



# Top tips when preparing for your appointment

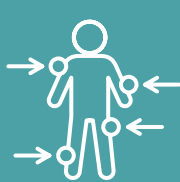
## Sharing your personal PNH experience

No one experiences PNH as you do. Everyone with PNH is unique, it is important to speak openly so that your healthcare team can provide the best support for you.

Sharing certain aspects of your PNH may feel daunting or uncomfortable as your experience is very personal. **Your physician can help you manage your PNH symptoms. Anything you discuss will be kept private.**

### Ask yourself

Before your next appointment, it can be helpful to make a self-assessment on your current situation with PNH, your needs and aspirations for the future.



#### Symptoms and treatment

- What are the most common symptoms I am experiencing and how regularly over the last month?
- Have my PNH symptoms interfered with my work, studies and everyday life?
- Am I happy with my current treatment?
  - If not, am I aware of other treatment options?
- Do I feel supported enough by my healthcare team?



#### Everyday life

- How does PNH impact my daily activities?
- How does PNH affect me emotionally?
- Do I have any worries linked to PNH?
- What does my PNH currently stop me from doing?
- What would I like to achieve in my everyday life and in the long run?



#### Support network

- Does PNH affect my relationships with my family, friends and colleagues?
- Do I feel adequately supported by them?
- Do I talk to other people with PNH?
- Am I aware of any PNH patient organisations?
- Would I like to connect with people that share similar experiences?

### Prepare well

You can also take notes between appointments to monitor:



- Prioritise questions you may want to ask your healthcare team
- PNH symptoms you are currently experiencing – for support with this, you can refer to the **my-PNH Symptom Tracker** which can help monitor your specific symptoms over time
- Any changes you notice in your physical and/or emotional wellbeing
- Sleeping schedule
- Level of tiredness
- Changes in medications (including over-the-counter medicines and supplements)
- Disturbances caused by your PNH symptoms, such as days missed from work or school

### Follow-up

Your appointment doesn't have to end once you walk out the door. If you have further questions, a member of your healthcare team is usually available for support after your appointment.

Always speak to your physician before making any changes to your treatment plan.



### Keep going



Continue monitoring and tracking how your PNH symptoms affect your everyday life



Continue learning more about PNH and trying different strategies to improve your wellbeing, if needed



Communicate your specific needs to your support network and be open about your experience



Reach out to local patient organisations and other people that may share similar experiences

Everyone experiences PNH differently. For your healthcare team to understand your needs, it is important to highlight what matters most to you during those conversations.

**Sobi is striving to help patients manage their disease and overall, improve their quality of life. For more information, visit [my-pnh.com](https://my-pnh.com).**