THALASSEMIA TRACKING JOURNAL

Keeping track of your thalassemia symptoms for conversations with your care team

This journal features real patients who have been compensated for their participation.

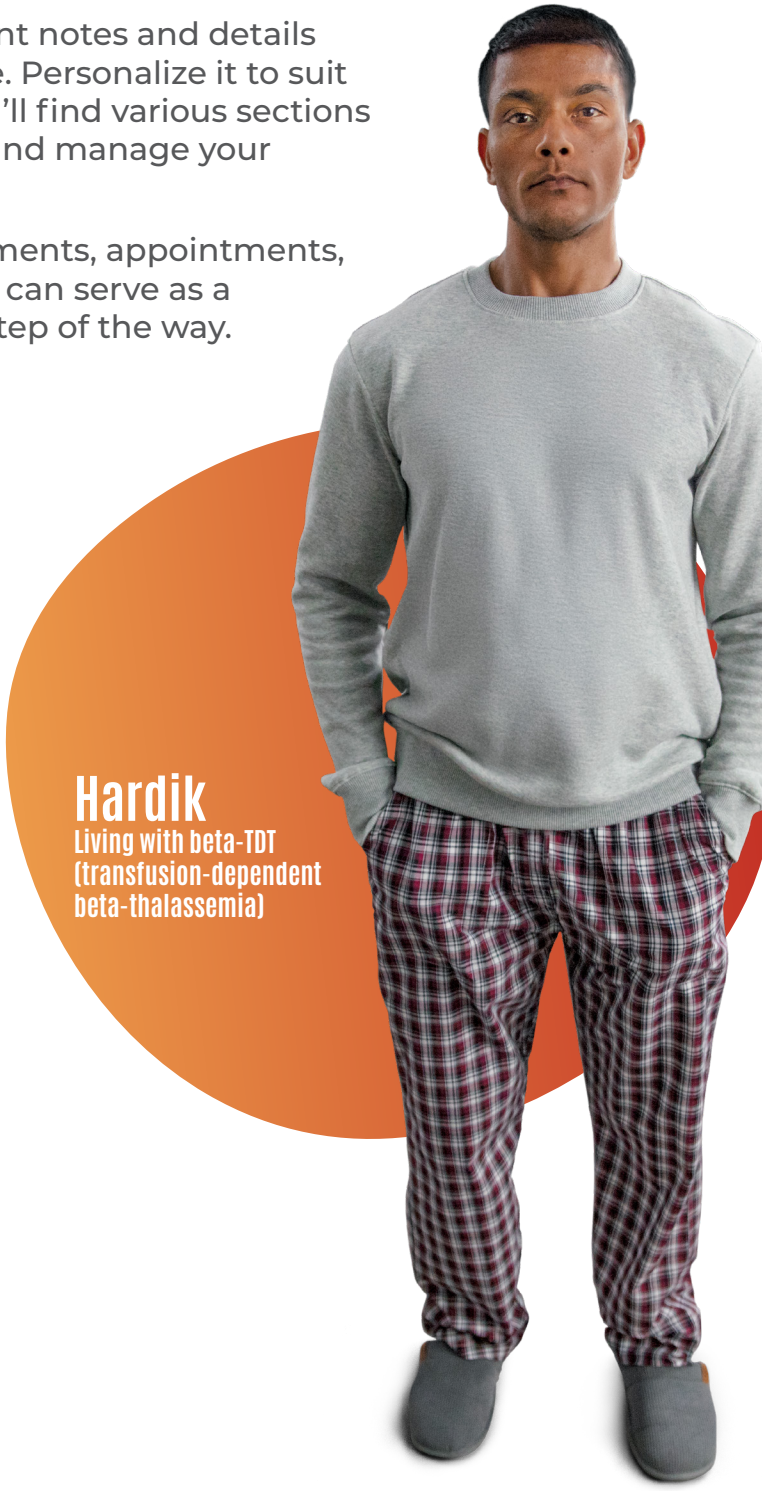
Contents

Welcome to your Thalassemia Tracking Journal

What's the purpose of this journal?

Use this journal to organize and record important notes and details about your thalassemia in one convenient place. Personalize it to suit your specific needs and preferences. Inside, you'll find various sections and topics that are designed to help you track and manage your condition effectively.

Whether you're documenting symptoms, treatments, appointments, or any other important information, this journal can serve as a comprehensive resource to support you every step of the way.



What is thalassemia?

Thalassemia is a group of rare inherited blood conditions. It affects the production of a protein called hemoglobin.

- Hemoglobin is a key part of red blood cells (RBCs). Hemoglobin holds onto oxygen and delivers it to cells throughout the body. Cells use oxygen to function
- In thalassemia, hemoglobin is not made properly. As a result, healthy RBCs cannot be made properly
- Thalassemia results in chronic anemia that can last throughout life

What complications can occur with thalassemia?

Chronic anemia is associated with many complications that can result in end-organ damage and be life-threatening if not properly monitored and managed. These complications include blood clots leading to cardiovascular issues or stroke, brittle bones and increased risk of fractures, iron overload that can damage organs, liver disease, low hormone production, pulmonary hypertension, and production of blood cells outside the bone marrow.

