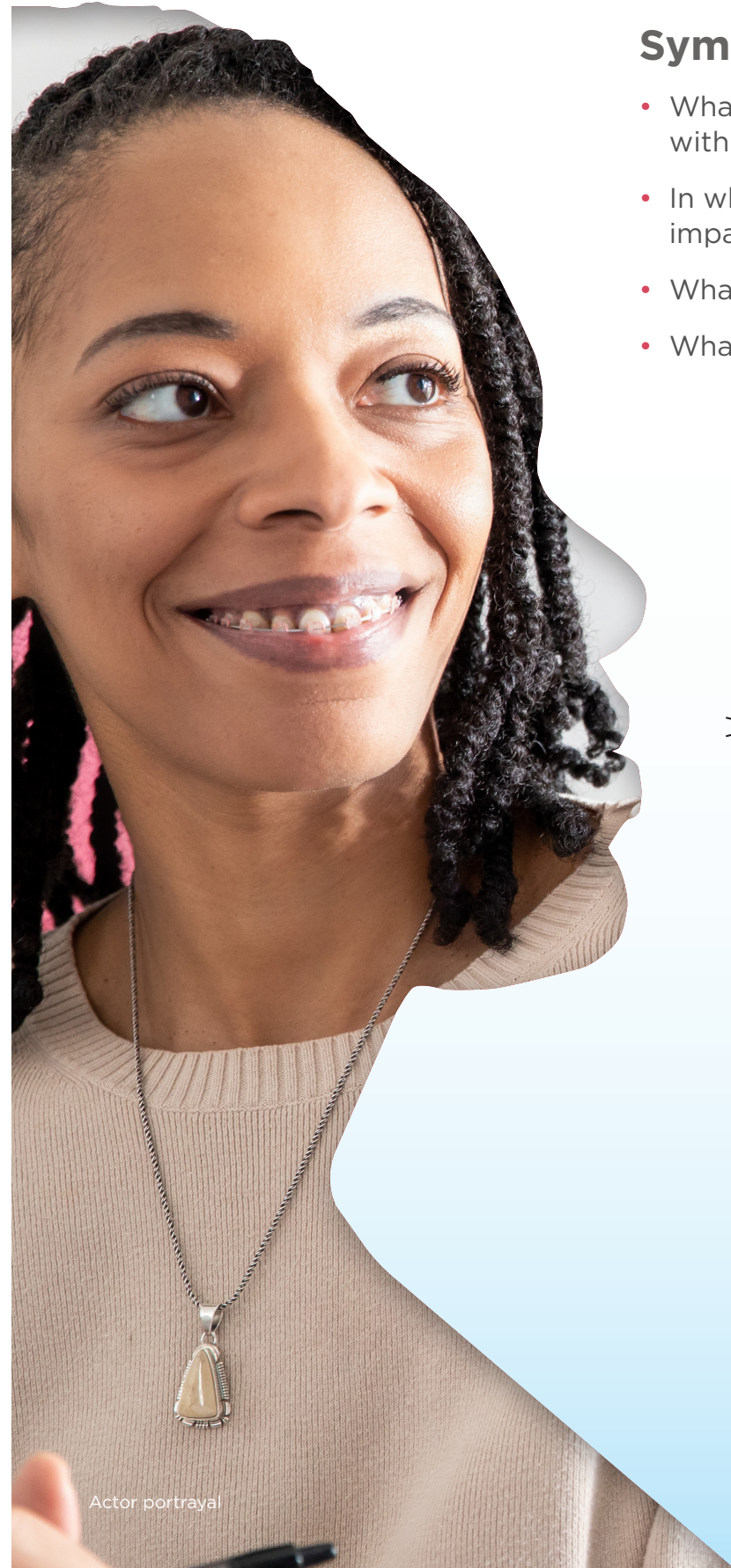
- Suggestions for questions you might want to ask your healthcare team
- General strategies for getting the most out of visits to your healthcare provider



Your healthcare team is a partner in your care. Remember that you should strive to make disease management decisions together. You are your number one advocate, and it's up to you to speak up if you disagree with the course of action or want more information before making a decision.



