Carrying Haemoglobin O Arab

A carrier can use this booklet to…

- *help explain carrying haemoglobin O Arab to their partner, blood relatives and others.*
- *show to any health professional (doctor, nurse or midwife) they see about having a family , or pregnancy, or carrying haemoglobin O Arab.*

Contents

Introduction

Haemoglobin O Arab is one of a range of variations in the blood called *haemoglobin gene variants*. Here we call them *haemoglobin variants* for short.

Carriers of haemoglobin O Arab are also sometimes said to be A/O Arab, or to have haemoglobin O Arab trait.

Haemoglobin O Arab is inherited. That is, it is passed on from parents to their children, like height, hair colour or eye colour. It is passed on equally by men and women. It is present at birth, and it remains the same for life.

It is important to distinguish clearly between people who *carry haemoglobin O Arab* and people who *have a haemoglobin disorder*.

Carriers of haemoglobin O Arab…

… inherited haemoglobin O Arab from one of their parents. Carrying haemoglobin O Arab does not affect their own health. However, if their partner is also a carrier they could have children with a haemoglobin disorder.

People who have a haemoglobin disorder…

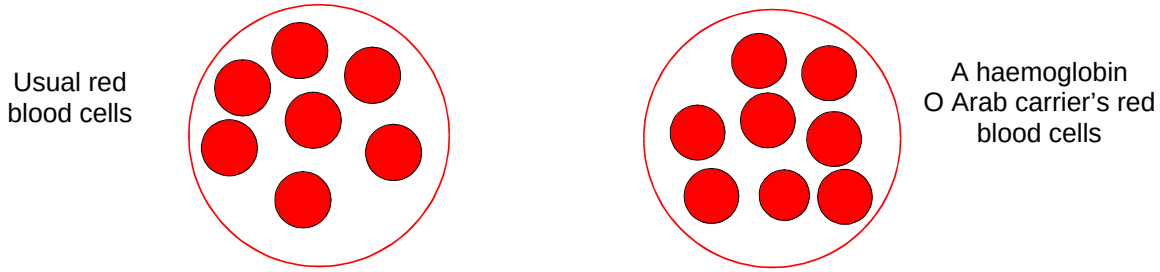
… inherited two haemoglobin variants, one from each of their parents. Together, the two variants cause a serious inherited anaemia that can lead to life-long health problems.

This document is about carrying haemoglobin O Arab.

What does it mean to carry haemoglobin O Arab?

Blood is made up of millions of *red blood cells* floating in a fluid called *plasma*. Red blood cells are full of haemoglobin, which is red. This is why blood is red. The heart pumps blood round the body through the blood vessels. The body needs oxygen to function. Haemoglobin picks up oxygen as blood passes through the lungs, and carries it to the rest of the body as the blood circulates.

The usual type of haemoglobin is adult haemoglobin or haemoglobin A. Carriers of haemoglobin O Arab have an unusual haemoglobin called haemoglobin O Arab as well as haemoglobin A. They also have smaller red blood cells, but more of them than other people. You can see the difference between other peoples' red blood cells and a haemoglobin O Arab carrier's red blood cells by looking down a microscope.



Haemoglobin O Arab is *inherited* - it is handed on from parents to their children, it is present at birth, and it remains the same for life.

How is haemoglobin O Arab inherited?

It is inherited through *genes.* Every human characteristic, such as eye colour, or height, or type of haemoglobin is controlled by genes that parents pass on to their children. A child inherits two genes for every characteristic, one from each parent. Most people inherit two genes for the usual type of haemoglobin, *haemoglobin A.* Each gene is responsible for making half of the haemoglobin A in each red blood cell.

A carrier of haemoglobin O Arab has inherited a gene for haemoglobin A from one parent and a gene for haemoglobin O Arab from the other. The haemoglobin O Arab gene makes a type of haemoglobin that is very slightly different from haemoglobin A. It also makes less haemoglobin than usual. As a result each of their red blood cells contains both haemoglobin A and haemoglobin O Arab, and is slightly smaller than usual. They make up for this by making more red blood cells. Their blood functions normally, and carrying haemoglobin O Arab does not cause them any health problems.

