King's College Hospital
NHS Foundation Trust

Pregnancy and sickle cell disease

Information for patients

Every year around 200 women with sickle cell disease become pregnant in the UK, thanks to improved management of the condition. At King's we run a joint haematology and obstetric clinic to ensure the best possible outcome for you and your baby. Here is an outline of what to expect from your care and how to stay well during pregnancy and beyond.

Confirming your identity

Before you have a treatment or procedure, our staff will ask you your name and date of birth and check your ID band. If you do not have an ID band we will also ask you to confirm your address. If we do not ask these questions, then please ask us to check. Ensuring your safety is our primary concern.

Planning your pregnancy

Planning a pregnancy increases the chances of it being successful. Make an appointment to see your haematology team before you start trying to get pregnant.

Continue to take 5mg of folic acid a day to help reduce the risk of spina bifida and ensure you have enough folate, which is essential for healthy red blood cells.

We also recommend that you take one 10mcg vitamin D supplement a day. Your GP can prescribe these for you.

Your haematologist will review your health and arrange blood tests, eye tests and an echocardiogram (heart scan). They will review your medications and decide what needs to change to maximise your overall wellbeing.

Some medicines are **NOT** recommended in pregnancy and should be stopped, unless your team suggests otherwise. These include:

- **hydroxycarbamide** – used to boost healthy red cells in your blood, reduce sickle cells and improve overall health and survival in sickle cell disease
- **enalapril or ramipril and other ACE inhibitor medications** – to protect your kidneys, and control blood pressure to protect your brain and heart
- **deferasirox** – used to remove excess iron from your body
- **non-steroidal anti-inflammatory drugs (ibuprofen and diclofenac)** – used for pain control

Genetic counselling

Sickle cell is an inherited disease that could affect your baby, so you may be offered genetic counselling. Your partner may need a blood test to check if they are a sickle cell carrier. If they are, you will discuss the potential risk to the baby and your options, such as testing the baby in pregnancy or pre-implantation genetic diagnosis (PIGD). PIGD is a form of IVF that involves testing the embryo to select one that does not have the disease.

When you become pregnant

As soon as you find out you are pregnant, contact your haematology team to review medications and plan care. Complete an online maternity self-referral booking form for King's College Hospital. This will be sent to the Ruskin team, the specialist team of midwives who care for women with sickle cell disease (SCD). If you live in the catchment area for Princess Royal Hospital (PRUH), we may recommend you attend appointments with the Ruskin team at King's College Hospital. You will also be sent a date for your first ultrasound scan, which will happen when you are around 12 weeks pregnant.

Specialist clinic for pregnancy and sickle cell disease

Every month you will see the obstetrician and haematologist to review your health and discuss the plan for your pregnancy. You will also see your specialist midwives at this meeting. Additional appointments will take place to test your blood and discuss the birth.

We assess all pregnant women for their individual risk of blood clots (deep vein thrombosis and pulmonary embolism). Most pregnant women with sickle cell disease are offered daily aspirin and enoxaparin (Clexane) injections to prevent blood clots, either throughout pregnancy, or from later

pregnancy, and for six weeks after giving birth. We may also prescribe 250mg of penicillin V to help prevent infections.

How will pregnancy affect my sickle cell condition?

Every woman is different. For some, pregnancy has little impact, but for others it can increase the risk of health problems.

Pregnancy can:

- increase the likelihood of having a sickle cell crisis and sometimes hospital admission is necessary to manage pain – this is more likely towards the end of the pregnancy
- increase the risk of anaemia, especially as the pregnancy progresses – this may mean you need more blood transfusions during pregnancy

Fortunately, serious complications are rare.

How will sickle cell disease affect my pregnancy?