Questions? Thoughts? Write it all here

We encourage you to write down any questions, thoughts, or topics you'd like to discuss with your care team or learn more about, such as the following:

- These are the symptoms I'm experiencing and how often they make me miss out on activities
- These are activities I'm no longer or rarely able to do because of my symptoms
- How often should my hemoglobin and ferritin levels be checked?
- What is the plan for regular screenings and tests?
- Are there specific signs of complications I should be aware of?
- Are there any new treatments or clinical trials available that might be suitable for me?
- What are the possible complications we should be monitoring for?
- How should I manage symptoms or complications between appointments?

Notes:

Symptoms of thalassemia may vary from person to person

Check in with yourself: How are you feeling? What are you experiencing? Mark any of the symptoms below that you're experiencing and make sure to share them with your care team.

Common symptoms include:

- [ ] Fatigue
- [ ] Weakness
- [ ] Shortness of breath
- [ ] Dizziness and fainting
- [ ] Headaches
- [ ] Paleness

Other symptoms may include*:

- [ ] Yellowing of the skin and eyes
- [ ] Pain in the stomach area due to enlargement of the spleen or liver
- [ ] Changes in facial bones
- [ ] Dark urine
- [ ] Poor appetite
- [ ] Difficulty focusing

Use the following pages to record any symptoms you experience and note the date on which they occur. Discuss any changes with your doctor, including potential complications and warning signs to watch for.

*These are not all possible symptoms. It is important to note all changes you experience.

MY THALASSEMIA SYMPTOMS, CONTINUED

Anytime you notice a symptom, write down the date and the symptom you're experiencing. It might be something that affects your:

Physical well-being
Feeling tired or weak

Functional well-being
Not being able to work, exercise, or walk up stairs

Emotional well-being
Feeling depressed or anxious

*Be sure to note the symptom and rate the severity, with **1 being mild** and **5 being most severe**.*

Date:	Symptom / What I'm feeling or experiencing:	Severity:
		1 2 3 4 5
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MY THALASSEMIA SYMPTOMS, CONTINUED

Date:	Symptom / What I'm feeling or experiencing:	Severity:
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MY THALASSEMIA SYMPTOMS, CONTINUED

Date:	Symptom / What I'm feeling or experiencing:	Severity:
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OTHER NOTES ABOUT SYMPTOMS

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Hemoglobin and ferritin testing are important parts of regular monitoring

Hemoglobin levels: Typically tested as part of a complete blood count, known as CBC. Your hemoglobin levels will indicate how well your red blood cells are delivering oxygen.

Ferritin levels: Indicate the amount of iron in your blood. People with higher ferritin levels may have a higher risk of thalassemia complications.

In healthy adults who do not have thalassemia, hemoglobin levels typically range from 14 g/dL to 18 g/dL in men and 12 g/dL to 16 g/dL in women. Ferritin levels typically range from 40 to 300 ng/mL for men and 20 to 200 ng/mL for women.

Date:	Hemoglobin level:	Ferritin level:	How I'm feeling (physical well-being, functional well-being):

Work with your doctor to develop a monitoring plan that's right for you

What exactly should you be monitoring?

Early and regular monitoring is critical for all types of thalassemia. Experts recommend regular monitoring for complications in everyone with thalassemia, whether they receive transfusions regularly (transfusion-dependent thalassemia, or TDT), or occasionally / not at all (non–transfusion-dependent thalassemia, or NTDT).

Knowing which tests are needed can help you and your doctor prevent or manage complications. It's important to work with your care team to build a personalized monitoring plan based on your thalassemia type and transfusion experience.

Some things you should be tracking regularly over time:

- Lab tests—complete blood count (hemoglobin levels), serum ferritin levels (iron in your blood), liver and kidney function
- Blood cells formed outside of the bone marrow
- Heart function
- Bone health

This tracking journal can be used alongside the monitoring plan you create with your care team.

More information for monitoring thalassemia

Explore monitoring resources detailing recommended tests and their frequency for individuals aged 18 and over with NTDT or TDT, whether alpha- or beta-thalassemia. This information can support discussions with your doctor about thalassemia monitoring.

Jesse
Living with alpha-TDT (transfusion-dependent alpha-thalassemia)

Download the NTDT Monitoring Guide*

Get TDT Monitoring Information

*The monitoring guide is based on Thalassaemia International Federation (TIF) guidelines and input from thalassemia experts (who were compensated for their time).

Thalassemia monitoring: Key questions

As you work with your care team to build a personalized monitoring plan based on your thalassemia type and transfusion experience, use this page to write down learnings, questions, or thoughts.

Questions you may want to ask:

- What tests or scans do I need at my next visit?
- What other doctors should I add to my care team?
- What are some signs of complications that I can watch for?

Notes:

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You're one of a kind.
The support you get should be, too.

Clinical Nurse Educators (CNEs) offer a wide range of services, including:

- **Thalassemia education**
- **Individualized support**
- **Community connections**

For thalassemia educational support and resources, including opportunities to attend programs about important thalassemia topics, **scan the QR code to go to RethinkThalassemia.com**. Resources are available in multiple languages.

You can also contact a myAgios® Clinical Nurse Educator at **1-877-77-AGIOS (1-877-772-4467)**. Support is available in your preferred language via live interpreters.

CNEs are employees of Agios Pharmaceuticals and do not provide medical advice. For medical advice or treatment-related questions, please talk to your healthcare team.

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