NHS
University Hospitals of Liverpool Group

Patient information

Sickle Cell Disease and Pregnancy

Clinical Haematology Department

This is an information sheet about sickle cell disease and pregnancy. If you have any questions or concerns, please do not hesitate to speak with your haematology doctors or the sickle cell nurse specialists.

Does SCD affect fertility?

Sickle cell disease can affect fertility in both males and females. In men, it can lead to lower sperm counts, testicular dysfunction and other issues with the sperm. Women with sickle cell disease may have a lower ovarian reserve which can result in reduced fertility, increased risk of miscarriage and early menopause.

Some patients worry that hydroxycarbamide, a medication used to treat sickle cell disease, may affect their fertility. There is currently no evidence that hydroxycarbamide affects fertility in women. In men, sperm count may be reduced whilst taking the drug however this usually reverses on stopping treatment. Your sickle cell team can discuss sperm analysis and storage with you.

Will my pregnancy be affected if I have sickle cell trait?

No, carriers do not usually experience symptoms, but you can pass the condition on to your children if your partner is also a carrier or has SCD (see below).

I have SCD. What should I think about before becoming pregnant?

It is important that you let your SCD team know that you are planning to have a baby. They will be able to help you to be in the best possible health before you become pregnant. Until that time, they can advise you on which contraception is best for you.

If you have SCD, you should consider finding 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.

If your partner has SCD or is a carrier, specialist counselling is available. This will help you both decide whether to have tests when you become pregnant to find out whether your baby has the condition. This can be a difficult decision for many couples and further information is available from the NHS Sickle Cell and Thalassaemia Screening Programme at: http://sct.screening.nhs.uk and http://sct.screening.nhs.uk/professional-leaflets.

You may also be eligible for a treatment called pre-implantation genetic diagnosis (PIGD) which is used in conjunction with In Vitro Fertilization (IVF) to perform genetic testing on an embryo prior to implantation to ensure that it is not affected by sickle cell disease.

Whether you are planning a pregnancy or not, you should see your SCD team at least once a year. The checks may include:

- 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.

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 using contraception for thrree months before you become pregnant. If you become pregnant whilst taking hydroxycarbamide, you should stop taking this medication and inform your sickle cell team.

You should not take hydroxycarbamide during your pregnancy or whilst breastfeeding. Your SCD team will also review any other medicines you are taking.

What medicines should I take in pregnancy?

People with SCD are at extra risk of infection, so you may be advised to take a daily dose of antibiotics (usually penicillin) throughout your pregnancy. Your vaccinations for hepatitis B, flu and pneumonia should be up to date.

You will also be advised take:

- high-dose folic acid (5 mg) daily throughout your pregnancy
- low-dose aspirin (150 mg) daily from early pregnancy to reduce the risk of pre-eclampsia.
- during your final trimester you may be advised to take an anticoagulant injection to reduce the risk of blood clots. You may be advised to continue this medication for around six weeks following the birth of your baby

You can take painkillers such as paracetamol, tramadol and dihydrocodeine. 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.

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

Most women with SCD will have a straightforward pregnancy and not have serious problems. However, painful crises can be more common during pregnancy. Cold weather, dehydration and doing too much physical activity can bring them on. You may need to take it easy. If you start to feel tired or have mild pain, you should rest.

SCD can also cause serious problems such as sudden anaemia and lung problems. If you have morning sickness (which can lead to dehydration) or have any other concerns, contact your maternity unit as soon as possible.

Pregnant women have a higher risk of developing blood clots in the legs (venous thrombosis) compared with women who are not pregnant. SCD makes you even more likely to develop a venous thrombosis.

You can find out more about this from the RCOG patient information leaflet Reducing the risk of venous thrombosis in pregnancy and after birth: information for you, which is available at:**www.rcog.org.uk/en/patients/patient-leaflets/reducing-the-risk-of-venous-thrombosis-in-pregnancy-and-after-birth.**

There is a higher chance that you may get pre-eclampsia (a condition of high blood pressure and protein in the urine) in later pregnancy. You can find out more about this from the RCOG patient information leaflet Pre-eclampsia: information for you, which is available at: **www.rcog.org.uk/en/patients/patient-leaflets/pre-eclampsia.**

SCD may affect the growth of your baby because it can affect how your placenta works. You can find out more about this from the RCOG patient information leaflet Having a small baby: information for you, which is available at: **www.rcog.org.uk/en/patients/patient-leaflets/having-a-small-baby.**

You are more likely to go into labour early. If you don't, you are likely to be advised to have your labour started off (induced) at some point before your due date, to reduce the risks to you and your baby. You are also more likely to need a caesarean section. Your obstetrician and midwife will talk to you about your options.

What extra care will I receive when I am pregnant?

You should be looked after by an obstetrician, a midwife and a haematologist (a blood specialist) with expertise in SCD. If you have not had the recommended tests in the previous year, they should be carried out. Your vaccinations for hepatitis B, flu and pneumonia should be updated if necessary. These vaccinations are safe in pregnancy.

You should be seen at the antenatal clinic at least every four weeks until your 24th week, and then every one – 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 may be needed. If so, this will be discussed with you. In some cases, pregnant women with sickle cell disease may be started on a red cell exchange programme to reduce the risk of severe painful crisis while they are not taking hydroxycarbamide.

Your risk for thrombosis (blood clots in your legs or lungs) should be assessed in early pregnancy. If you have any other risk factors that make you more likely to get a blood clot, for example being overweight, you may be advised to have daily heparin injections throughout your pregnancy. This is 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.

You should ask the team looking after you for contact details of whom you should call (usually your maternity unit) if you develop problems such as a sickle crisis, so that you can be seen promptly if you have difficulties in between clinic appointments.

What if I have a crisis during pregnancy?

If you become unwell, contact your maternity unit as soon as possible so that you can be seen urgently by medical staff and given treatment.

You will be given strong painkillers, oxygen to breathe, and fluids through a drip in your arm if you are dehydrated. You will also be checked for other causes of your symptoms and you may be given antibiotics. You should also be given heparin 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 be checked.

What happens in labour?

You should have your baby in a hospital that is able to manage SCD complications. You will be kept warm to reduce the risk of developing a crisis in labour. You may be given fluids through a drip to prevent dehydration and you may need oxygen. 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. Many women with sickle cell disease require induction of labour or caesarean section however it may be possible to have a normal vaginal delivery if you do not have any complications and your medical team advise that this is safe.

What about pain relief?

You should see an anaesthetist before you go into labour to discuss pain relief. All the usual methods should be suitable for you except pethidine as it could cause complications.

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 help stop blood clots forming in your legs. You should be offered special stockings and daily heparin injections (to help thin the blood) for at least a week to reduce the risks further. You may be advised to continue heparin for six weeks if you have any other risk factors, for example caesarean section.

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

Parents of all babies in the UK are given the opportunity to have their baby tested for SCD (together with other health checks) from a heel prick blood spot sample on about day five after birth.

What about contraception?

You will be offered contraception following delivery of your baby. This will allow your body time to recover from your pregnancy and labour before becoming pregnant again.

Progesterone-only pills, injections (Depo-Provera), implants (Nexplanon), the Mirena coil and barrier methods (sheaths and caps) are safe and effective. The combined estrogen/progesterone oral contraceptive ('the pill') and copper coil can be used but only if the above methods are unsuitable for you. You can talk to your GP or family planning specialist.

Feedback

Your feedback is important to us and helps us influence care in the future.

Following your discharge from hospital or attendance at your outpatient appointment you will receive a text asking if you would recommend our service to others. Please take the time to text back, you will not be charged for the text and can opt out at any point. Your co-operation is greatly appreciated.

Further information

Contact Details:

Specialist Haemoglobinopathy Team:

Consultant Haematologist
Clinical Nurse Specialist
Haematology Specialist Registrar (Rotational Position)
Clinical Psychologist

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All Trust approved information is available on request in alternative formats, including other languages, easy read, large print, audio, Braille, moon and electronically.

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