Information + Taking Control = Best Outcome

Hematology

Fast Facts Information Sheets for Patients

Beta Thalassemia

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HEALTHCARE

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Understanding Beta Thalassemia

You or a family member have been diagnosed with beta thalassemia (BT). This leaflet will give you some basic information about the condition and help answer some of your questions.

What is BT?

BT is a blood disorder that causes your body to make less hemoglobin. Hemoglobin is a protein in your red blood cells which transports oxygen from your lungs to the rest of your body.

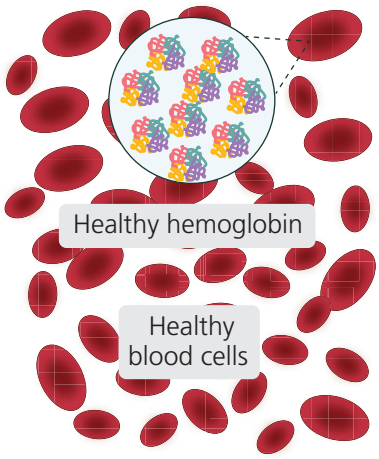
When your body makes less hemoglobin it leads to anemia. The organs in your body do not get enough oxygen and cannot work properly when you have anemia. This can cause serious health problems.

How is BT diagnosed?

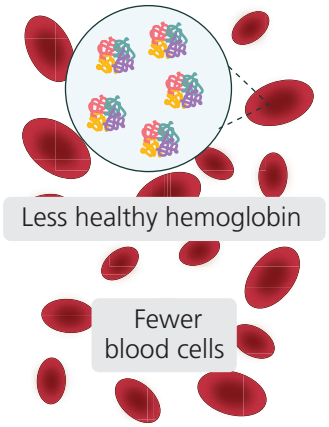
Your doctor will take a blood sample for analysis. Tests to diagnose the condition may include:

- Complete blood count (CBC)
- Iron level test (usually by testing your level of ferritin)
- Hemoglobin analysis by high-performance liquid chromatography (HPLC), or sometimes electrophoresis
- Genetic testing.

Your doctor will also examine you and ask about your health and your family's health.



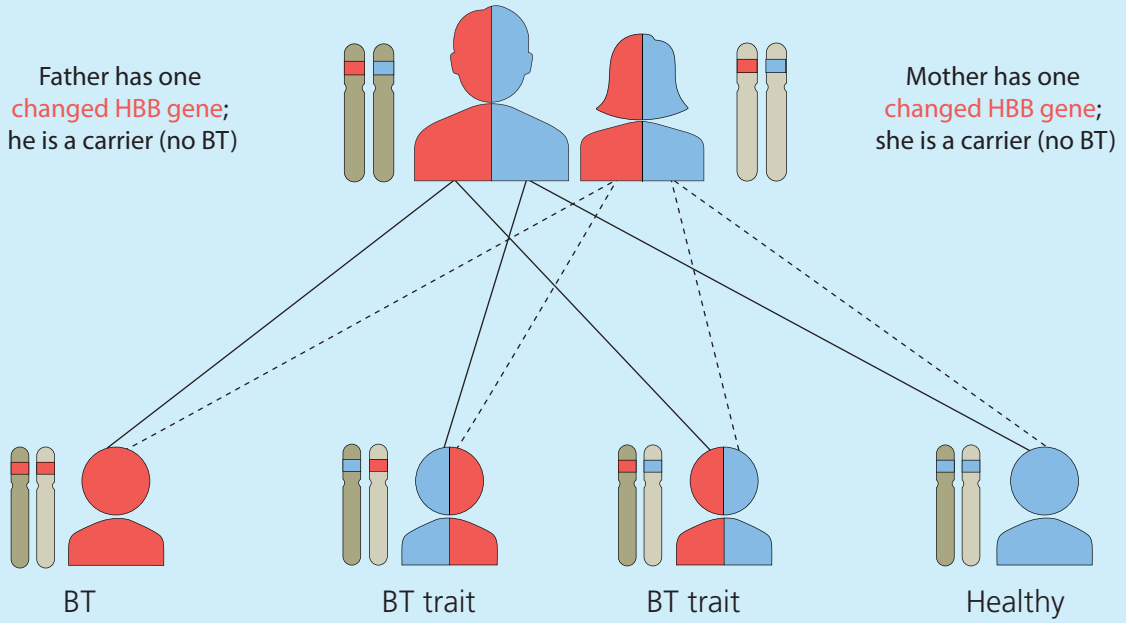
Healthy blood



Anemic blood

What causes BT?

