

Goal Setting Planner

This planner is designed to help you set meaningful goals to support you to stay on track with your treatment with FABHALTA®.

Get the support you need with



replenishEd
pnh education & support

As a patient starting treatment with Fabhalta® (iptacopan) you are invited to enrol in the **replenishEd patient support program**.

By joining **replenishEd** you will have the option to receive:

-  Educational emails on managing PNH with oral therapy
-  Monthly phone calls with a haematology nurse
-  SMS reminders about medication



Please scan the QR code to enrol in the replenishEd patient support program, or go to:
www.replenished-pnh.com.au

Trouble signing up? Call 1800 290 652
or email support@replenished-pnh.com.au

▼ There is additional monitoring in place for FABHALTA® (iptacopan) to help quickly identify new side effects. If you experience any side effects, talk to your doctor, nurse or pharmacist/other healthcare professional. This includes any possible side effects not listed in this guide. If you have any questions or concerns about FABHALTA®, speak with a healthcare professional.



Getting started with FABHALTA®

Newly diagnosed with paroxysmal nocturnal haemoglobinuria (PNH)?

If you've just been diagnosed with PNH, you probably want to start feeling better as soon as possible to keep doing the things you love. You may find that starting treatment will help you adapt to your diagnosis.

Switching PNH treatments?

If you've previously been diagnosed with PNH and you're switching from another PNH treatment, there are a few changes you will have to make as part of your treatment journey. If you previously had an infusion therapy given to you by your healthcare team, you may find the switch to an oral therapy can take a little getting used to.

Whether you're newly diagnosed or switching therapy, the most important part of your treatment is adherence – making sure that you take your treatment twice a day as prescribed by your doctor.

Learn more about
your new treatment
in the **Patient
and Caregiver
Treatment Guide**

Setting your goals

Why are goals important?

Goals can provide a roadmap to achieve the things you care about. You can set short-term goals (30–90 days) and you can also set long-term goals (90 days and beyond). You will begin to see how your short-term goals can be a stepping stone to achieving your long-term goals.

Short-term goals

Setting short-term goals can help focus and empower you to manage your PNH and life in a positive way. One helpful and memorable way to set them is by using the letters **S-M-A-R-T**. See how the **S-M-A-R-T** example on the right can help you think through your short-term goals.

Long-term goals

Long-term goals are achievements you want to accomplish in the future. Setting long-term goals can help to provide motivation and direction for your personal growth and self-improvement. The short-term goals you create will provide a foundation for your long-term success.

Long-term goals can feel overwhelming but using the **S-M-A-R-T** system can provide a clear target to aim for, so you know exactly when and how you will achieve your goal.

Tip!
Share your goals with a friend or loved one to help keep you committed to your goal



Specific – what specifically will you do?

I will take my new treatment two times a day, in the morning with my breakfast and before brushing my teeth at night.



Measurable – how will you measure your action?

I will record taking my medicine in a note on my phone.



Achievable – is it doable and realistic?

Yes! Taking my medicine alongside routine daily activities will help me to stick to my treatment schedule.



Relevant – why is it meaningful now?

Taking my treatment every day will help to control my PNH symptoms.



Time bound – when will you complete it?

1. I will check the time I take my medication in 5 days
(Do I need to adjust the time?)
2. I will check my records on my phone in 2 weeks
(Should I take any new measures?)
3. I will check the full process in 4 weeks
(Do I feel comfortable with my new treatment?)

See a few examples of short-term and long-term goals on the next page, including both treatment-related and life-related goals.

Short-term goals

My short-term goal:

I will take my new treatment every day at 8 am with my breakfast and before brushing my teeth at night.

Action steps:

- 1. Set daily morning and evening reminders on my phone.*
- 2. Put the medicine next to the kettle in the kitchen.*

How I will track my progress:

I'll record taking my medicine in a note or app on my phone.

My short-term goal:

I will spend more time with loved ones.

Action steps:

I will contact a friend or family member to meet up once a week, even if it's only for a short time.

How I will track my progress:

Add a 'social calendar' into my normal calendar to help track my weekly meet-ups.

