

Fertility and contraception advice in sickle cell disease

Sickle Cell and Thalassemia Service

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Information for Patients

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Introduction

During the teenage years our bodies produce more natural chemicals (hormones). These can make your sickle cell disease worse.

Some women with sickle cell disease find that their pain is worse during their menstrual period.

Fertility:

- **In women:** Sickle cell disease does not seem to affect the fertility of women. But it can cause problems during pregnancy and childbirth. It is best to have a well planned pregnancy.
- **In men:** Sickle cell disease can reduce fertility in men. This is especially if they have had a condition that causes painful erections (priapism).

If you have had difficulty becoming pregnant (conceiving) after one year of regular unprotected sex, you should be offered tests to look into this.

Contraception

It is best to use contraception if you are not planning to have children. An unplanned pregnancy can be challenging for the health and wellbeing of women with sickle cell disease.

There is a wide range of contraception available. You can talk about different methods with your health care team. They will take into account your medical history. Listed on page 2 are different contraceptive methods and a small explanation about each of them.

**Health information and support is available at www.nhs.uk
or call 111 for non-emergency medical advice**

Visit www.leicestershospitals.nhs.uk for maps and information about visiting Leicester's Hospitals
To give feedback about this information sheet, contact InformationForPatients@uhl-tr.nhs.uk

Oral contraceptive pills

There are 2 types:

1. Combined oral contraceptive pill

This is sometimes called 'the pill'. It has the hormones 'progesterone' and 'oestrogen'. These stop an egg from being released by the ovaries each month.

The pill may not be suitable for you if you have had a blood clot in your legs or lungs. This is because this pill slightly raises your risk of getting a blood clot. People with sickle cell disease have higher risk of getting blood clots so doctors often advise against using this. This method is 99.7% effective. But this is reduced if the pill is not taken regularly. Or if you suffer from vomiting or diarrhoea. Or take medication that can affect pill absorption.

2. Progestogen only pill (POP) also called the 'mini pill'

The progestogen-only pill has the hormone progestogen. It does not have oestrogen. It thickens the mucus in the cervix to stop sperm from reaching the egg. If the pill is taken correctly, following the instructions as prescribed, it is 99% effective. The effectiveness of this is reduced if not used correctly like missing doses.

There are 2 different types of progestogen-only pill:

- 3 hour progestogen only pill (traditional progestogen-only pill): this must be taken within 3 hours of the same time each day.
- 12 hour progestogen only pill (desogestrel progestogen-only): this must be taken within twelve hours of the same time each day.

You must follow the instructions that come with your pill packet for more advice and what to do if you miss a dose.

There is some evidence that progesterone protects against sickling so it may be a suitable choice for those with sickle cell disease.

What should I do if I have diarrhoea and vomiting whilst taking oral contraception?

Like with all pills, you should use another method of contraception if you have had diarrhoea or sickness (vomiting) at any time while taking the pill. This could be a barrier method like a condom. Or if you have already had sexual intercourse then you should take the pill the morning after. You can get this from a pharmacy with this service or from a local sexual health clinic.

Contraceptive injections

Contraceptive injections have the hormone progestogen. There are 3 types: Depo-Provera, Sayana Press and Noristerat (not commonly used in the UK). These last for 8 to 13 weeks. They work by stopping your ovaries releasing eggs each month (ovulation). They also thicken the mucus from your cervix (entrance to the womb), making it difficult for sperm to move through it to reach an egg. They also make the lining of the womb thinner and less likely to accept a fertilised egg.

The injection needs to be given as prescribed. It is 99% effective and safe to use if you are breastfeeding. Contraceptive injections are a safe and effective choice for women with sickle cell disease.

Implants

The contraceptive implant is a tiny plastic rod that goes under the skin in your upper arm. A doctor or nurse puts it there. It lets out a hormone called progesterone into your blood. This stops eggs from being released each month. It works for 3 years. One common implant is called 'Nexplanon'. Sometimes, you might have irregular bleeding, mostly in the first 6 months.

