

Information and advice for patients

Sickle Cell and Thalassaemia

What is sickle cell trait?

Sickle cell trait means that you carry a gene for sickle cell disease, but do not have the disease. Sickle cell disease is where the red blood cells, which are normally round, become shaped like a sickle (crescent shape). A person with sickle cell trait has a small amount of sickle haemoglobin but not enough to cause complications.

What are the symptoms of sickle cell trait?

Sickle cell trait does not cause any symptoms, but people with sickle cell trait are more at risk of the following:

- Blood in the urine
- Being less able to get rid of waste products in the urine
- Damage to part of the kidneys
- A rare type of kidney cancer

In addition to this, if you are in a situation where the level of oxygen in your body is extremely low, you are severely dehydrated or are doing extreme exercise, sickle cells can form and block some of your small blood vessels. This can lead to a sickle cell crisis which can cause the following complications:

- Pain in your bones, muscles, tummy or chest.
- A lack of oxygen to your spleen which can cause part of the spleen to become damaged.
- Muscle tissue breaking down and causing protein to leak into your urine which can cause kidney failure.
- Sudden life-threatening complications.

Despite these, people with sickle cell trait have an average life expectancy similar to that of the general population.

What causes sickle cell trait?

We all inherit haemoglobin genes from our parents; 1 from our mother and 1 from our father. Haemoglobin is the substance that carries oxygen around the body and gives blood its red colour. Normal haemoglobin (Hb) is known as adult haemoglobin, or haemoglobin A. Sickle haemoglobin is known as haemoglobin S.

• If you inherit 2 normal adult haemoglobin genes you will have normal blood; this is called HbAA.



Information and advice for patients

Sickle Cell and Thalassaemia

- If you inherit 2 sickle haemoglobin genes you will have sickle cell disease; this is called HbSS.
- If you inherit 1 normal adult haemoglobin gene and 1 sickle haemoglobin gene you will have sickle cell trait; this is called HbAS.

Sickle cell trait is common in many areas of the world, but particularly those areas where malaria is found because it gives a higher immunity to malaria. This includes:

- Africa
- The Caribbean
- The Mediterranean
- The Middle East
- Asia

How is sickle cell trait diagnosed?

Sickle cell trait is diagnosed by testing a sample of your blood. All new-born babies in the UK can have a blood test when they are a few days old (known as the 'heel prick' or 'blood spot' test) to find out if they have sickle cell disease, sickle cell trait or a number of other conditions.

Does sickle cell trait need treatment?

Sickle cell trait is not an illness, and you will not need treatment for it. However, because you are at risk of complications if you become very dehydrated have very low oxygen levels or do extreme exercise you should follow this advice to reduce the risk of these situations occurring:

- Make sure you are well hydrated by having plenty to drink, especially when you are exercising.
- Avoid high altitudes (such as climbing mountains).
- Avoid travelling in an unpressurised aircraft (some smaller aircraft may be unpressurised).
- Don't suddenly increase the amount of exercise you do without proper training, build up slowly.
- Do not smoke.

Will I pass sickle cell trait on if I have children?

If you have children they could inherit your sickle gene from you. If both you and your partner have sickle cell trait and have children together, your children could be born with either normal adult haemoglobin (HbAA), sickle cell disease (HbSS) or sickle cell trait (HbAS). The diagram below shows how likely it is that your children will inherit these:



Information and advice for patients

Sickle Cell and Thalassaemia

There is a:

- 25% chance that each child will have normal adult haemoglobin (HbAA)
- 25% chance that each child will have sickle cell disease (HbSS)
- 50% chance that each child will have sickle cell trait (HbAS)

If your partner has normal adult haemoglobin then your children will either have normal adult haemoglobin or sickle cell trait.

If your partner has sickle cell disease then your children will either have sickle cell trait or sickle cell disease.

Other unusual haemoglobins

If your partner is a carrier of another type of haemoglobin, your children could inherit this from them and could also inherit your sickle gene. There are unusual haemoglobins such as HBD, HBE HBO and others. Children can also inherit thalassaemia and the same time as a sickle gene. If this happens the child will have another type of sickle cell disorder, such as sickle haemoglobin C disease (also called SC disease) or sickle beta thal.

It may also be the case that your partner is the sickle trait and you have the other unusual haemoglobin.

Because of this, it is a good idea for your partner to have a blood test to check what type of haemoglobin they have before you have children together, so you can get specialist advice. This is known as partner screening. You can ask your GP for partner screening for unusual haemoglobins.

Contact details

Sickle Cell and Thalassaemia Centre at City Hospital

0121 507 6040

Monday, 9am - 5pm

Tuesday, 9am – 6pm

Wednesday, Thursday and 9am – 5pm

Friday, 9am – 4pm

Saturday blood transfusion service only

The information in this leaflet is general and is intended to be a guide only. Please discuss the specific details of your treatment with your GP/doctor.



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Sickle Cell and Thalassaemia

Further information

For more information about our hospitals and services please see our website www.swbh.nhs.uk, follow us on Twitter @SWBHnhs and like us on Facebook www.facebook.com/SWBHnhs.

Sources used for the information in this leaflet

- Sickle Cell Society (2018) Standards for the clinical care of adults with sickle cell disease in the UK. [Online]. London: Sickle Cell Society. Available at: https://www.sicklecellsociety.org/ wp-content/uploads/2018/05/Standards-for-the-Clinical-Care-of- Adults-with-Sickle-Cell-inthe-UK-2018.pdf [Accessed 02 October 2023].
- Patient (2023) *Sickle Cell Disease: Sickle Cell Anaemia*. Available at: https://patient.info/allergies-blood-immune/sickle-cell-disease-sickle-cell-anaemia [Accessed 02 October 2023].
- National Institute for Health and Care Excellence (2021) Clinical Knowledge Summaries:
 Sickle cell disease. Available at: https://cks.nice.org.uk/sickle-cell-disease [Accessed 02 October 2023].

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