How do people find out that they carry haemoglobin O Arab?

By having a special blood test "for haemoglobin disorders". This usually involves two steps.

- The first step is to measure the size of their red blood cells. This shows that they have smaller red blood cells than usual.
- The second step is to analyse the types of haemoglobin in their blood. This shows that their blood contains haemoglobin O Arab as well as haemoglobin A.

Can carrying haemoglobin O Arab affect your health?

Carriers of haemoglobin O Arab are not ill, and are no more likely to get ill than other people. Carrying haemoglobin O Arab does not make them weak, and they can do any kind of work they choose.

Though carrying haemoglobin O Arab does not cause health problems it can sometimes lead to misinformation, and uneccessary treatment with iron medicine.

The commonest type of anaemia is iron deficiency anaemia. It occurs in people whose diet contains too little iron, or who lose blood for some reason. People with iron deficiency anaemia may also have small red blood cells.

Occasionally a doctor thinks a person who carries thalassaemia must be 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. A carrier should take iron medicine only if a special blood test (serum iron or serum ferritin) shows that they are short of iron.

Can a carrier of haemoglobin O Arab also get iron deficiency anaemia?

They can. They should have a diet with enough vitamins and iron to make sure that this does not occur.

What about pregnant women?

Like other pregnant women, women who carry haemoglobin O Arab can become iron deficient and may need extra iron.

Is there any treatment to get rid of haemoglobin O Arab?

No, a person who is born carrying haemoglobin O Arab will always carry it.

Can carrying haemoglobin O Arab turn into a serious haemoglobin disorder?

It cannot.

Can people catch haemoglobin O Arab from a carrier?

They cannot.

Can a carrier of haemoglobin O Arab be a blood donor?

They can give blood like other people, provided they are not anaemic (do not have a lower haemoglobin level than usual).

Is it a bad thing to carry haemoglobin O Arab?

It is not. Haemoglobin O Arab is a mild type of thalassaemia, and thalassaemia carriers may be healthier than other people in several ways. For example, they have some natural protection against severe forms of malaria.

Malaria parasites live inside red blood cells, and are most comfortable in the red cells of people who do not carry any haemoglobin variant. Thalassaemia carriers can be infected with malaria like anyone else, but the parasites cannot grow well in their small red blood cells. Therefore they have less severe infections and less chance of dying from malaria than other people.

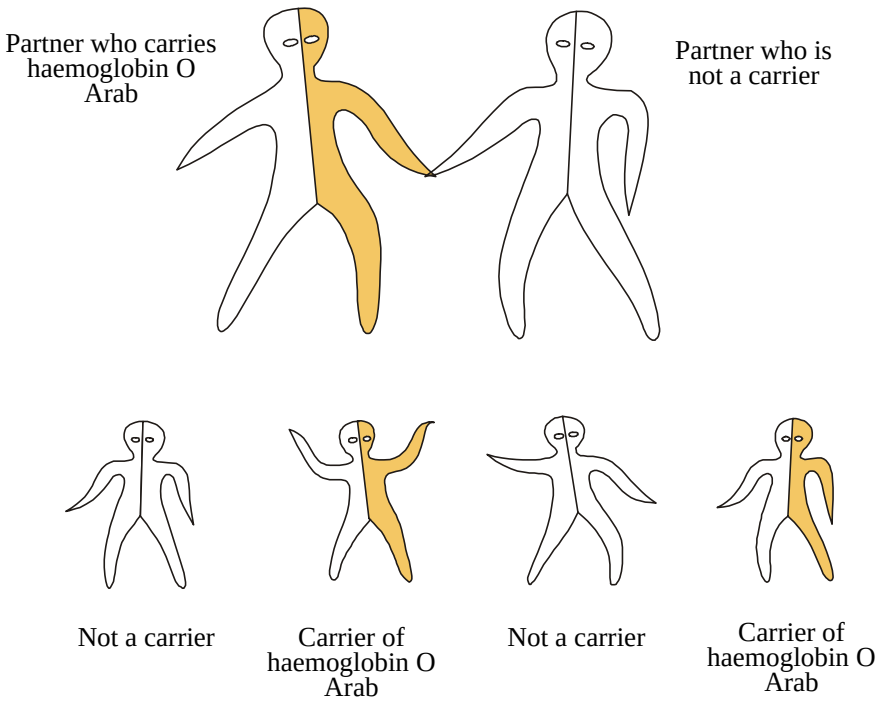
In countries where it was common malaria used to kill many children. Children who carried thalassaemia survived better than other children and passed thalassaemia on to their children in turn. As time passed carrying thalassaemia became very common in such areas, and that is why there are now so many carriers in the world.

