Sexual health and contraception: Information for patients with thalassaemia and sickle cell disease

This is an information sheet on sexual health and contraception for people with sickle cell and thalassaemia. If you have any questions or concerns, please do not hesitate to speak with any of the clinics listed, your haematology doctors or the sickle cell nurse practitioners.

Why is this important?

Awareness of sexual health and contraception is important for all sexually active people. It is important for people with sickle cell disease (SCD) or thalassaemia, both to prevent sexually transmitted infections and prevent unplanned pregnancy.

While most contraceptive methods allow you to choose when and whether you want a baby, they do not protect you from sexually transmitted infections (STIs), apart from condoms (male or female condoms). You should therefore use condoms in addition to any other method you are using to prevent pregnancy and to protect both you and your partner’s health.

Sexually transmitted infections (STIs)

Sexually transmitted infections can occur to all people from all walks of life however there are many things you can do to reduce your risk, for example:

- Protect yourself by using the right contraception, condoms work well when used consistently and in the correct way.
- Limit the number of sexual partners you have as this reduces the chances of you getting an STI.
- Have open communication with your partner about STIs and prevention methods before sexual activity.
- Do not rely on symptoms to know if you have contracted an STI, get tested.
- Be aware that alcohol and drug use reduce your ability to make good decisions and make you less able to fully consent to any activity including sex.
Which type of contraception should I use?

The full range of contraceptive choices can be offered to women and men with SCD and thalassaemia, examples include:

- **Barrier contraceptives** such as condoms (male or female) are a good option as they protect against STI as well as reducing the risk of pregnancy.

- **Progesterone only contraceptives**, which are available in different forms (tablets, injection, and implant) are also a good option for pregnancy prevention in women.

- The combined oral contraceptive pill is one of the most effective contraceptives but there has been concern about its use in women with SCD due to its association with an increased risk of blood clots. However this increase in risk is small and is considered to be outweighed by its benefit in preventing unwanted pregnancy. Preparations containing lower doses of oestrogen are available. There are also lower dose formulations available which are now commonly used with no additional risk.

- **Intrauterine devices** such as the mirena coil are also used successfully in women with SCD or thalassaemia for prevention of pregnancy.

Each of the above methods of contraception has their own advantages and disadvantages – for more information on these and to discuss the options available to you please contact your GP or local sexual health clinic (please see list of clinics on page 3 and 4).

You can also contact the Family Planning Association for more information on the contraceptive options available via their website: [www.fpa.org.uk/helpandadvice/contraception](http://www.fpa.org.uk/helpandadvice/contraception) or their helpline on 0845 122 8690 from England or 0845 122 8687 from Northern Ireland.

**Emergency Contraception**

The morning after pill (Emergency Hormonal Contraception (EHC)) can be taken up to 72 hours after unprotected sex but works best the earlier it is taken. It can be obtained free from your GP and some chemists.

**Pregnancy in sickle cell and thalassaemia**

In sickle cell disease (SCD) and thalassaemia, pregnancy is often associated with significant complications to both the mother and baby. This includes severe crises in patients with SCD and premature birth in both groups. It is also important to be aware that use of some of the medicines used to manage these conditions during pregnancy, such as hydroxyurea (hydroxycarbamide), bisphosphonates, deferasirox and desferrioxamine, may harm the developing foetus.
So before getting pregnant you should take the following important steps to reduce the risk to both yourself and your baby:

- You should let your doctors in the sickle cell and thalassaemia clinic know that you are planning a pregnancy so they can ensure your partner is screened and you are both counselled about the chances of your baby having SCD or thalassaemia and what options are available to you.

- Your medical team will also review all of your medicines and stop the ones that pose a risk to your baby. Some of these (e.g. hydroxyurea) have to be stopped three months before conception. Your medical team will also check other important things such as your vaccination status. If you are receiving regular transfusions then we will also carry out extra tests, for example we will check your iron level and red cell antibody status.

- Once you become pregnant you will be followed up in the monthly specialist obstetrics haemoglobinopathy clinic which is run by a consultant obstetrician (a doctor who looks after pregnant women) alongside a consultant haematologist (a doctor who specialises in blood) and midwives with expertise in looking after women with SCD and thalassaemia through pregnancy.

