

Your PNH wellbeing guide

When you have PNH, you are probably facing a significant amount of stress and burdens. This makes it really important to take time to focus on your physical and mental wellbeing. This guide is designed to give you useful hints and tips for ways to manage your wellbeing when living with PNH.

Dealing with feelings during your diagnosis¹

Accept the ups and downs

It's normal to experience a variety of emotions, especially early in your diagnosis. Be kind to yourself and know that extreme mood swings are likely to calm down over time.



Educate yourself

People diagnosed with PNH may experience anxiety about what lies ahead. It can help to learn about the illness, ensuring that you use reliable information resources. Don't hesitate to talk to your healthcare team.



Set daily goals

Small accomplishments can help to improve your mindset. Completing simple everyday tasks can deliver an uplifting sense of achievement.



Find support

Being diagnosed with PNH may feel overwhelming and isolating. It can be helpful to communicate with others via support groups and patient organisations.



Living with PNH²

PNH affects people in different ways, and it's difficult to know how the disease might progress. Here are some tips to help you cope with the more challenging times:



Think about what you can manage each day. Prioritise the necessary tasks and save energy for the things you care about most.



You may experience complications due to your PNH. If so, tell your healthcare team as soon as possible.



If you're struggling to sleep at night, avoid consuming caffeine and alcohol before bed. Some people find that reading, listening to music or relaxation through meditation can help with falling asleep.



Eating a healthy, balanced diet is important for people with PNH. Aim to have the right nutrients, avoid unnecessary sugars and drink plenty of water.

It's helpful to keep a diary to document how you're feeling, including your symptoms and daily activities to discuss with your healthcare team.

Supporting your physical wellbeing

Stay physically healthy²

- It is important to stay active for your physical health and mental well-being.
- Remember that physical activity can include housework, gardening and walking as well as more intensive activities, such as running or cycling.
- Your healthcare team will be able to offer guidance on exercises and activities appropriate for you.



Supporting your mental wellbeing

Stay mentally healthy^{1,2}

- You might feel a sense of longing or nostalgia for the future you had envisioned. Know that it's okay to feel this way. Talk to your doctor; they may have information and resources to help.
- Find ways to release stress, to help your mind and body. This could be through exercising, spending time in nature or enjoying a hobby.
- Many people with PNH feel they are unable to cope with daily activities. It's important to ask for help and support from friends and family.
- Consider seeking professional psychological support early.



If you have any questions about your physical or mental wellbeing, please speak to a member of your healthcare team

PNH, Paroxysmal Nocturnal Haemoglobinuria.

References

1. Everyday Health. 7 Ways to Manage the Emotional Aspects of Paroxysmal Nocturnal Hemoglobinuria. Available at: <https://www.everydayhealth.com/paroxysmal-nocturnal-hemoglobinuria/ways-to-manage-the-emotional-aspects/> (Last accessed: November 2023).

2. EMBT. Understanding PNH. Available at: https://www.ebmt.org/sites/default/files/migration_legacy_files/document/EBMT_Practical%20Guides%20for%20Patients_Paroxysmal%20Nocturnal%20Haemaglobinuria%20%28PNH%29_UK.pdf (Last accessed: November 2023).