

# Screening for sickle cell disease and thalassaemia

An **easy guide** to screening tests when you are pregnant



# Contents: what is in this booklet

## Page



Your choice

3



About these tests

4



Sickle cell disease  
and thalassaemia

6



Test results

7

## Your choice



This booklet has information about a test you can have.

The test can find out if your baby may have sickle cell disease or thalassaemia. These are serious conditions.

The test can find conditions your baby may have. The test may not find every condition.



You can choose if you want to have the test.

If we find a condition early we can give you information or tell you about treatment for you or your baby. This can help you make choices about your care when you are pregnant.



If you are worried, you can talk to your midwife or doctor.

If you say no to the test then your baby can have a test for sickle cell disease when they are born instead.

**PRIVATE**

We will keep your test results private.

We only show the results of the test to health staff who need to see them.



It is important to tell your midwife or health visitor if you have sickle cell disease or thalassaemia.

It is also important to tell your midwife or health visitor if your baby's father has one of the conditions.



This test takes a small drop of your blood to find out if you may give your baby sickle cell disease or thalassaemia.

All women are offered screening for thalassaemia.

Some women are offered screening for sickle cell disease.



You can have the blood test at any time but it is best to have the blood test before you are 10 weeks pregnant.



You will be asked questions about which country you and your baby's father come from.

This is to help health staff know if you need a test and to do the test properly.



Sickle cell disease and thalassaemia are more common for people whose family comes from:

- Africa
- the Caribbean
- the Mediterranean
- India
- Pakistan
- south and south east Asia
- the Middle East





Sickle cell disease and thalassaemia are serious blood conditions.

You get them from your parents. You have them for life.



Sickle cell disease can cause problems in your blood that can make you pale, very tired and weak.

Sickle cell disease can give you very bad pain and very serious illnesses.

A baby with sickle cell disease can have medicines after they are born. Medicines will help them to be healthy.



Thalassaemia gives you very serious problems in your blood that can make you pale, very tired and weak.

If you have thalassaemia you need blood transfusions every 4 to 6 weeks and you need medicine for life.

A blood transfusion is when blood is taken from a healthy person and put into an ill person.

## Test results



You will usually get the results at your next appointment.

We will contact you if the test shows you may pass on sickle cell disease or thalassaemia to your baby.

The person who does your test will tell you about this.



If the test shows you may pass on sickle cell disease or thalassaemia to your baby then it is really important for your baby's father to get tested too.

We will offer you another test if your baby's father can also pass on sickle cell disease or thalassaemia.



The second test has a very small chance of making you miscarry.

If you miscarry then your baby dies.

You can say no to this test.



This second test may show if your baby has sickle cell disease or thalassaemia.

If your baby has sickle cell disease or thalassaemia you will be given information about the condition to help you decide what to do.



Some babies have the condition worse than others. The test cannot tell you how serious the condition will be.



If you are told your baby has sickle cell disease or thalassaemia then you and your baby's father can decide to carry on with the pregnancy or have an abortion.

If you have an abortion this means your baby dies.

You will be given support. This is your decision.





**New home**

It is important to tell your midwife or health visitor if you move home.

**First published:** February 2017

Updated: June 2020

**© Crown copyright 2020**

Re-use of Crown copyright material (excluding logos) is allowed under the terms of the Open Government Licence, visit [www.nationalarchives.gov.uk/doc/open-government-licence/version/2/](http://www.nationalarchives.gov.uk/doc/open-government-licence/version/2/) for terms and conditions.

**Images courtesy of:**

Photosymbols – calendar (page 5), house move (page 9)

Unsplash (Naassom Azevedo) – group of people sitting (page 5)

NHS Photo Library (pages 6 and 8)

**PHE publications gateway number:** GW-1291



Find out how Public Health England and the NHS use and protect your screening information at [www.gov.uk/phe/screening-data](http://www.gov.uk/phe/screening-data).

Public Health England (PHE) created this leaflet on behalf of the NHS