## Understanding what can happen with PNH



### Symptoms of PNH

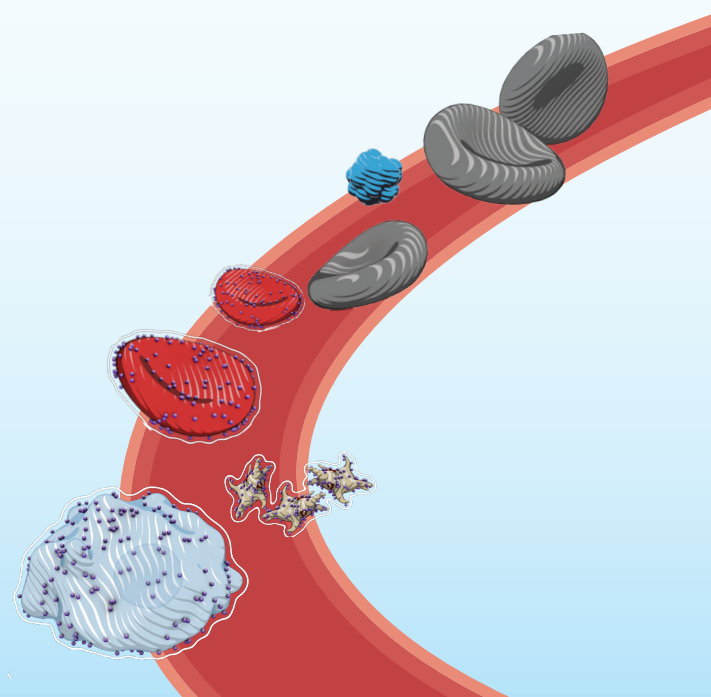
- What symptoms might I experience with PNH?
- In what ways could these symptoms have an impact on my life?
- What can I do to manage the symptoms of PNH?
- What should I do if my symptoms worsen?

### About Hemolysis

- What is hemolysis?
- What are the signs of hemolysis?
- How do you measure hemolysis?



*Bring a friend or family member with you. They can help you advocate for your health and take notes for you.*



**PNH is characterized by serious health problems such as intravascular hemolysis and thrombotic events. By preparing for your medical visits and asking questions, you are advocating for yourself and doing your best to effectively manage your PNH with your healthcare team.**

## Talking about your PNH management plan

### Managing PNH

- How is PNH managed?
- What options are right for me?
- How will you or I know if my plan needs to be changed?

### Setting Goals

- What are your goals for managing my PNH?
- What does successful management look like?
- Are there additional steps to take if management goals are not reached?

### Monitoring PNH

- How will you measure whether my condition is getting better or worse?
- In what ways will you measure my condition's impact on my quality of life?
- How often will you order lab tests to help track my PNH, especially my lactate dehydrogenase (LDH) levels?



*Working with your healthcare team, you'll learn that living with PNH can be manageable.*

## Staying on track

### Between Office Visits

- How can I measure how I am doing between office visits?
- What are the best ways to inform you about how I am feeling?
- Are there any types of activities that I should avoid?



*See your healthcare provider regularly. If it's been a while, then it's time to make an appointment.*



# Personalized Patient Support From Alexion

This complimentary program offers customized support including disease information, community resources, and ongoing encouragement for patients living with PNH and their caregivers. No matter where you are in your journey, OneSource™ and the OneSource Case Managers can help.



**The OneSource support program is here to help you navigate your insurance coverage, understand your condition, and connect with others in the community. Learn more by calling OneSource at 1-888-765-4747.**

## Making the most of your next appointment



### Preparing for your next appointment

Use this guide to start thinking of questions you want to ask your healthcare provider.

Using a notebook or your phone, start writing your questions. Think about any day-to-day challenges you might be experiencing as well as any long-term concerns. Also, be prepared to update your doctor on any recent tests or lab work.



### At your appointment

Bring your list of questions with you and, if possible, invite a friend or family member who can listen closely, support you, and take notes.

Go through your questions one at a time early in the visit rather than waiting until the end to bring them up. During the conversation, be an active listener and ask follow-up questions. If you don't understand an answer, ask your healthcare provider to explain further.



### Don't hold back

This is your health and the right time to be completely honest with your healthcare provider. Take the time you need to feel satisfied with the conversation.

If you are still feeling like you don't have enough time with your healthcare provider, ask to schedule your next appointment for a longer duration.



**Find additional information and resources at [PNHSource.com](https://pnhsources.com)**

**PNHSource™**