

# What Are Sickle Cell and Thalassaemia?

**Please note:** The information provided in this section has been sourced from the ARC website and was not created by Ellie's Gift. ARC has been instrumental in supporting the development of Ellie's Gift and their contribution has been significant to the content within our specific TFMR area. ARC were also involved in the focus groups that helped inform and shape the content that has been developed to support families experiencing TFMR.

## What are sickle cell and thalassaemia?

Sickle cell disease and thalassaemia are inherited blood conditions. People who have these conditions need specialist care throughout their lives.

Anyone can be a carrier of sickle cell or thalassaemia. But it's more common among people with an African, Caribbean, Mediterranean, Indian, Pakistani, south and southeast Asian, or Middle Eastern background.

## **Pre-pregnancy testing for sickle cell and thalassaemia**

Anyone can ask their GP for a test for sickle cell or thalassaemia at any time. GPs are contracted to provide access to this testing for those who want to find out if they are a carrier before pregnancy.

## **Who is offered testing in pregnancy for sickle cell and thalassaemia?**

All pregnant women are offered a blood test for thalassaemia, but not all women are automatically offered a blood test for sickle cell.

In areas where the conditions are more common, women are automatically offered a blood test for sickle cell.

In other areas where they are less common, a questionnaire called a Family Origin Questionnaire is used to identify your family origins and the origins of the baby's biological father.

If the questionnaire shows that either you or the baby's biological father is at higher risk of being a sickle cell carrier, you'll be offered a screening test.

Importantly, even if you are not offered the testing, you can ask to have it.

If you've previously had screening outside the UK, you will usually be asked to have the test again.

As with all screening tests, it is your choice whether or not to have the test.

### **NHS screening for sickle cell and thalassaemia**

Screening for sickle cell and thalassaemia involves a blood test.

It's recommended to have the test as early in pregnancy as possible; ideally, before you're 10 weeks pregnant. This is because if the first test shows you're a carrier you'll be offered more tests to find out whether your baby will be affected.

By having the test early in pregnancy, you and your partner can find out about your options and decide whether to have further testing.

If the result shows that you are a carrier of sickle cell or thalassaemia, the biological father of the baby will be offered a test.

### **If both parents are carriers of the same condition**

There is a 1 in 4 chance (25%) that your baby will inherit the condition and a 3 in 4 chance (75%) that your baby will not inherit the condition.

There is a 1 in 2 chance (50%) that your baby will be a carrier of the condition.

There is a 1 in 4 (25%) chance that your baby will not have or carry the condition.

### **Diagnostic testing**

If both parents are carriers you will be offered an invasive diagnostic test in pregnancy to find out if your baby is a carrier or has inherited sickle cell or thalassaemia. Read more [about diagnostic tests](#).

Unfortunately, non-invasive prenatal diagnosis (NIPD) for sickle cell and thalassaemia is not currently an option.

For more information about sickle cell and thalassaemia

- [NHS Sickle Cell and Thalassaemia Screening Programme](#)
- [The Sickle Cell Society](#)
- [The UK Thalassaemia Society](#)

### **ARC - Call our helpline**

Want to talk? We're here as often as you need us. Our helpline is answered by trained staff.

**020 7713 7486**

Monday to Friday: 10.00am – 5.30pm

Or text: **07908 683004**

Tuesday and Thursday: 8 – 10pm – email  
[info@arc-uk.org](mailto:info@arc-uk.org) to arrange an evening call.

### **Disclaimer**

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Please check the original source or relevant organisation directly for the most up-to-date information.