



Sickle cell disease and pregnancy

A patient's guide

1. What is sickle cell disease (SCD)?

SCD is a disorder of the body's red blood cells that is genetically inherited and lifelong.

It is caused by an abnormality in haemoglobin (the part of red blood cells that carries oxygen round the body), which makes the red cells become inflexible and sticky. This in turn makes other blood cells as well as the vessels they travel in sticky. When this happens, the blood flow becomes interrupted and an inflammatory cascade occurs – a process where one inflammatory reaction causes another. This process may cause pain, known as vaso-occlusive crisis, and also problems in the organs where the sickling is happening.

For more information about SCD, please see our leaflet, **Sickle cell disease in adulthood**.

2. How common is SCD?

SCD is the most common inherited condition in the world and mostly affects people whose family origins are in the Middle East, Sub-Saharan Africa, parts of India and parts of the Mediterranean.

Between 12,000 and 15,000 people in the UK have SCD and just under 300 babies are born with the condition in this country every year. Parents of all babies born in the UK are given the opportunity to have their baby tested for SCD in the first week of life (the heel prick test).

3. Will my baby be affected?

If you have SCD or are a carrier of sickle or an abnormal haemoglobin, you should find out whether your partner is also affected before getting pregnant.

If your partner does not have SCD and is not a carrier, your baby will not have SCD. However, they will be a carrier of one of your two abnormal haemoglobin genes.

If your partner has SCD or is a carrier of an abnormal haemoglobin, or if you are unsure what their haemoglobin type is, you or your haematology team can arrange an appointment at the haemoglobinopathy genetics clinic.

During this appointment, any necessary tests will be carried out and both you and your partner will be offered specialist counselling if needed. The information and counselling will help you both decide whether to have tests when you become pregnant to find out if your baby has the condition or to opt for the pre-implantation genetic diagnosis. Pre-implantation genetic diagnosis is when genes of embryos created through IVF are checked for any conditions that can be passed on by the parents.



We realise that this can be a difficult decision for many couples. Further information is available from the NHS Choices at: www.nhs.uk/Conditions/Sickle-cell-anaemia/Pages/Diagnosis.aspx

4. What should I think about before becoming pregnant?

It is important that you let your haematology team know that you are planning to have a baby. They will help you to be in the best possible health before you become pregnant. Until that time, they can advise you which contraception is best for you. For more information about contraception, please ask staff for a copy of our leaflet, **Sexual health, contraception and preparing for pregnancy: Information for patients with thalassaemia and sickle cell disease (SCD)**

Your haematology team will also advise you on any complications you may have during pregnancy, and recommend some tests and checks, including:

- a detailed scan of your heart (echocardiogram)
- blood pressure, urine and blood tests
- a special eye test (retinal screening) to detect problems at the back of the eyes.

5. Will I need to change my normal treatment before I become pregnant?

If you are taking hydroxycarbamide (hydroxyurea), you should stop taking it and continue to use contraception for three months before you become pregnant. If you experience a lot of problems due to your sickle cell disease, a regular transfusion programme may be appropriate for you.

Your haematology team will review any other medicines you are taking and check your blood for antibodies that may have developed after blood transfusions. You should also make sure that all your vaccinations are up to date.

For more information, please ask staff for a copy of our leaflet, **Medications, vaccinations and travel in sickle cell disease**.

You should start taking folic acid three months before you get pregnant.

6. What are the risks to me and my baby in pregnancy?

Many women with sickle cell disease have healthy babies and problem-free pregnancies. However, pregnancy is a physically and emotionally demanding time for the mother, and complications may develop for a variety of reasons, some of which may or may not be related to the SCD.

To ensure that you and your baby thrive during the pregnancy, and that any problems are identified early and managed properly, you will be seen by many healthcare professionals and have more frequent visits and scans.

- Painful crises can be more common during pregnancy and can be brought on by cold weather, dehydration and doing too much physical activity. If you have morning sickness (which can lead to dehydration) or any other concerns, contact your maternity unit as soon as possible.
- Crises in pregnancy can also lead to worsening anaemia or acute chest syndrome. If you feel particularly tired, short of breath, or you think you are having a crisis, please contact your haematology team and the maternity unit as soon as possible.