Malaria has been eradicated in many countries, so being a carrier is less advantageous than it used to be. Haemoglobin O Arab does not go away when malaria is eradicated, or when a carrier moves to a different part of the world, because it is inherited.

Carriers of haemoglobin O Arab should not rely on their natural protection against malaria when they visit a malarious country. Their protection is limited. They should take antimalarial tablets like everybody else.

Implications for a carrier's children…

If one partner carries haemoglobin O Arab and the other does not carry any haemoglobin variant, their children could not have a serious haemoglobin disorder



In each pregnancy, there are two possibilities.

- The child may not carry any haemoglobin variant.
- The child may carry haemoglobin O Arab. This is harmless.

This couple has the same chance of a healthy family as other couples do.

There is also no risk of a serious haemoglobin disorder if one partner carries haemoglobin O Arab and the other carries any of the following:

alpha thalassaemia

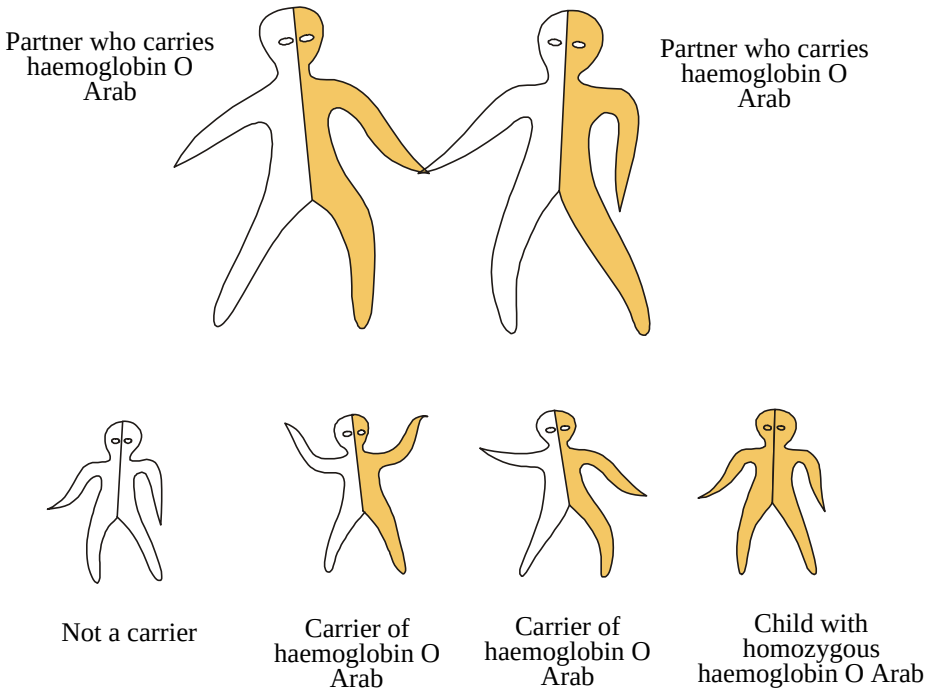
haemoglobin C

haemoglobin D

hereditary persistence of fetal haemoglobin (HPFH)

one of a range of possible rare haemoglobin variants

If both partners carry haemoglobin O Arab, their children could have homozygous haemoglobin O Arab

