



This material has been developed and funded by Novartis Pharmaceuticals UK Ltd and is intended only for UK patients with paroxysmal nocturnal haemoglobinuria (PNH) who have been prescribed iptacopan.

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[®]▼ (iptacopan).

This material does not replace the patient information leaflet (PIL) that comes with your medication. You should read the PIL carefully before you start taking this medicine because it contains important information for you.

If you have any questions, ask your doctor or care team.

Connected – Stronger Together is a patient support programme developed and funded by Novartis Pharmaceuticals UK Ltd.

Reporting side-effects

If you get side-effects with any medication you are taking, talk to your doctor, pharmacist or nurse. This includes any possible side effects not listed in the information leaflet that comes in the pack.

▼ The medicine referred to in this material is subject to additional monitoring. This will allow quick identification of new safety information.

You can help by reporting any side-effects you may get. Please see www.mhra.gov.uk/yellowcard for instructions on how to report side effects.



Getting started with iptacopan

Newly diagnosed with paroxysmal nocturnal haemoglobinuria (PNH)?

If you've just been diagnosed with PNH, you probably want to start managing your symptoms 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 meetups.

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 and keep a note of my energy levels.

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 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 iptacopan treatment. Use the stickers in your starter kit to visualise your progress over time.



My short-term goal:

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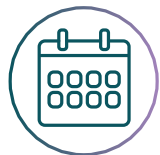
Action steps:

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How I will track my progress:

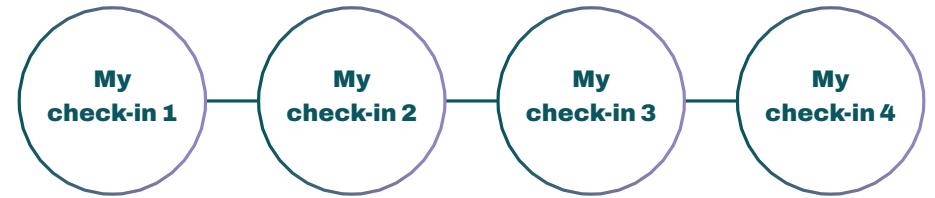
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Add stickers here to visualise your progress over time



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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 twice-daily as prescribed 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 iptacopan 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:

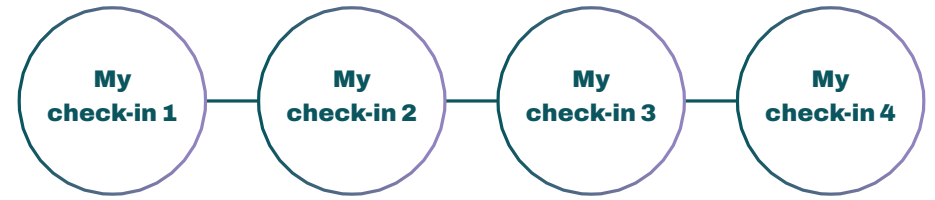
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Add stickers here to visualise your progress over time



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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 twice-daily as prescribed 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 emphasising 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 think more positively

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 treatment and remember the benefits that come from sticking to your treatment schedule



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

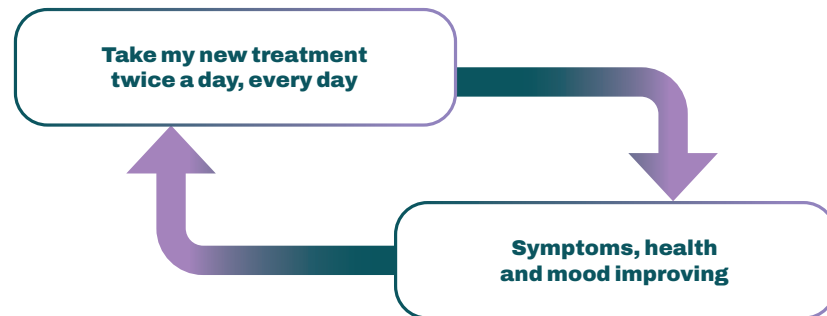
Visualise the positive impact you're making

Visualisation can help improve confidence, decrease anxiety, boost motivation, and help adopt healthier habits.

Here are some examples of how taking your treatment consistently may 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 can help 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

Will I have any side effects from my iptacopan treatment?

As with all medicines, side effects can occur. Although not everyone experiences them, there is a chance that you may experience some unwanted side effects while taking your treatment.

In clinical studies, the most common side effects reported by more than 1 in 10 people taking iptacopan were:

- Infections of the nose and throat (upper respiratory tract infection)
- Headache
- Diarrhoea

The most commonly reported serious side effect is urinary tract infection.

If you experience any symptoms of serious infection you should immediately contact your doctor. Information on the symptoms to look out for can be found in your guide: Patient and caregiver guide to treatment with FABHALTA[®]▼ (iptacopan). Some people taking iptacopan may also experience a decrease in their blood platelet count. This is a common side effect that can occur in up to 1 in 10 people taking iptacopan. This may cause you to bleed or bruise more easily.

Some other common (may affect up to 1 in 10 people) side effects include:

- Persistent cough or irritation of the airways (bronchitis)
- Low levels of platelets
- Dizziness
- Pain in the stomach (abdomen)
- Feeling sick (nausea)
- Joint pain (arthralgia)

Uncommon (may affect up to 1 in 100 people) side effects include:

- Lung infection (which can cause chest pain, cough and fever)
- Itchy rash (urticaria)

What are platelets?

Platelets are small cell fragments found in your blood. They help your blood form clots, which is important to control bleeding. A low platelet count means your body doesn't have enough platelets to form clots. This may cause bleeding or bruising more easily than normal.

What should I do if I get side effects from my iptacopan treatment?

Whilst no one wants to have side effects from their treatment, just remember that it isn't unusual to experience them. What's most important is that you speak to your healthcare team immediately, so that they can advise you on how to proceed. You may also wish to report your side effects to the MHRA Yellow Card scheme at: www.mhra.gov.uk/yellowcard.

Should I stop taking my treatment if I experience side effects?

Stopping your treatment with iptacopan can make your condition worse and may increase your risk of red blood cell breakdown (haemolysis). It is important that you adhere to the scheduled treatment regimen. **Do not stop taking iptacopan without talking to your healthcare team first.**

If your healthcare team decides to stop your treatment, you will be monitored closely for at least 2 weeks for any signs of haemolysis due to PNH. Your healthcare team may prescribe a different PNH medicine or have you restart iptacopan treatment.

If you stop treatment, be aware of signs or symptoms of haemolysis, including:

- Lower level of haemoglobin in your blood
- Tiredness
- Blood in your urine
- Shortness of breath
- Pain in your stomach (abdomen)
- Blood clots (thrombosis)
- Trouble swallowing
- Erectile dysfunction (impotence)

If you experience any of these symptoms or problems after stopping treatment, please contact your healthcare team immediately.

Common terms to know

Anaemia

A low level of healthy red blood cells in the blood.

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

Happens suddenly, occurs over and over again.

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.

Red blood cells

Blood cells that carry oxygen from the lungs to the rest of the body.





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