The majority of women experience very few problems, but there is an increased chance of:

- miscarriage and pregnancy loss
- reduced growth of the baby
- high blood pressure and pre-eclampsia
- blood clots such as deep vein thrombosis – you may be prescribed a blood thinning drug, called enoxaparin (Clexane), to prevent this
- having your labour induced if you need to be delivered before your due date
- having a Caesarean section to deliver your baby

Keeping yourself healthy in pregnancy

It is likely that you will feel well during your pregnancy, but you should take extra care to prevent complications:

- Drink plenty of fluids as dehydration can trigger a crisis. Aim for two to three litres a day. If you experience severe vomiting in early pregnancy, you should see a doctor as soon as possible to control the problem and prevent dehydration.
- Eat plenty of fresh fruit and vegetables and ensure your diet is well balanced. Eating plenty of fibre will help stop constipation. You may find snacks and frequent small meals are more appealing than large meals. This will also reduce the problem of indigestion and reflux.
- Rest regularly and avoid taking on too much work. Pregnancy makes all women feel more tired than usual but sickle cell disease is likely to increase fatigue.
- Stay warm and wear extra layers in cold weather. It is well known that being cold can trigger a crisis
- Avoid unnecessary infections. If you notice any symptoms of urinary tract or chest infection, it is important to see a doctor as soon as possible for treatment and testing. Infections can trigger a crisis and be more serious in pregnancy.
- Have the recommended vaccinations, including whooping cough, flu and the pneumococcal vaccine. Your GP can arrange these or we have a vaccination clinic at King’s.

What happens if you have a sickle cell crisis in pregnancy?

If you develop symptoms of a crisis, such as chest pain or difficulty breathing, you should contact the hospital as soon as possible. Before 16 weeks of pregnancy attend the Emergency Department and explain you are pregnant and have sickle cell disease. After 16 weeks, you should call our Labour Ward Assessment Line (see number below) and a doctor will assess you and decide how best to manage your pain and any underlying infection or complication. You may be admitted for treatment and monitoring. Pain relief often includes opiates, which are safe for you and your baby.

Blood transfusions and exchange blood transfusions

If you are on a regular exchange transfusion programme, this will continue as normal throughout the pregnancy.

If you become anaemic during the pregnancy, you may need a top-up blood transfusion to increase your number of healthy red blood cells. Your haematology team will arrange this for you.

Will labour and delivery be affected?

Most women have their baby around their due date, but if you have frequent crises or become unwell, it may be best to deliver you earlier.

If you are planning to have a normal delivery, we hope you will go into labour naturally. If this has not happened by the time you have reached your due date, we will ask you to come into hospital for an induction of labour. This means we will start your labour for you.

Many women worry about how they will cope in labour, especially if tiredness and pain are likely to trigger a crisis. In fact, most women cope very well with the stresses of labour, but you could choose to have an early epidural to reduce the pain. This also means you will be able to rest more during the labour.

We can also offer you gas and air or an injection of diamorphine as pain relief. Pethidine is not recommended for women with sickle cell disease.

After the birth

We advise most women with sickle cell disease to complete six weeks of daily enoxaparin (Clexane) injections after giving birth, in order to prevent blood clots. This medication reduces the risk of blood clots by about 70%, and you can safely breastfeed while on treatment.

If there are no complications, your baby will stay with you. Most women are able to breastfeed their babies but there are some medications that you should not take if you are breastfeeding. We will review and discuss this with you before the delivery, so you are prepared and have a feeding plan.

All babies can have a heel prick test five days after delivery, which includes testing for sickle cell disease.

You are likely to feel very tired after the delivery, so try to arrange for friends and family to support you in the weeks after the birth, so you can rest and enjoy spending time with your baby.

Useful contact numbers:

Community clinical nurse specialist: 020 3049 5993

Ruskin Midwives: 07870 524674

Haematology Outpatients Clinic: 020 3299 5554

Labour Ward Assessment Line (24-hour): 020 3299 8389

Care provided by students

King's is a teaching hospital where our students get practical experience by treating patients. Please tell your doctor or nurse if you do not want students to be involved in your care. Your treatment will not be affected by your decision.

PALS

The Patient Advice and Liaison Service (PALS) is a service that offers support, information and assistance to patients, relatives and visitors. They can also provide help and advice if you have a concern or complaint that staff have not been able to resolve for you.

PALS at King's College Hospital, Denmark Hill, London SE5 9RS:
Tel: 020 3299 3601
Email: kch-tr.palsdh@nhs.net

You can also contact us by using our online form at **www.kch.nhs.uk/contact/pals**

PALS at Princess Royal University Hospital, Farnborough Common, Orpington, Kent BR6 8ND
Tel: 01689 863252
Email: kch-tr.palspruh@nhs.net

If you would like the information in this leaflet in a different language or format, please contact PALS on 020 3299 1844.

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