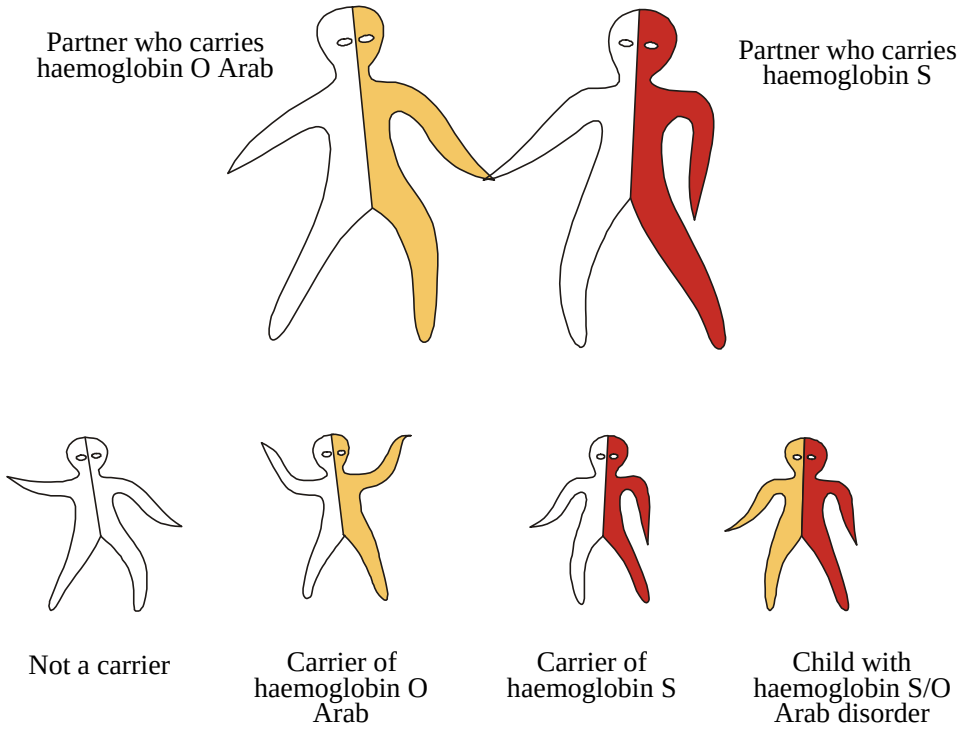


In each pregnancy, there are three possibilities

- The child may not carry any haemoglobin variant.
- The child may carry haemoglobin O Arab. This is harmless.
- The child may inherit haemoglobin O Arab from both parents. Such a child would have hoozygous haemoglobin O Arab. This is also known as having only haemoglobin O Arab. It is harmless.

This couple has the same chance of a healthy family as other couples do.

If one partner carries haemoglobin O Arab and the other carries haemoglobin S (sickle cell), their children could have haemoglobin S/O Arab



In each pregnancy there are four possibilities:

- The child may not carry any haemoglobin variant.
- The child may carry haemoglobin O Arab. This is harmless.
- The child may carry haemoglobin S. This is harmless.
- The child may inherit haemoglobin O Arab from one parent and haemoglobin S from the other. This child would have haemoglobin S/O Arab disorder.

In each pregnancy there is a 3 in 4 chance of a healthy child, and a 1 in 4 risk of child with haemoglobin S/O Arab disorder.

What is haemoglobin S/O Arab disorder?