BT is a genetic condition, which means it passes from one generation to the next. If you have the condition, you have inherited a changed (mutated) gene from both of your parents. They are both healthy **carriers** of a mutated *HBB* gene. This is also called **BT trait** or **BT minor**. Carriers have one mutated *HBB* gene and one healthy *HBB* gene and do not have BT. However, they can pass on the mutated gene to their children. The only way to know if a person is a carrier is to get tested.



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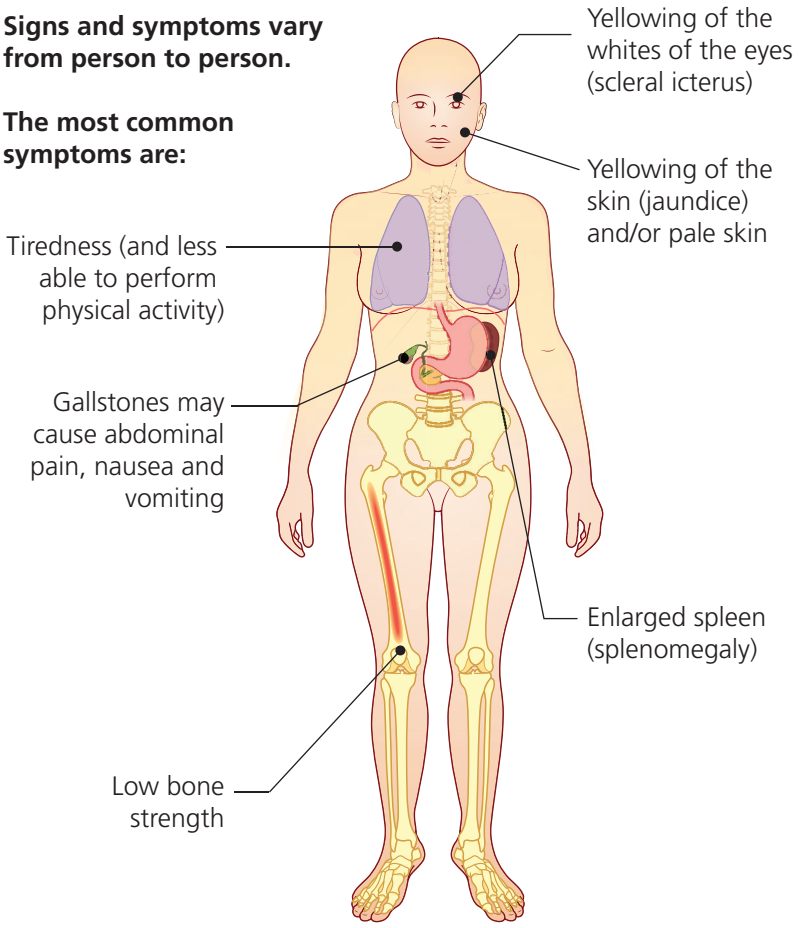
How will beta thalassemia affect me and what treatment will I need?

Signs and symptoms vary from person to person.

The most common symptoms are:



Are there different kinds of BT?

BT major is a more severe type of thalassemia. It is usually found in early childhood.

BT intermedia has less severe symptoms. They can appear later in childhood or when you are an adult.

BT trait usually causes no symptoms but some people may have mild anemia.

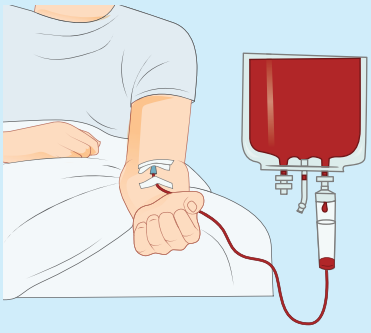
What is the treatment?

BT major patients need **blood transfusions** every few weeks.

BT intermedia patients usually do not need transfusions but they may occasionally need them during periods of stress or infections or in pregnancy. Some people may need more regular transfusions as they get older. People with BT trait generally do not need any treatment.

What is a blood transfusion?

