

# Information for adults

## You are a sickle cell carrier



### Easy Read version

This leaflet has quite a lot of difficult words and ideas in it



**healthier  
scotland**  
SCOTTISH GOVERNMENT

We have made this leaflet as accessible as possible. There are still some difficult ideas in it. You might need to ask a friend, family member, carer or health professional to help you read this booklet.



If you see the symbol on the left it means there is a difficult medical word. This is a word that you might hear when you visit your doctor. You might also see it on letters and leaflets you get from your doctor.



Leaflets with the green thumbs up symbol on the cover have a small number of difficult words and ideas in them.



Leaflets with the orange thumbs up symbol on the cover have a few difficult words and ideas in them.



Leaflets with the red thumbs down symbol on the cover have quite a lot of difficult words and ideas in them.

## What is my test result?

You had a blood test recently. The test result shows that you are healthy – there is no need to worry about being unwell.



**Carrier.** This is what we call a person who can give a disease to other people but doesn't get ill from it themselves.

But the result shows that you are a **carrier** of a blood disease called sickle cell.

This leaflet gives you information about being a carrier, and what this means for you and your family.

## What is a sickle cell carrier?

Sickle cell is a blood disease which means a person's blood can't keep their body healthy.

One of your parents passed this on to you. You do not have the disorder yourself so you are healthy. But you could pass it on to your children. This is called being a carrier.



## What does this result mean for me?

The reason why you need to understand about being a carrier is because you could pass it on to your children.

## Rare health problems

Being a carrier does not make you ill. In day-to-day life you are just as healthy as anyone else.

The only times there may be a health problem are when you might not be able to breathe properly. That could happen because of these things:

- **When you have an operation.** If you need an operation, you should tell your doctor that you are a sickle cell carrier, so they can make sure you can breathe properly.
- **When you do extreme sports like deep-sea diving.** If you do sports like these, you should take care that you get enough air.
- **If you do a lot of regular exercise,** you should drink plenty of water and not get too tired.

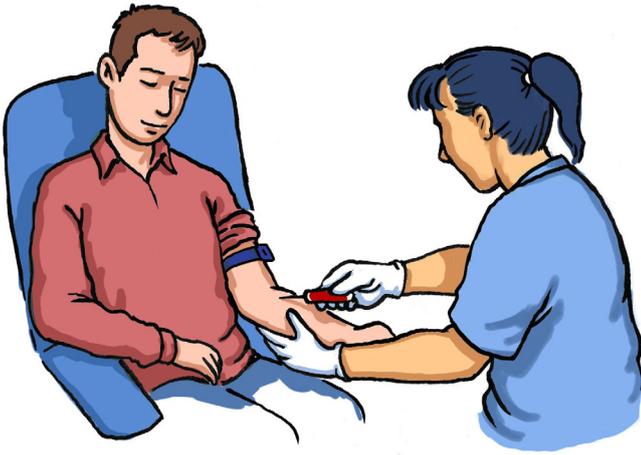
Apart from these situations, you live a completely normal life.



## What could my result mean for my children?

As a carrier, there is a chance that any children that you have could be carriers too. They might get a serious health condition.

The chances of you passing along the blood condition to your children are different depending on the type of blood your partner has.



Your partner will only know they are a carrier if they have had a special blood test. We will offer fathers-to-be this test when screening shows the mother is a carrier. But both men and women can ask for a test at any time from their GP.

## **What kind of disease could I pass on to my child?**

There are a number of blood diseases. Some are more serious than others.

The type of disease you could pass on to your child will depend on what types of blood both parents have.

If your partner is also a carrier, there is a chance that you could pass on a blood condition to your children. Some of these conditions are serious. If the blood test shows your partner is a carrier, your doctor will tell you more about this.



## **What does my result mean for other people in my family?**

If you are a carrier then other members of your family could be carriers too.

It is a good idea to talk to your parents, brothers, sisters, uncles, aunts and cousins and ask them to get a test before they start a family or have any more children. Showing them this leaflet may help.

## **Information about sickle cell disease**

Please remember that you are a 'carrier' and do not have sickle cell disease.

### **People with sickle cell disease:**

- can have attacks of very bad pain.
- can get serious infections that could kill if they're not treated.
- are usually anaemic. This means that their blood has difficulty keeping their body healthy.
- need medicines and injections when they are children and throughout the rest of their lives to stop infections.

There are also other, less common blood disorders. Many of these are not serious.

### **Common questions**

#### **Why didn't I know about this? I have had blood tests before.**

Blood tests don't always show that you are a carrier. More tests are needed to confirm this.

#### **What's the difference between being a carrier and having a disease?**

Carriers are generally well and are only spotted after special tests are done. People with a disease are usually ill and need treatment.

## **As a carrier could I get sickle cell disease?**

No, you cannot get sickle cell disease. But you will always be a carrier.



## **Is being a carrier infectious?**

No, you can only be a carrier if you have it passed to you from one of your parents. You can also pass being a carrier to any children you have.

## **Does being a carrier mean I can't have children?**

No, you can still have children.

## **What should I do now?**

- Let your family doctor (GP) know that you are a carrier.
- If you are expecting a baby or planning to have a baby, your partner should get tested to see if they are a carrier.
- If you already have adult children, they might want to be tested to see if they are also carriers.
- It is a good idea to talk to other members of your family and ask them to have a test before they start a family, or have any more children. Men and women should both be tested.
- The test is a simple blood test and only takes a few minutes. People can ask for the test at any time in their life.

## More information?

If you have any questions about any of the information in this leaflet, please talk to your Health Visitor, GP or local genetics service.

### **West of Scotland Regional Genetics Service**



Level 2, Laboratory Medicine Building

Southern General Hospital

1345 Govan Road

Glasgow

G51 4TF



Phone: 0141 354 9200

For people who live in: Greater Glasgow, Argyll & Clyde, Ayrshire & Arran, Forth Valley, Lanarkshire and Dumfries & Galloway

### **East of Scotland Regional Genetics Service**

Human Genetics Unit



Level 6 Ninewells Hospital and Medical School

Dundee

DD1 9SY



Phone: 01382 632035

For people who live in: Dundee, Perth, North Fife, Angus and Perthshire

## **North of Scotland Clinical Genetics Service**

Ground floor, Ashgrove House



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AB25 2ZA



Phone: 01224 552120

For people who live in: Grampian, Highland, Orkney, Shetland and Western Isles

## **Inverness Clinical Genetics Office Maternity Annexe**

Raigmore Hospital



Old Perth Road

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Phone: 01463 705902

For people who live in: Grampian, Highland, Orkney, Shetland and Western Isles

## **South East of Scotland Regional Genetics Service**



Department of Clinical Genetics

Western General Hospital

Crewe Road

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For people who live in: Lothian, Fife and the Borders

## **UK Thalassaemia Society**



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Website: [www.ukts.org](http://www.ukts.org)

## **The Sickle Cell Society**



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Website: [www.sicklecellsociety.org](http://www.sicklecellsociety.org)

## **Accessible Publishing of Genetic Information (APoGI)**



Website: [www.chime.ucl.ac.uk/APoGI](http://www.chime.ucl.ac.uk/APoGI)



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