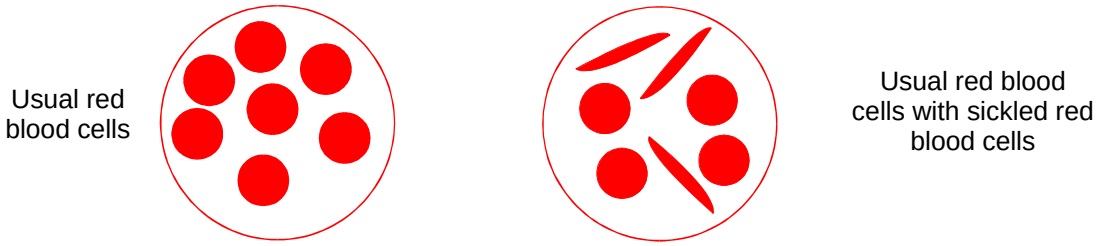
It is a severe *sickle cell disorder*. Sickle cell disorders can cause anaemia, infections, chest problems and painful crises. A painful crisis is an unpredictable attack of very severe pain, that can occur anywhere in the body. The hands and feet are often affected in young children, the limbs and back in adults.

Severe sickle cell disorders can cause serious problems including stroke in children, or damage to bones, joints, eyesight or kidneys, and ankle ulcers in adults.

About one third of people with a severe sickle cell disorder have few medical problems. Most have two or three infections or painful crises a year, and may need to be admitted to hospital from time to time. About one in 20 have frequent serious problems, and may need regular transfusions to avoid organ damage. There is an increased risk of premature death, even for people with few other problems.

What causes haemoglobin S/O Arab?

When a person has one gene for haemoglobin S and one for haemoglobin O Arab their red blood can *sickle* when they are short of oxygen. This means that they change from their normal disk-like shape to a sickle shape (long, curved and pointed). Sickled red blood cells can become jammed in small blood vessels, block the blood supply, and cause pain in that part of the body.



What is the treatment for sickle cell disorders?

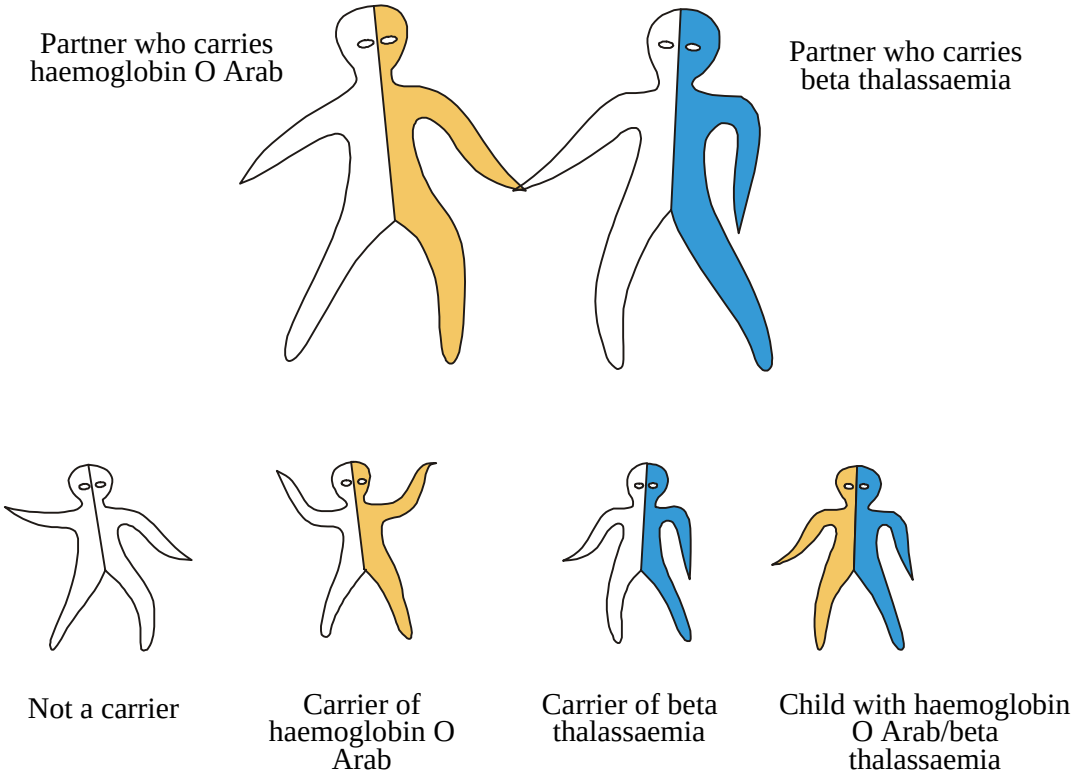
People with a sickle cell disorder, and their family, need to understand the condition so that they can take steps to avoid problems as far as possible. For example they can reduce the risk of painful crises by drinking plenty of fluid and avoiding extremes of heat and cold. They should take penicillin daily to reduce the risk of infections, and their diet should contain adequate vitamins. They should attend a sickle cell clinic regularly so that problems can be detected and treated as early as possible.

