

Probably carrying alpha thalassaemia

The information in this leaflet applies for people who probably carry alpha thalassaemia, whose ancestors are NOT black Africans or black African Caribbeans

Sometimes blood tests show that a person has small red blood cells, but this is not due to iron deficiency or carrying typical beta thalassaemia. The most likely explanation is that the person carries alpha thalassaemia. This is called an “exclusion diagnosis of probable alpha thalassaemia”.

People who may carry alpha thalassaemia need to know that...

- A carrier of alpha thalassaemia is a healthy person.
- Carrying alpha thalassaemia does not weaken them physically or mentally.
- They do not need any medical treatment because they carry alpha thalassaemia.

What does it mean to carry alpha thalassaemia?

Alpha thalassaemia is one of many possible variations in the blood called *haemoglobin gene variants* or *haemoglobin variants*.

Haemoglobin is what makes blood red. It is packed into red blood cells. Thalassaemia carriers have smaller red blood cells but more of them than other people.

A carrier will always be a carrier and no-one can catch it from them. They inherited alpha thalassaemia from one of their parents, and could pass it on to their children.

Alpha thalassaemia is extremely common. About 1 in 4 people who originate from the Indian sub-continent, the Mediterranean area, parts of the Middle East or South East Asia carry it. About 1 in 3 people who originate from Africa or the Caribbean area carry it. It also occurs among North Europeans.

Can carrying alpha thalassaemia cause any health problems?

Carrying alpha thalassaemia is not an illness and will never turn into an illness. Carriers can eat what they want and do any work they choose.

Occasionally a doctor thinks a carrier is short of iron because they have small red blood cells. If the doctor prescribes iron medicine, in the long run this could do more harm than good. Carriers should take iron medicine only if a special blood test (*serum iron* or *serum ferritin*) shows that they are short of iron.

Carriers can give blood providing they are not anaemic (do not have a lower haemoglobin than usual).

Why is it useful for people to know that they probably carry alpha thalassaemia?

Whenever they have a blood test, it may show they have small red blood cells. If they already know that they probably carry alpha thalassaemia, they can avoid being misinformed and having unnecessary tests.

Could a person who probably carries alpha thalassaemia have children with a serious haemoglobin disorder?

Only if both they and their partner carry particular types of alpha thalassaemia.

However, with medical help, such a couple can have healthy children.

What should a person who probably carries alpha thalassaemia do, if they are thinking of having children?

They should tell their partner that they probably carry alpha thalassaemia, and ask him or her to have a blood test “for haemoglobin disorders”. This test should be done before they start a pregnancy, or as soon as possible once a pregnancy has started. Their GP can arrange it.

If their partner is not also a carrier, there is nothing to worry about.

What should they do if their partner is also a carrier?

They should have a “DNA test” to diagnose the exact types of thalassaemia they both carry. They should ask their GP for an immediate appointment with a specialist counsellor. This is particularly important if they have already started a pregnancy. They can also contact the counselling service directly.

Is there anything else that a carrier should do?

If a carrier has brothers or sisters, or already has children, they need to know that they may also carry alpha thalassaemia. They should ask their GP for a blood test “for haemoglobin disorders”.

Counselling services for haemoglobin disorders are provided in this area by: