University Hospitals of Leicester
NHS Trust

Sickle cell disease and pregnancy: what you need to know

Sickle Cell and Thalassaemia Service

Information for Patients

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What is sickle cell disease (SCD)?

When you have sickle cell disease, the round red blood cells turn into long rod-like cells called sickle cells. These rod-like red cells are sticky. They cannot move easily through small blood vessels. The blood vessels can easily become blocked. This causes pain and damage to different parts of the body. This can lead to a sickle cell "crisis".

Your body breaks down the sickle cell red blood cells but your body cannot replace them with healthy round red blood cells quickly enough. This leads to a shortage of red cells. This is called anaemia.

What causes sickle cell disease?

- SCD is the name of a group of health problems that affect the haemoglobin. This is a protein found in red blood cells. They are passed down in families.
- We all have 2 copies of the haemoglobin gene. 1 gene comes from our father. 1 is from our mother.
- 2 abnormal genes lead to the development of sickle cell disease.
- Some people may have 1 abnormal gene and 1 normal gene. These people are known as 'carriers' or as having the sickle cell trait. Carriers will not get sickle cell disease. They are well in themselves. There is a chance that they could pass the sickle cell gene on to their children.
- SCD is a common genetic health problem across the world. It mostly affects people whose family come from Africa, Middle East, India, the Mediterranean and the Caribbean.

Will sickle cell disease be passed on to my child?

It is important that we test your partner to see if they have the sickle cell gene. If both parents have the sickle cell gene, there is a risk that your baby can get SCD. If you have SCD but your partner does not have the sickle cell gene, then your baby will have the trait. They will be a carrier.

Each year, about 300 babies are born with sickle disease in the UK. All babies born in the UK are offered newborn screening in the first few days of life to find genetic conditions such as SCD.

How does having sickle cell disease affect pregnancy?

Pregnancy puts more stress on your body. This can mean your SCD gets worse. You may have a rise in the number of sudden painful episodes (often known as a sickle cell crisis).

Please remember that a sickle cell crisis can be brought on if you are cold, have not had enough to drink and have done too much physical activity. So wrap up warmly when it is cold outside, drink plenty of water and take rests when you need to.

You are also likely to become more anaemic during your pregnancy. Having SCD can make this worse.

Most pregnant people with sickle cell disease have few problems. But there is a higher risk of certain complications. The risk of complications varies between the different types of sickle cell disease. Studies suggest that 1 in 2 pregnant people will need to be admitted to hospital due to a crisis. 1 in 2 pregnant people with the worst type of sickle cell disease will need a blood transfusion in pregnancy.

Possible problems for your unborn baby:

- SCD affects how well the red blood cells carry oxygen. This is very important for your unborn baby.
- Your baby may not grow as they should.

Possible problems for you

- Higher risk of high blood pressure, and more protein in the pee (pre-eclampsia)
- Higher risk of infections, mainly pee infections
- Higher risk of blood clots in the legs and lungs

Pregnancy-related complications

There is a higher risk of miscarriage, early (premature) birth and of bleeding more during the birth.

There is also a higher risk that you may need a ceasarean section to have your baby.

Can someone with SCD have a healthy pregnancy?

Most pregnant people with SCD have a safe pregnancy with few problems. This is because they have had a plan of care made by their haematologist, specialist nurse, obstetrician and midwife. It is important that we make a plan that is right for you and your baby. Talk to your haematologist about your plans for having a baby before getting pregnant. In this way we can work with you to help you have a healthy and successful pregnancy.

Before you get pregnant

It is very important to tell your Sickle Cell Disease team when you are planning to have a baby. This is so that we can:

1. Look at the medications you are taking. Some may need to be stopped. These include;
    - Hydroxycarbamide – should be stopped for 3 months before getting pregnant
    - Certain medicines for high blood pressure
    - Non-steroidal anti-inflammatory drugs (NSAIDs), such as ibuprofen, Nurofen, diclofenac and naproxen should only be taken if your doctor says so. If given, it is usually for 2 to 3 days.
2. Give you a full check-up to see how the SCD has affected you. This includes a scan of your heart (echocardiogram), blood pressure check, pee and blood tests and eye (retinal) screening.
3. Talk to you about taking antibiotics to help protect you from infection. Check that you have had all your vaccinations and that they are up-to-date. These include: meningococcal C, pneumococcus, H. influenza type b, flu and Hepatitis B.
4. Test your partner for SCD to find out their haemoglobin status.
5. Talk to you about the chance of your child being affected by SCD.
6. Talk to you about taking folic acid to:
    - lower the risk of your anaemia getting worse
    - help the body to make red blood cells
    - help you have a healthy pregnancy by preventing spina bifida in your baby

What should I do once I find out I am pregnant?

Tell your Sickle Cell Disease team as soon as you find out you are pregnant. You will need:

- regular midwife reviews
- monthly appointments at a joint haematology and obstetrics clinic. We can check you and your baby's health and plan your pregnancy.

Antenatal care: what to expect during your pregnancy

Medications

You are likely to be prescribed:

- Aspirin (150 mg once a day) to reduce the risk of pre-eclampsia

- Folic acid 5mg once a day
- Iron supplements if your blood tests show that you have low iron levels
- Heparin injections to thin your blood. This will reduce the risk of you r body making blood clots. The risk of blood clots is higher in SCD. It is also higher when you are not moving about as much normal, for example when you are in hospital. We tend to start these injections from 28 weeks of pregnancy. But some pregnant people may need them earlier and/or during any hospital admissions.

Monitoring

We will:

- check your blood pressure at every appointment during your pregnancy
- do blood and pee tests to check how your body is coping with pregnancy

You will also need ultrasound scans at 7 to 9 weeks, 11 to 14 weeks, 20 weeks and monthly scans from 24 weeks. These scans help us to make sure that your baby is developing and growing well.

Important advice

Keep warm: Extremes of temperature, mainly being too cold, are known to trigger a crisis. It is important to keep warm. Wear warm clothes in winter. Try to make sure your home and work are heated and warm.

Eating and drinking: Drink plenty of fluids (water) during the day. Try to drink 3 to 4 litres a day. If you do not drink enough, this may trigger a crisis. Many pregnant people suffer with feeling sick and being sick in early pregnancy. Being sick can lead to dehydration, This can also trigger a crisis. It is important to get medical attention early if you are worried about being sick and you are not able to keep drinks down.

Eating a healthy, balanced diet will also help you and your unborn baby to have a healthy pregnancy.

Get enough rest: Do not do too much physical activity during pregnancy. This could trigger a crisis. You should think about making changes to your working and home life. Make sure you get plenty of time to rest.

It is also important to avoid emotional stress. This could trigger a crisis.

You may begin to feel more tired than usual during pregnancy. This could be a sign that your anaemia is getting worse. You may need iron supplements. In severe cases of anaemia, you may need a blood transfusion. This will give you more red blood cells.

Blood transfusion: Some pregnant people with SCD need regular blood transfusions or a red cell exchange program during their pregnancy. We will talk to you about this at your first clinic appointment. We will review this regularly during your pregnancy.

Looking out for complications:

Infection – get medical attention if you

- have a fever (high temperature),
- burning pain on passing pee or pee that is more smelly than usual (urine infection)
- a cough, bringing up yellow-green spit,
- shortness of breath
- chest pain (chest infection)
- **Blood clots:** Blood clots can cause swelling and pain and are more likely to form in your legs. But get medical attention if you notice swelling or pain, in an area of your body.

What should I do if I have a sickle cell crisis?

Even though you have looked after yourself and tried to avoid things that trigger problems, you may still have a sickle cell crisis. If you begin to get pain, start by taking painkillers, such as paracetamol or weak opioids such as co-codamol. Drink plenty of water. In some cases, it may be safe for you to use non-steroidal anti-inflammatory pain killers (for example, ibuprofen, diclofenac). You should only take these if your doctor has told you to. You will usually only be asked to take them for 2 to 3 days.

If your pain cannot be controlled at home or seems different to normal, or if you have a high temperature (fever), shortness of breath or chest pain, you must get urgent medical attention. Come to the hospital right away. If you are less than 23 weeks pregnant, ring the Haematology Helpline (telephone 0808 178 2212). If you are 23 weeks pregnant or over, call the maternity hospital (telephone 0116 258 6111). We will admit you on to a ward for monitoring and care by a team of specialists.

What will happen when I am due to give birth?

You and your health care team will decide on a plan of options. This will include when and how you plan to give birth to your baby (vaginal birth or caesarean section). We will talk about your pain relief options during labour. We will also talk about care of your baby after the birth. We will write a personal plan for you. It will be agreed by you and the team.

It is recommended that pregnant people with SCD, who have had no problems give birth to their baby after 38 weeks, in a hospital. In hospital we have specialist medical care to support your needs. Giving birth to your baby at this time lowers the risks that can increase due to any problems with the placenta towards the end of your pregnancy.

You may be offered induction of labour or a planned caesarean section. We will talk to you about this. We will listen to your personal wishes and make a birth plan with you. We will check your unborn baby's heartbeat all the time during labour. This will help your midwife and doctor to see if there are any signs that your baby is becoming distressed during your labour. If we see signs of distress, we can do something right away.

What will happen after I have given birth?

If you have had a vaginal birth, you are well, and there are no complications you may go home within 1 to 2 days. If you had a caesarean section or have any other complications, you may need to stay in hospital for longer.

To reduce the risk of blood clots you will;

- need to wear anti-thrombotic stockings
- need blood thinning injections. All post natal people with sickle cell disease will be prescribed a 6 week course of injections to carry on taking at home.

Your baby will be tested for sickle cell disease after birth. This is done as part of the newborn blood spot heel prick test. This test is offered to all babies on day 5 of life. We can do earlier tests if we think you are at high risk of having a baby with SCD.

Useful contacts

Sickle Cell and Thalassaemia Service

Ground Floor, Osborne Building, Leicester Royal Infirmary, Leicester LE1 5WW

Mon to Fri, 9.00am-5.00pm
Telephone: 0116 258 6081 (Answerphone available)

Haematology helpline
24 hours 7 days a week
Telephone: 0808 178 2212

Further information

Sickle Cell Society

www.sicklecellsociety.org

NHS website https://www.nhs.uk

Sickle Cell and Thalassaemia Screening Programme www.gov.uk/guidance/sickle-cell-and-thalassaemia-screening-programme-overview

اگر آپ کو یہ معلومات کسی اور زبان میں درکار ہیں، تو براہِ کرم مندرجہ ذیل نمبر پر ٹیلی فون کریں۔
على هذه المعلومات بلغةٍ أُخرى، الرجاء الاتصال على رقم الهاتف الذي يظهر في الأسفل
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Previous reference:

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