Carrying Haemoglobin D

A carrier can use this booklet to…

- *help explain carrying haemoglobin D 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 D.*

Contents

Introduction

Haemoglobin D 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 D are also sometimes said to to be AD, or to have haemoglobin D trait.

Haemoglobin D 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 D* and people who *have a haemoglobin disorder*.

Carriers of haemoglobin D…

… inherited haemoglobin D from one of their parents. Carrying haemoglobin D does not affect their own health. However, if their partner carries haemoglobin S (sickle cell) 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 D.

What does it mean to carry haemoglobin D?

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 D have an unusual haemoglobin called haemoglobin D as well as haemoglobin A.

Haemoglobin D 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 D 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 D has inherited a gene for haemoglobin A from one parent and a gene for haemoglobin D from the other. Each of their red blood cells contains both haemoglobin A and haemoglobin D. Haemoglobin D is only slightly different from haemoglobin A. Their blood functions normally, and carrying haemoglobin D does not cause them any health problems.

How do people find out that they carry haemoglobin D?

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 nothing unusual.
- The second step is to analyse the types of haemoglobin in their blood. This shows that their blood contains haemoglobin D as well as haemoglobin A.

There are seven known types of haemoglobin D. Only one, haemoglobin D Punjab, can cause a serious haemoglobin disorder. A DNA test can show whether a person who carries haemoglobin D carries haemoglobin D Punjab or a harmless type of haemoglobin D.

Can carrying haemoglobin D affect your health?

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

Is there any treatment to get rid of haemoglobin D?

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

Can carrying haemoglobin D turn into a serious haemoglobin disorder?

It cannot.

Can people catch haemoglobin D from a carrier?

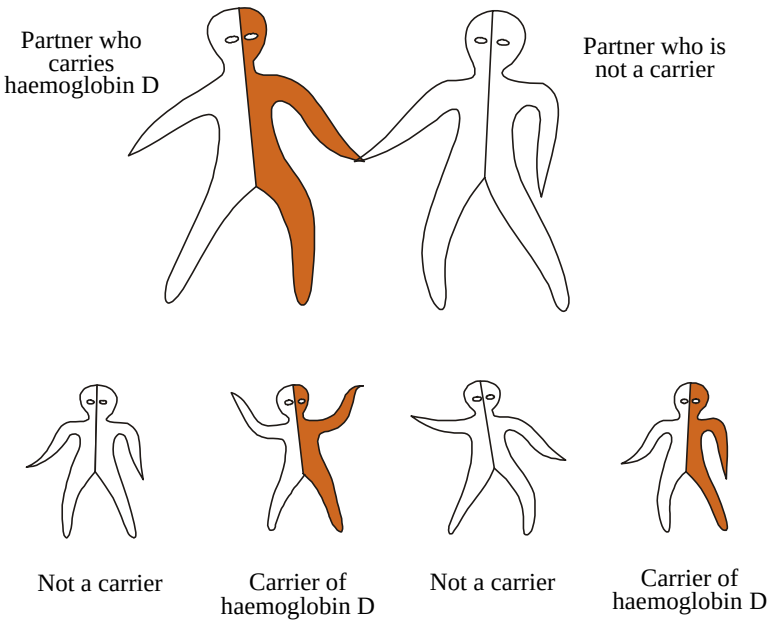
They cannot.

Can a carrier of haemoglobin D 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).

Implications for a carrier's children…

If one partner carries haemoglobin D 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 D. 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 D and the other carries any of the following:

alpha plus thalassaemia

beta thalassaemia (including unusual forms such as delta-beta thalassaemia or haemoglobin Lepore)

haemoglobin C

haemoglobin D

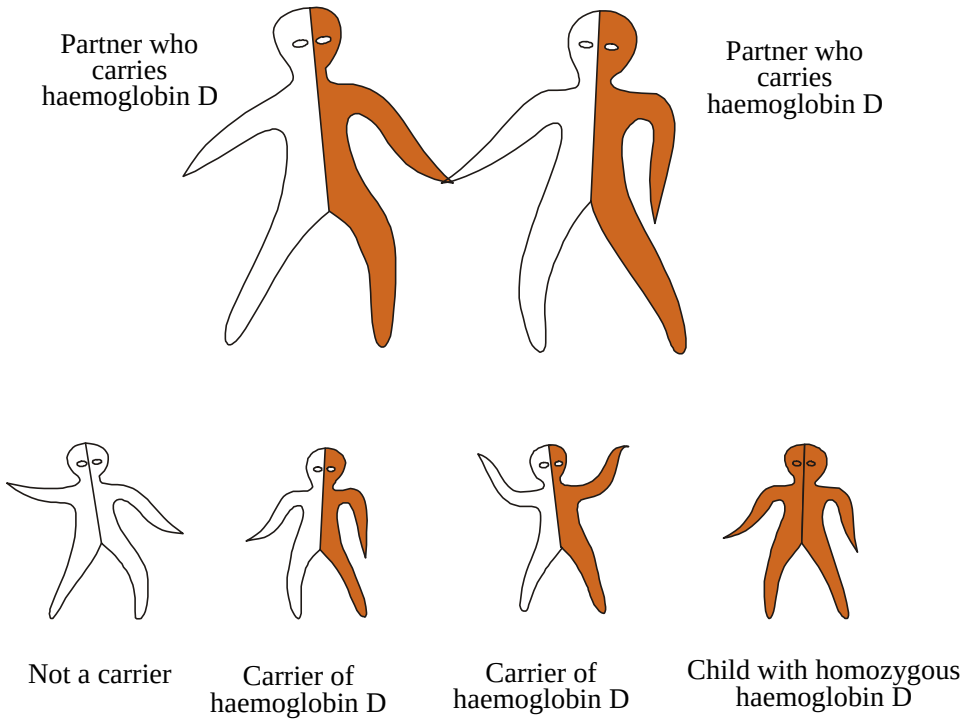
haemoglobin E

haemoglobin O Arab

hereditary persistence of fetal haemoglobin (HPFH)

one of a range of possible rare haemoglobin variants

If both partners carry haemoglobin D, their children could have homozygous haemoglobin D (DD).



In each pregnancy there are three possibilities:

- The child may not carry any haemoglobin variant.
- The child may carry haemoglobin D. This is harmless.
- The child may inherit haemoglobin D from both parents. Such a child would have homozyogous haemoglobin D (DD). This is also known as having only haemoglobin D. It is harmless.

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

If one partner carries haemoglobin D and the other carries haemoglobin S…

It is not possible to say whether there is a risk to the children without further investigation.

Only one of the seven known types of haemoglobin D, haemoglobin D Punjab, causes a risk of a sickle cell disorder in the children when the partner carries haemoglobin S.
As far as is known, the other types do not involve any risk of a sickle cell disorder when the partner carries haemoglobin S.
A DNA test is required to show whether a person who carries haemoglobin D carries haemoglobin D Punjab or a harmless type of haemoglobin D.

Therefore in this situation the carrier of haemoglobin D should have an urgent DNA test to find out whether or not there is a risk for the health of their children.

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 D, 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 D

A carrier inherited haemoglobin D 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 D. They should ask their GP or practice nurse for a blood test “for haemoglobin disorders”.

Carrying haemoglobin D

(also known as being AD, or having haemoglobin D 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 D like you. Encourage them to have the same blood test.

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