They can have a wide range of other problems each requiring different, appropriate treatment.

Is it possible to predict how severe haemoglobin S/O Arab will be?

It seems to be a severe sickle cell disorder in almost every case.

If one partner carries haemoglobin O Arab and the other carries beta thalassaemia, their children could have haemoglobin O Arab/beta thalassaemia



In each pregnancy, there are four possibilities.

- Tthe child may not carry any haemoglobin disorder.
- The child may carry haemoglobin O Arab. This is harmless.
- The child may carry beta thalassaemia. This is harmless.
- The child may inherit haemoglobin O Arab from one parent, and beta thalassaemia from the other. This child would have haemoglobin O Arab/ beta thalassaemia.

In each pregnancy there is a 3 in 4 chance of a healthy child, and a 1 in 4 risk of child with haemoglobin O Arab/ beta thalassaemia.

There is also a known risk of a serious haemoglobin disorder when one partner carries haemoglobin O Arab and the other carries any of the following:

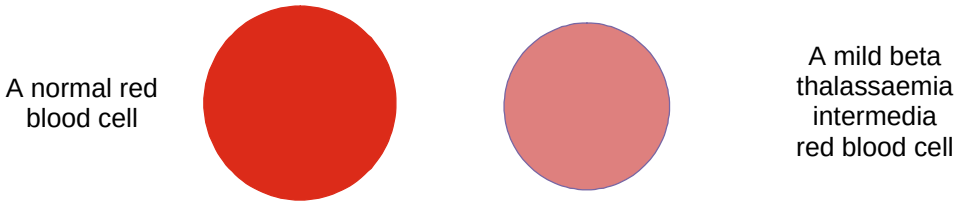
delta-beta thalassaemia

haemoglobin Lepore

What is haemoglobin O Arab/beta thalassaemia?

It is a mild form of beta thalassaemia intermedia.

People with mild beta thalassaemia intermedia cannot make quite the usual amount of haemoglobin, and so cannot make normal red blood cells. Their red blood cells contain less haemoglobin than usual, and they make fewer of them than other people. They have a moderate anaemia.



A child with mild beta thalassaemia intermedia becomes slightly anaemic by about one year of age. The anaemia may become a little more marked up to four years of age, but then usually settles at a steady level. They may be slightly jaundiced (yellow).

People with mild beta thalassaemia intermedia grow up normally, have a normal education, work, find a partner and have a family of their own. They are expected to live a normal length of life.

They can have some medical problems. Their spleen may become enlarged, they may develop gallstones, or their bones may become thin when they get old. These problems can all be corrected.

What is the treatment for mild beta thalassaemia intermedia?

People with midl beta thalassaemia intermedia should take folic acid daily. They should see a specialist at regular intervals so that any problems can be detected early and treated appropriately.

Can serious haemoglobin disorders be prevented?

Carrier couples who know of the risk for their children have a number of choices. They can take steps to make sure that they have healthy children, and can make sure that affected children have the best possible care from birth. Their choices are not simple. They need to know their risk early, so that they have enough time to make the decisions that are right for them.