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Long-term goals

My long-term goal:

I will take up my evening yoga class again at my local gym at least once a week.

Action steps:

I will continue taking my treatment as prescribed, so I don't feel as tired in the evenings.

How I will track my progress:

Keep a note of how many classes I attend.

My long-term goal:

I will find a PNH support group to get involved with and attend a face-to-face meeting over the next 6 months.

Action steps:

- 1. I will search online for local PNH support groups and start to make a list of potential groups to attend.*
- 2. I will ask my healthcare team if they can recommend PNH support groups at my next appointment.*

How I will track my progress:

I will set a reminder to come back to my list every 60 days to check how many PNH support groups I have contacted.

Now it's your turn!

Use the previous examples to help guide you to fill in your own **short-term goals**, actions, and steps to track your progress with your FABHALTA® treatment. Use the stickers in your starter kit to visualise your progress over time.



My short-term goal:

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Action steps:

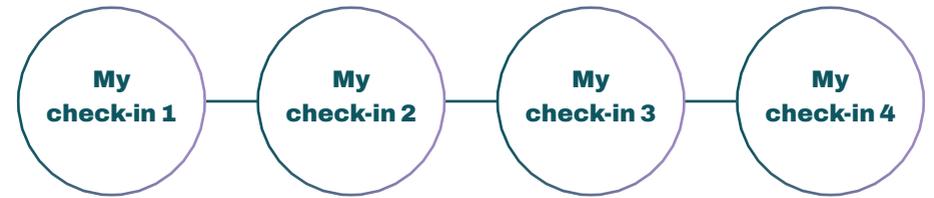
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How I will track my progress:

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Add stickers here to visualise your progress over time



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You can choose the time points for your check-ins. Weekly check-ins can help you keep on top of your short-term goals. Use the space below the circles to note the timing for your check-in, or you can use the timing stickers provided.

It's essential that you take your treatment daily to manage your PNH symptoms and minimise potential side effects.

Please refer to the Patient and Caregiver Treatment Guide for what to do if you miss a dose.



Now it's your turn!

Use the previous examples to help guide you to fill in your own **long-term goals**, actions, and steps to track your progress with your FABHALTA® treatment. Use the stickers in your starter kit to visualise your progress over time.



My long-term goal:

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Action steps:

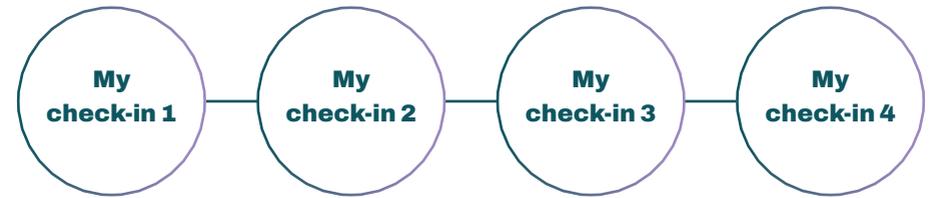
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How I will track my progress:

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Add stickers here to visualise your progress over time



You can choose the time points for your check-ins. Monthly check-ins can help you keep on top of your long-term goals to start with. You may be able to extend the time between check-ins as you get used to your new routine. Use the space below the circles to note the timing for your check-in, or you can use the timing stickers provided.

It's essential that you take your treatment daily to manage your PNH symptoms and minimise potential side effects.

Please refer to the Patient and Caregiver Treatment Guide for what to do if you miss a dose.



Helping you stay committed to your treatment

Did you know that it takes on average 2 months to set a new routine into your life?

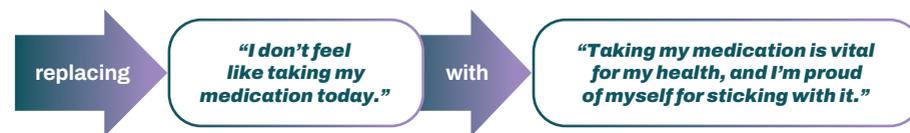
PNH is a lifelong condition, so your care is lifelong too. It's perfectly normal that at times you may find staying motivated and committed to your treatment challenging. Here are some suggestions to help you stay on the right track:

Maintain a positive mindset

Research suggests that having a positive outlook can benefit your physical health.