Implants are 99% effective and safe for women with sickle cell disease.

- **Intrauterine device (IUD or coil)**

An intra-uterine device (IUD) is a small T-shaped plastic and copper device that a doctor or nurse puts in your uterus (womb). It has 1 or 2 thin threads on the end that hang through your cervix (the entrance to the uterus) into the top of your vagina. It releases copper to stop you getting pregnant. It works by stopping sperm reaching an egg.

It works for 5 or 10 years, depending on the type. An IUD is also called a 'coil' or 'copper coil' and is 99% effective. Some IUDs might increase the risk of infection or heavy bleeding.

- **Intra Uterine System (IUS)**

An IUS is a small, T-shaped plastic device. The doctor or nurse put this into your womb (uterus). It releases the hormone progesterone to stop you getting pregnant. It lasts for 3 to 8 years depending on the type. There are 5 brands of IUS used in the UK: Mirena, Levosert, Kyleena, Jaydess, Benilexa .

The IUS is similar to the IUD. The IUD releases copper. IUS releases the hormone progesterone into the womb. This thickens the mucus in the cervix which makes it more difficult for sperm to move through the cervix. It also thins the lining of the womb so that the egg cannot implant itself. When inserted correctly, it is 99% effective. An IUS is a suitable choice for those with sickle cell disease. IUS can make periods lighter, shorter, and less painful. It can be an effective treatment for heavy periods. The IUS coil is the preferred choice for women with sickle cell disease.

Barrier methods

- **Male condom**

This is a rubber sheath-shaped barrier device. It is the most common barrier method. The male puts it on his penis to stop sperm from entering inside the female's body during sex. It is 98% effective if used correctly. If used incorrectly, like not placed on the penis correctly or splits, it is not effective. You should then use another form of contraception, such as the morning after pill. The condom also stops most types of sexually transmitted infections like HIV, gonorrhoea and chlamydia.

- **Female condom**

This works the same way as the male condom but is inserted inside the female before having sex. If used correctly, it is 95% effective. It is not effective if not inserted properly.

- **Diaphragm or cap**

This is a rubber circular dome that has a chemical on it that destroys sperm (spermicide). It is placed over the cervix before having sex. It covers the cervix so that sperm cannot get into the womb. It is prescribed by a doctor or nurse who will show you how to use it. It is 92% to 96% effective. It does not protect against sexually transmitted infections. It is not effective if not inserted properly.

- **Vaginal Ring**

You put the vaginal ring inside your vagina. It is made of soft plastic and is about 5cm across. It stops pregnancy by releasing the hormones oestrogen and progesterone into the blood. This stops the ovaries releasing an egg each month. It can be left in place for 21 days and then a rest period of 7 days before another one can be inserted. The vaginal ring is 99% effective if you use it correctly all the time. If not used correctly, it's less effective.

- **Contraception Patch**

The contraceptive patch is a small square patch that you wear on your skin. The size of the patch is 5cm by 5cm. It prevents pregnancy by releasing the hormones oestrogen and progesterone into the blood. This stops the ovaries releasing an egg each month. The patch is worn for 7 days and then replaced with a new one. It is 99% effective if you use it correctly all the time. If not used correctly it is less effective.

Sterilisation

This is a permanent solution. This is for people who are very sure that they have completed their family and do not want anymore children. It involves a small surgical procedure.

- **Female sterilisation**

In this procedure the tubes which carry the egg from the ovary to the womb (fallopian tubes) are either blocked or sealed off. This involves keyhole surgery. This is often done as a day case which means you can go home the same day. Sterilisation is meant to be permanent. There are reversal surgeries, they are not often successful. This procedure is 99% effective.

- **Male sterilisation (vasectomy)**

This involves a surgical procedure to cut or seal the tubes that carry a man's sperm. The man can still ejaculate but there will be no sperm in the semen. It does not affect sex drive or production of male hormones. Vasectomy reversal is possible but the procedure is not always successful. This procedure is 99% effective.

