Information + Taking Control = Best Outcome

Hematology

Fast Facts Information Sheets for Patients

Alpha Thalassemia

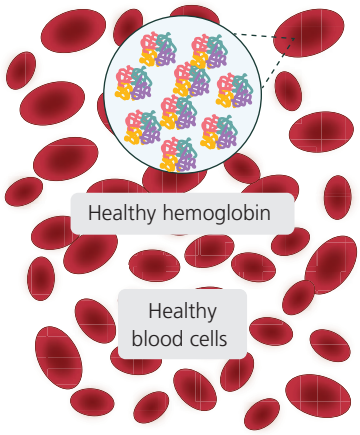
Kevin HM Kuo

HEALTHCARE

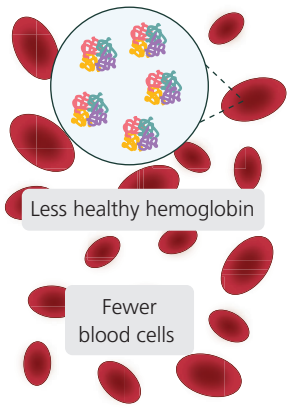
Karger

Understanding Alpha Thalassemia

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



Healthy blood



Anemic blood

What is AT?

AT 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 can lead 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.

AT is a **genetic disease**. This means it passes from parents to children through genes.

More about genes

Hemoglobin is made of two different proteins: alpha and beta.

The **alpha globin protein** is made by the *HBA1* and *HBA2* genes. We usually have four copies of these genes: two copies of the *HBA1* gene (one from each parent), and two copies of the *HBA2* gene (one from each parent).

What kind of AT you have depends on how many and which genes are changed.

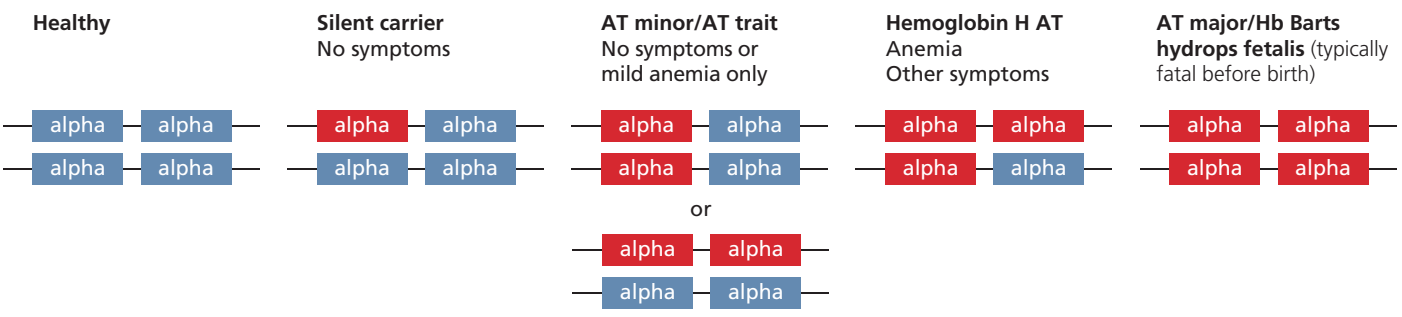
What are the types of AT?

Silent carrier: Blood tests are usually normal. You will often have no symptoms, but you can pass the changed gene on to your child.

AT minor/trait. You may have no symptoms or have mild anemia. You can pass the damaged gene(s) on to your child.

Hemoglobin H (HbH) AT. There is just one working gene. You may have moderate to severe anemia. You have a greater risk of having a child with AT major.

AT major. All four genes are missing. This causes severe anemia. In most cases, if there is no treatment given in the womb, a baby with this condition will die before birth.



Are you pregnant?

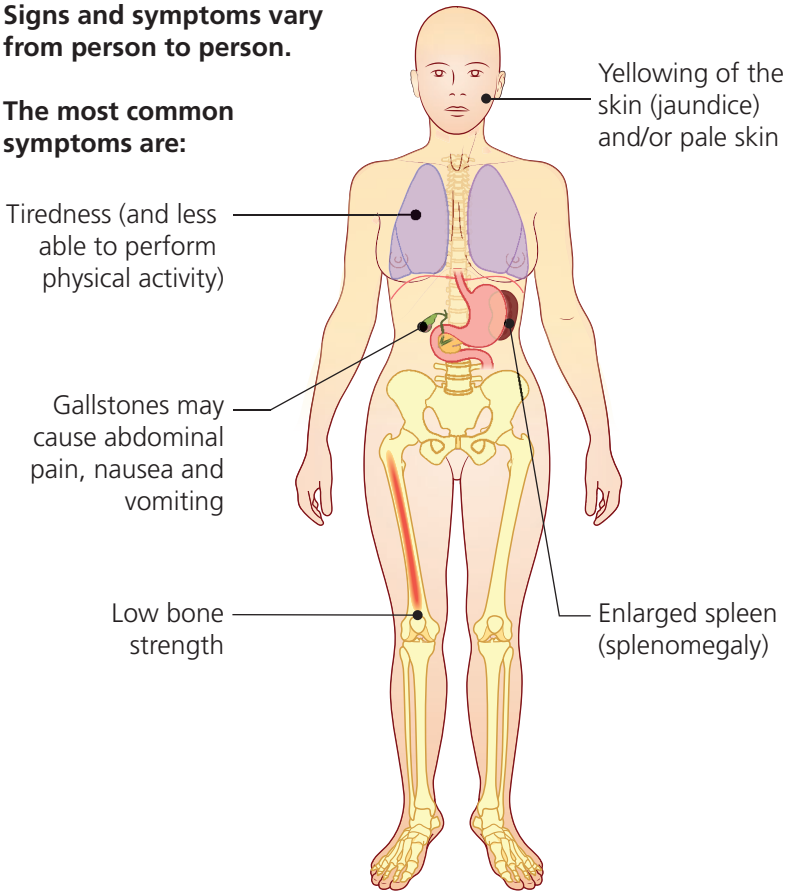
Your doctor will do genetic testing early in the pregnancy in case your baby needs treatment before birth. This helps to prevent your baby arriving too early and can help prevent serious health complications for you and your baby. Ask your doctor for more information.