In the UK, it is national policy to identify and inform as many carriers as possible before they have children, so that they can have an informed choice. The NHS is expected to take the following steps.

- *Offer carrier testing*. At present this is usually offered by midwives to pregnant women. In some districts it is offered to all pregnant women, and in others only to pregnant women with ancestors from areas where haemoglobin variants are common.
- *Inform carriers.* They need information on (a) the possible risk to the health of their children, and (b) the need for their partner to have a carrier test.
- *Inform carrier couples*. Couples who are both carriers need to see a specialist counsellor for haemoglobin disorders. The counsellor will find out whether they are "at risk" for having children with a serious haemoglobin disorder, and inform them of the exact nature of the risk and the possibilities for avoiding it.

All at risk couples should be offered both *prenatal diagnosis* and *neonatal diagnosis* (new-born diagnosis).

- Prenatal diagnosis means testing an unborn baby to see whether it has a serious disorder. DNA tests are done on a tiny amount of tissue taken from the developing placenta. This can be done as early as 11 weeks of pregnancy. If the baby is affected, the parents can decide whether to continue the pregnancy and plan the best possible care for the baby, or to terminate the pregnancy and try again for a healthy child.
- Neonatal diagnosis is done after the baby is born, using blood taken from the umbilical cord or by pricking the baby's heel a few days after birth. Neonatal diagnosis for thalassaemia is done by DNA tests. When there is a risk of a sickle cell disorder, early diagnosis and treatment can be life-saving for the child.

It is now recognised that screening during pregnancy often identifies at risk couples too late. Carrier testing should be offered by family doctors either before pregnancy, or as soon as a pregnancy has started.

Asking a partner to have a blood test

A carrier who is thinking of having children needs to tell their partner that they carry haemoglobin O Arab, and ask him or her to have a blood test “for haemoglobin disorders”.

Is it difficult for a carrier to ask their partner to have a blood test?

It can be easy in some cases and difficult in others. It is easier if both the carrier and their partner know that:

- Carrying a haemoglobin variant is common.
- The test will probably show that the partner does not carry a haemoglobin variant.
- If they do carry a haemoglobin variant it will not affect their health or lifestyle in any way.
- A couple who are both carriers can have a healthy family, with medical help.
- Expert counselling is available.
- No-one will try to tell the couple what to do: all the choices are theirs.
- The results of blood tests, and the couples’ decisions, are completely confidential.

If a couple are both carriers, can it interfere with their relationship?

It is unusual for a relationship to suffer because one or both of a couple carry a haemoglobin variant. On the contrary, many couples draw closer together to deal with their problem. This is true whether they are just starting their relationship or have been together for a long time.

When is the best time for a carrier to ask their partner to have a blood test?

Ideally as early as possible, because it can take time to arrange a blood test, and a couple who are both carriers need time to decide what to do. Of course, the best timing depends on the couple’s relationship with each other. It may also be influenced by their families’ views, and the culture they belong to.

In practice a carrier might suggest a blood test to their partner at one of the following points.

- Before they settle down together.
- After they settle down together but before they start a pregnancy.
- As soon as they have started a pregnancy.

Telling the family about haemoglobin O Arab

A carrier inherited haemoglobin O Arab from one of their parents, so their brothers and sisters and other blood relatives could also be carriers. For example a brother or sister has a 1 in 2 chance of being a carrier.

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

Carrying haemoglobin O Arab

(also known as being AO Arab, or having haemoglobin O Arab trait)…

… is not an illness, and will never become an illness. It was passed to you by one of your parents and you could pass it on to your children.

There is nothing to worry about, unless your partner is also a carrier.

- If your partner is also a carrier, together you could have children with a serious inherited illness. However, with medical help, a couple who are both carriers can have healthy children.
- If you are thinking of having children, your partner should have a blood test “for haemoglobin disorders”.
- If you have children or brothers and sisters, they could carry haemoglobin O Arab like you. Encourage them to have the same blood test.

To find out more, see your GP or a specialist counsellor.