- Pregnant women are generally at an increased risk of developing blood clots in the legs or lungs (venous thrombosis). SCD further raises this risk. For more information, please read the patient information leaflet developed by the Royal College of Obstetricians and Gynaecologists, **Reducing the risk of venous thrombosis in pregnancy and after birth: information for you**. It is available at: www.rcog.org.uk/en/patients/patient-leaflets/reducing-the-risk-of-venous-thrombosis-in-pregnancy-and-after-birth
- You are also at an increased risk of high blood pressure during the pregnancy. This is known as pre-eclampsia and tends to happen later in pregnancy. To minimise this risk, all women with sickle cell disease are offered low dose aspirin as soon as pregnancy is confirmed. For more information, please read the patient information leaflet developed by the Royal College of Obstetricians and Gynaecologists, **Pre-eclampsia: information for you**. It is available at: www.rcog.org.uk/en/patients/patient-leaflets/pre-eclampsia
- SCD may also affect the growth of your baby because it can affect how your placenta works. To find out more, please read the patient information leaflet developed by the Royal College of Obstetricians and Gynaecologists, **Having a small baby: information for you**. It is available at: www.rcog.org.uk/en/patients/patient-leaflets/having-a-small-baby
- You are more likely than women without SCD to go into labour early or need a caesarean section. If you do not go into labour early, your maternity team may advise you to have your labour started off (induced) at some point before your due date to reduce the risks of becoming unwell to you and your baby. Your obstetrician and midwife will talk to you about your options.

7. What extra care will I receive when I am pregnant?

It is important that you let your haematology team and your GP know as soon as you find out you are pregnant. You will have consultant-led care rather than midwifery-led care because of your SCD, but you will often see a midwife too.

You will be seeing specialist teams throughout your pregnancy. If you did not have the recommended tests in the previous year, they should be carried out. Your vaccinations for hepatitis B and flu as well as the Pneumovax® vaccine should be updated if necessary. These vaccinations are safe in pregnancy.

You should have your appointments at the antenatal clinic at least every four weeks until your 24th week, and then every one to two weeks until you have had your baby. At each visit you will have your blood pressure checked and your urine tested. As well as the routine scans, you should have extra scans to check that your baby is growing normally.

Blood transfusions are not routinely given during pregnancy, but if they are needed, your haematology team will discuss this with you – there is currently a clinical trial to see if this treatment is effective.

Your risk for thrombosis should be assessed in early pregnancy in the high-risk obstetric clinic. This is in addition to your appointment with the sickle cell haematologist. If there are any other risk factors that make you more likely to get a blood clot, for example if you are overweight, you may need to have daily low molecular weight heparin (LMWH) injections throughout your pregnancy. These are safe to take while you are pregnant and should be continued for six weeks after your baby is born to reduce the risk of blood clots.

Please ask your haematology or maternity team about who to contact (it is usually your maternity unit) if you develop problems such as a sickle crisis. This is to ensure that you can be seen promptly if you have difficulties in between clinic appointments.



8. What medicines or treatment should I take in pregnancy?

You will be advised to continue your folic acid (5 mg) once a day and penicillin V 250 mg twice a day.

You should take low-dose aspirin (75 mg a day) from early pregnancy to reduce the risk of pre-eclampsia.

If you have significant problems with your SCD, you may need to be on regular transfusions for all or part of pregnancy. Your haematology team will discuss this with you at your clinic appointment. If you are at an increased risk of blood clots, you may need to take a blood-thinning medicine, such as low molecular weight heparin (LMWH), Fragmin® or tinzaparin. If you do not have to take it when you are pregnant, it is likely that it will be given to you after delivery. Your doctor will discuss this with you in clinic.

9. Medicines that are stopped during pregnancy

If you became pregnant unexpectedly and had not stopped your hydroxyurea, you should stop it as soon as you have a positive pregnancy test.

Chelation (treatment to reduce iron overload) is also stopped in pregnancy, although it may be started again right at the end of pregnancy if you have severe iron overload.

You can take painkillers, such as paracetamol and codeine. Like all pregnant women, you should not take painkillers such as ibuprofen before 12 weeks and after 28 weeks of pregnancy without talking to your doctor as they could cause problems for your baby.