A blood transfusion gives your body more red blood cells to carry oxygen. You receive blood through a small plastic tube inserted into one of the blood vessels in your arm. The procedure usually happens in a hospital or a special clinic for blood diseases. Babies, children and adults can have transfusions. The procedure will take a few hours each time.



What happens? Before your transfusion, the medical staff will match your blood type with the transfusion blood. The staff will always check on you during the procedure and measure your heart rate and blood pressure.

Are there any complications?

Iron overload is a common complication. Iron overload means the body has too much iron. This can happen because of the BT but it also happens during transfusion because donor red blood cells contain iron.

Too much iron is harmful for us. Treatment is available to remove it from your body. This is usually done with medications that you swallow or by a nightly infusion using a small electronic pump.

Your doctor will continually check for iron overload with blood tests or sometimes with a scan called an MRI.

It is very important to take your medication for iron overload

Your doctor will regularly check for other health complications and sometimes it is necessary to have an operation to remove your spleen and/or your gallbladder. If this is necessary, your doctor will explain why and give you information.

For more information about BT

- ukts.org
- thalassemiapatientsandfriends.com/
- thalassemia.org
- thalassaemia.org.cy

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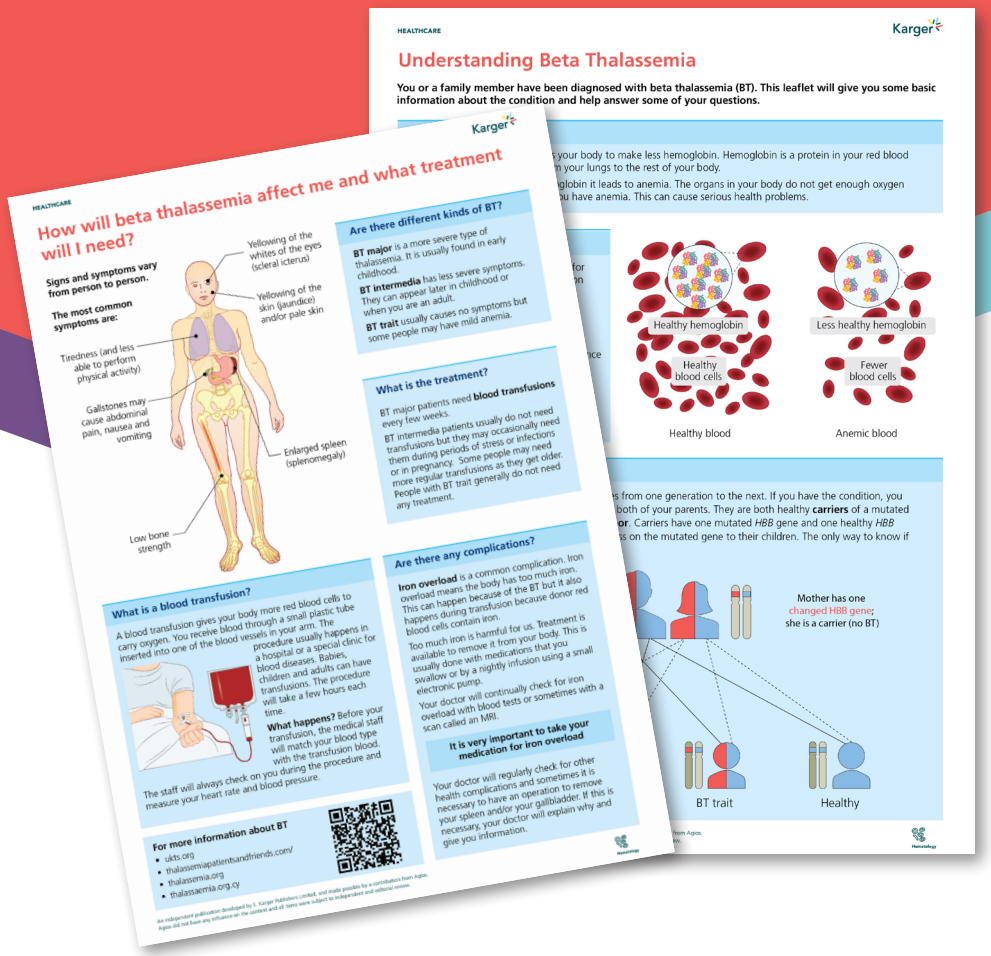

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