

A photograph of a doctor in a white lab coat and glasses looking at a patient in a blue shirt. The doctor is on the left, and the patient is on the right. The background is a blurred clinical setting.

You've Got Thalassemia ...Now What?

A pocket guide
just for you

So, you've just been told you have something called **Thalassemia**. That's a lot to take in. You might be feeling scared, confused, or just trying to wrap your head around what this diagnosis means for you.

First of all: you are not alone. This guide is here to help you make sense of what's happening — in plain, simple language.

What is Thalassemia?

Thalassemia is a blood disorder that you are born with. It happens when your body has trouble making one of the building blocks of hemoglobin — the protein in red blood cells that carries oxygen. This can lead to anemia (low blood count), which may cause **tiredness, weakness, or pale skin.**

Types of Thalassemia

- **Thalassemia trait/minor:** Mild form. Most people don't feel sick, but blood tests may show small red cells or mild anemia.
- **Thalassemia intermedia:** Moderate anemia. May cause symptoms and sometimes need medical care or occasional transfusions.
- **Thalassemia major (Cooley's anemia):** Severe form. Usually shows up in childhood and often needs regular blood transfusions and medicines.



Common Symptoms

- Feeling tired or weak
- Pale skin
- Slow growth or delayed puberty (in children with more severe disease)
- Enlarged spleen or bones (in more advanced forms)

How is it Diagnosed?

- **Blood tests (CBC)** to check size and number of red blood cells
- **Hemoglobin analysis** to see which types of hemoglobin are present
- **Genetic testing** to confirm the diagnosis and type

Treatment Options

- **Mild cases (trait):** usually need no treatment, just awareness
- **Moderate to severe cases:** may need
 - ▶ Regular blood transfusions
 - ▶ Medicines to remove extra iron from the body (iron chelation)
 - ▶ Folic acid supplements
 - ▶ Sometimes, surgery to remove the spleen
 - ▶ Bone marrow or stem cell transplant (curative in some patients)

Self-Care Guidelines

- Do not take extra iron unless advised by the doctor—many foods and supplements can contain added iron that may be harmful.
- Eat a healthy diet, stay well-nourished, and get enough calcium and vitamin D for bone health.
- Stay up to date with vaccines and avoid close contact with people who are sick to lower risk of infection, especially if the spleen has been removed.
- Regular exercise is encouraged, but ask your care team about what is suitable.



School, Work, and Travel

- With proper treatment, children and adults with thalassemia usually perform well in school and work.
- Bring up thalassemia with teachers and employers only if adjustments are needed.
- Plan ahead for travel, ensuring access to transfusions and medical care; carry medical information and necessary medications, especially after splenectomy.



Support & Long-Term Outlook

- Good medical care—including regular checkups, tests, and emotional support—helps people with thalassemia live longer and healthier lives.
- Support groups and foundations (such as the Cooley's Anemia Foundation) can offer guidance, educational resources, and assistance for patients and families.



Important Tips

- Follow treatment plans closely—adhering to transfusion and chelation schedules is vital for health and survival.
- Don't hesitate to ask your healthcare team about new treatments or if there are clinical trials available.
- Emotional support from friends, family, or networks is important for well-being.
- If thalassemia runs in your family, genetic counseling can help if you are planning children.



For more in-depth information or personal support, reach out to your healthcare provider, thalassemia centers, or patient organizations such as the Cooley's Anemia Foundation.