- Identify and challenge any negative thoughts that may discourage you from sticking to your treatment schedule
- Replace them with positive affirmations emphasizing the significance of your commitment to your new treatment

It can be something as simple as:



Life goals can help us to reframe negative emotions and live the life we truly want to live.

Learn more about the importance of **adherence, as well as what to do if you miss a dose**, in the **Patient and Caregiver Treatment Guide**

Be kind to yourself

Being kind to yourself puts the body in a state of safety and relaxation that is important for regeneration and healing. Research shows that people who are self-compassionate are less likely to be anxious and depressed, leading to greater life satisfaction.



It's natural to be self-critical at times when you might not be as committed to your treatment schedule as you know you should be. Don't judge yourself harshly as imperfection is natural as you start your treatment journey



Understand that there will be days when you don't feel as motivated or committed to your treatment schedule



Come back to your initial reasons for starting on your new treatment and remember the benefits that come from sticking to your treatment schedule



Treating yourself kindly and nurturing positivity can make you less self-indulgent, more accountable and more likely to stick to your new positive mindset and maintain a commitment to your treatment



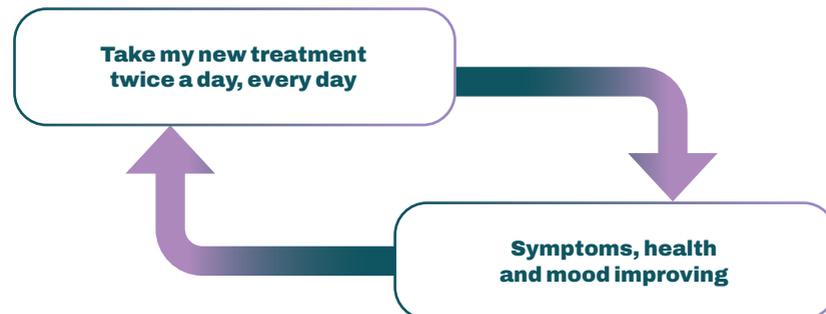
Visualise the positive impact you're making

Visualisation is proven to improve confidence, decrease anxiety, boost motivation, and help adopt healthier habits.

Here are some examples of how taking your treatment consistently can have a positive impact on your day-to-day life:

- Better management of PNH symptoms, such as haemolysis and fatigue
- General improvement in your overall quality of life
- Provides an opportunity to get back to “normal”, doing the things you love and enjoy
- Creates a feeling of empowerment as you take charge of your disease

Use this positive imagery to help you stick to your treatment schedule:



Strengthen your commitment to your treatment

Positive affirmations are proven to reduce stress, enhance wellness, and can aid in committing to new treatments. Tell yourself things like:

"I've successfully taken my medication every day this week."

"I'm effectively maintaining my treatment schedule."

Build a support system

Having a strong support system is crucial. Whether it is a friend, family member or healthcare provider, having someone to help you stay on track with your treatment is key.

Connecting with fellow PNH patients can be reassuring and reduce feelings of isolation, especially if you feel misunderstood.

Treatment goals and life goals can work hand-in-hand to help you achieve what matters most to you.

Please refer to the **Patient and Caregiver Treatment Guide** for more details on how to find PNH support groups

Common terms to know

Fatigue

Extreme, persistent exhaustion that does not or hardly improves despite supposedly sufficient rest or sleep.

Haemoglobin

A protein in red blood cells that transports oxygen around the body.

Haemoglobinuria

High amounts of haemoglobin in the urine.

Haemolysis

Destruction of red blood cells.

Paroxysmal nocturnal haemoglobinuria (PNH)

A rare and serious blood disorder in which red blood cells break apart more easily, leading to anaemia and other complications.





This material has been produced by Novartis Pharma AG.
This material is intended only for patients with paroxysmal nocturnal haemoglobinuria (PNH) who have been prescribed FABHALTA®. This is provided for information/educational purposes only and is not intended to replace discussions with your doctor or care team.

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