What should I do if I want to start a family?

- Before planning a family, we recommend that you both have some tests. This is often a blood test. This is to see if you are at risk of having a child with sickle cell disease. This information can help you to make an informed choice about having children.
- You should also talk to your doctor review any medical treatment or medicines you are taking. Some drugs such as hydroxycarbamide can be harmful to the growing baby. You should use an effective form of contraceptive while taking this medication, and for at least 3 months after stopping the drug. Your ability to become pregnant or father a child may be affected by taking this drug. You must talk to your doctor before starting treating.
- For males: hydroxycarbamide does not stop you from making a female pregnant. A male's sperm count may be reduced. But there is a possibility of abnormal sperm being made. This will often return to normal after the medication has been stopped for 2 to 3 months.

- As soon as you think you are pregnant you should tell your family doctor (GP) or hospital doctor. There may be extra health risks for you and your unborn baby due to sickle cell disease. Your anaemia levels should be checked carefully.

Who can I contact for more information?

We are always pleased to hear from patients and carers. If you have any suggestions about how our service is run please speak to a member of the team or telephone: 0116 258 6081

To talk about the different types of contraception, please make an appointment to see your doctor (GP), practice nurse or family planning clinic.

Contraceptive & Sexual Health Service - Leicester Sexual Health

Haymarket Health, 1st floor, Haymarket Shopping Centre, Leicester LE1 3YT

www.leicestersexualhealth.nhs.uk

Telephone: 0300 124 0102

Free, confidential service. With various clinics in Leicestershire, the service offers:

- Testing and treatment for sexual infections
- Contraceptive pills
- Contraceptive injection
- Contraceptive implant
- Emergency contraceptive pill (morning after pill)
- Free pregnancy testing, and referral for abortion (or to a midwife)
- Free condoms
- Sexual violence support (including child sexual exploitation, female genital mutilation and domestic violence)



Useful contacts

Sickle Cell and Thalassaemia Service

Leicester Royal Infirmary, Ground Floor, Osborne Building

Monday to Friday 9am to 5pm, call: 0116 258 6081

UHL Medicines Information: Monday to Friday 8.30 am to 5.30 pm, call: 0116 258 6491

Sickle Cell Society:

www.sicklecellsociety.org

Phone: 020 8961 7795

email: info@sicklecellsociety.org or visit:

UK Thalassaemia Society

www.ukts.org

Phone: 020 8882 0011

Email: office@ukts.org

NHS website

www.nhs.uk/conditions/contraception

www.nhs.uk/conditions/sickle-cell-disease

FPA

Sexual advice and information.

www.fpa.org.uk

اگر آپ کو یہ معلومات کسی اور زبان میں درکار ہیں، تو براہ کرم مندرجہ ذیل نمبر پر ٹیلی فون کریں۔
على هذه المعلومات بلغة أخرى، الرجاء الاتصال على رقم الهاتف الذي يظهر في الأسفل

જો તમને અન્ય ભાષામાં આ માહિતી જોઈતી હોય, તો નીચે આપેલ નંબર પર કૃપા કરી ટેલિફોન કરો

ਜੇ ਤੁਸੀਂ ਇਹ ਜਾਣਕਾਰੀ ਕਿਸੇ ਹੋਰ ਭਾਸ਼ਾ ਵਿਚ ਚਾਹੁੰਦੇ ਹੋ, ਤਾਂ ਕਿਰਪਾ ਕਰਕੇ ਹੇਠਾਂ ਦਿੱਤੇ ਗਏ ਨੰਬਰ 'ਤੇ ਟੈਲੀਫੋਨ ਕਰੋ।

Aby uzyskać informacje w innym języku, proszę zadzwonić pod podany niżej numer telefonu

Previous reference:

If you would like this information in another language or format such as EasyRead or Braille, please telephone 0116 250 2959 or email equality@uhl-tr.nhs.uk



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