An independent publication developed by S. Karger Publishers Limited, and made possible by a contribution from Agios.
Agios did not have any influence on the content and all items were subject to independent and editorial review.

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

Signs and symptoms vary from person to person.

The most common symptoms are:



How is AT diagnosed?

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

- CBC – complete blood count
- Iron level (usually done with a test of your ferritin level; ferritin is a protein that stores iron inside your cells)
- Hemoglobin analysis by HPLC – high-performance liquid chromatography – or sometimes electrophoresis
- Genetic testing.

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

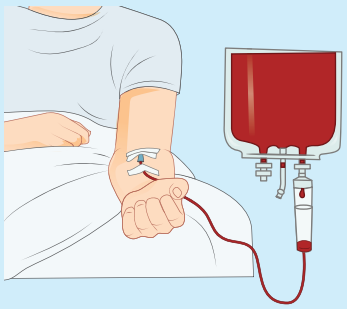
What is the treatment?

There is currently no cure for AT but we can treat your symptoms.

Depending on the type of AT you have, you may receive blood transfusions. Your doctor may also prescribe folic acid. Folic acid is a kind of vitamin.

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 AT 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 can 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 AT

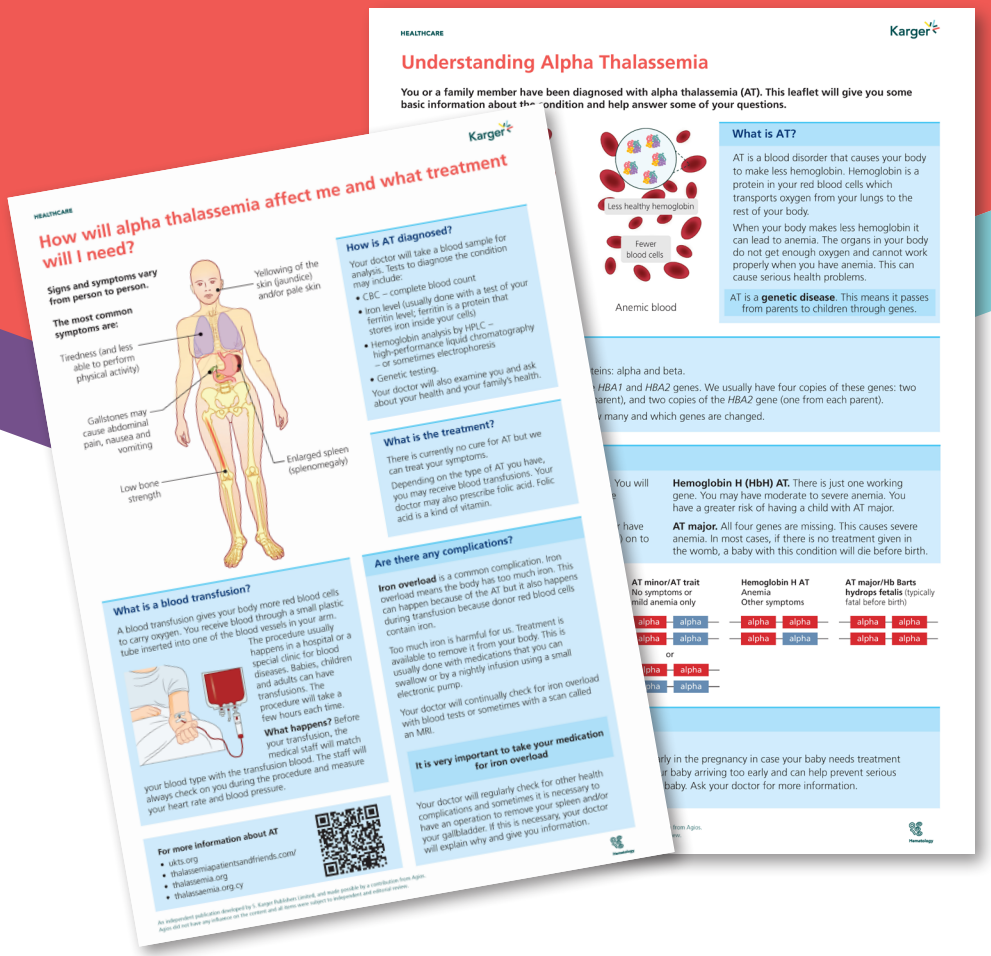
- ukts.org
- thalassemiapatientsandfriends.com/
- thalassemia.org
- thalassaemia.org.cy

An independent publication developed by S. Karger Publishers Limited, and made possible by a contribution from Agios.
Agios did not have any influence on the content and all items were subject to independent and editorial review.

Hematology

For a digital copy SCAN HERE

karger.com/fastfacts



Merchant House
5 East St Helen Street
Abingdon, Oxford
OX14 5EG, UK

Made possible by a contribution from Agios. Agios did not have any influence on the content and all items were subject to independent and editorial review.

agios

HEALTHCARE

Karger