10. What if I have a crisis or become unwell during pregnancy?

If you become unwell, contact the haematology advice line or the haematology team (contact details are on page 13). You will also receive other useful contact numbers for any pregnancy-related questions or issues during your first appointment with a midwife.

If you have a crisis, you will be given strong painkillers, oxygen if needed, and fluids through a drip in your arm if you are dehydrated.

Other causes of your symptoms will also be checked. If necessary, you may be prescribed antibiotic and given low molecular weight heparin (LMWH) injections to reduce the risk of blood clots. You will be monitored closely – often in a high-dependency area of the hospital. Your baby's wellbeing will also be checked.

11. What happens in labour?

You should have your baby in a hospital that is able to manage potential SCD-related complications.

You will be kept warm to reduce the risk of a crisis in labour. You may be given fluids through a drip to prevent dehydration and oxygen if needed. Blood that is suitable for you will be available in case you need a transfusion. Your baby's heartbeat will be closely monitored in labour.

You should be able to have a vaginal birth if there are no complications and you are in good health.



12. What about pain relief?

You should see an anaesthetist before you go into labour to discuss pain relief – this is often possible in the high-risk obstetric clinic.

All the usual methods of pain relief should be suitable for you, except pethidine as it is not used in sickle cell disease.

13. What happens after my baby is born?

You should be kept warm and well hydrated, and you may be given extra oxygen to prevent a crisis.

You will be encouraged to get up and about to prevent blood clots from forming in your legs. You may need to wear special stockings and have daily low molecular weight heparin (LMWH) injections for at least a week to reduce this risk further. Depending on any other risk factors relevant to you, and after caesarean section, you may be advised to continue low molecular weight heparin (LMWH) injections for six weeks.

Breastfeeding is recommended, and you will be given the support you need.

All parents in the UK are given the opportunity to test their babies for SCD and other conditions. This involves taking a blood sample from the baby's heel around day five after birth. This test is usually done by the community midwife when you are at home, or in hospital if you or your baby are still there.

The results usually take four weeks to come back. If there is a risk that your baby could have sickle cell disease, the red cell team can organise for the blood test to be done in hospital so that you can have the results on the same day or day after.

14. What about contraception?

The combined oestrogen/progesterone pill, progesterone-only pills, injections (Depo-Provera®), implants (Nexplanon®), the Mirena® coil and barrier methods (such as sheaths and caps) are safe and effective.

If you would like more information on contraception, please talk to your GP or family planning specialist. You can also ask for a copy of our leaflet, **Sexual health, contraception and preparing for pregnancy: Information for patients with thalassaemia and sickle cell disease (SCD)**.

15. Key points to remember:

- SCD is the most common inherited single-gene disorder in the world.
- Most women with SCD will have a relatively straightforward pregnancy and a healthy baby.
- If you are planning a pregnancy, let your haematology team know so that they can review your medicines and vaccinations and make sure your checks are up to date.
- You and your partner can meet a specialist or counsellor to discuss the risk of SCD being passed to your baby, and the tests available to you. This is best done in pregnancy.
- A specialist team will look after you and your baby very closely during pregnancy.
- Having your baby at some point before your due date is usually advised.
- You will be given support to breastfeed.



Contact details

Specialist nurses

Emma Prescott (nurse specialist, thalassaemia)	020 7288 5225
Matty Asante-Owusu (community matron, adults)	07920 711210
Edith Aimiwu/Sarah Cullen (nurse specialist, children)	07799 347161
Olivia Kudom (nurse specialist, sickle cell adults)	07887 987931

Haematology consultants

Dr Bernard Davis
 Dr Farrukh Shah
 Dr Ali Rismani
 Dr Emma Drasar

Paediatric consultants

Dr Andrew Robins
 Dr Janine Younis

If you or your family have any other questions please do not hesitate to contact any of the above healthcare professionals at Whittington Health.

Patient advice and liaison service (PALS)

If you have a compliment, complaint or concern please contact our PALS team on 020 7288 5551 or whh-tr.whitthealthPALS@nhs.net

If you need a large print, audio or translated copy of this leaflet please contact us on 020 7288 3182. We will try our best to meet your needs.

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