Should you find yourself pregnant unexpectedly it is important you let both your sickle clinic doctors and your GP know as soon as possible so we can implement measures to reduce the risk to both you and your baby.

Where to go for free confidential advice on sex, relationships, contraception and unwanted pregnancies?

Artesian Health Centre  
137-138 Grange Road, SE1 3GF  
t: 020 3049 4006

Clapham Manor Health Centre  
86 Clapham Manor Street SW4 6EB  
t: 020 3049 4040

Mawbey Brough Health Centre  
39 Wilcox Close, SW8 2UD  
t: 020 3049 4040/6800

Vauxhall Riverside Centre  
Hobart House, Wandsworth Road, SW8 2JB  
t: 020 3049 4006

Streatham Hill RSH Clinic  
41 A - C Streatham Hill, SW2 4TP  
t: 020 30494006

Walworth Road Clinic  
157-169 Walworth Road SE17 1RY  
t: 020 3049 8630

Camberwell Sexual Health Centre  
100 Denmark Hill, SE5 9RS  
t: 020 3299 5000
The Caldecott Centre  
King's College Hospital  
15- 22 Caldecott Road, SE5 9RS  
t: 020 3299 5000

Burrell Street Clinic  
4-6 Burrell Street, SE1 0UN  
t: 020 7188 6666

The Lloyd Clinic at Guy’s Hospital  
St. Thomas Street, SE1 9RT  
t: 020 7188 6666

For those aged under 25 years:

Brook Clinics:  
Confidential Advice for under 25s.  
w: www.brook.org.uk/brook-london

Brook Brixton:  
Brixton Road, Brixton, SW9 7AW  
t: 020 7787 5000  
Mon – Fri (closed Tues) 1:00pm-6:00pm  
Sat 1:00-4:00pm

Brook Southwark:  
24-26 Westmoreland Road, SE17 2AY  
t: 020 7703 9660  
Mon-Thurs 1:00pm-6:00pm  
Fri 12:00pm-5:00pm  
Sat 10:30am-1:00pm

Central Booking Service for abortions  
If you need to get an appointment to talk about an abortion, call the Central Booking Service on 0845 345 9911. Lines are open: 8:00am to 8:00pm on Monday to Friday; 8:30am-6:00pm on Saturday; 9:30am-2:30pm on Sunday.

Family Planning Association  
w: www.fpa.org.uk/helpandadvice/contraception  
t: Helpline on 0845 122 8690 from England or 0845 122 8687 from Northern Ireland.
Contact us
If you have any questions or concerns, please contact the sickle team on 020 7188 7188 and request bleep 1879 or 1843. Out of hours, please contact the haematology specialist registrar on call, also via switchboard on 020 7188 7188.

Sickle cell team contacts:

**Sickle cell nurse practitioners:** 020 7188 2710 or bleep 1879/1843 via switchboard.

**Haematology Day unit:** 020 7188 2715/020 7188 2727

**Psychologists:** 020 7188 2725/ 020 7188 2718

To bleep the sickle cell nurse practitioners, call the hospital switchboard on 020 7188 7188 and ask for the bleep desk. Ask for bleep 1879 or 1843 and wait for a response. This will connect you to the sickle cell nurse practitioners directly.

Pharmacy medicines helpline
For information about any medicines that you have been prescribed at Guy's and St Thomas' hospitals, you can speak to the staff caring for you or call our helpline.
**t:** 020 7188 8748 9am to 5pm, Monday to Friday

Patient Advice and Liaison Service (PALS)
To make comments or raise concerns about the Trust’s services, please contact PALS. Ask a member of staff to direct you to the PALS office or:
**e:** 020 7188 8801 at St Thomas’  **t:** 020 7188 8803 at Guy’s  **e:** pals@gstt.nhs.uk

Knowledge & Information Centre (KIC)
For more information about health conditions, support groups and local services, or to search the internet and send emails, please visit the KIC on the Ground Floor, North Wing, St Thomas’ Hospital.
**t:** 020 7188 3416

Language support services
If you need an interpreter or information about your care in a different language or format, please get in touch using the following contact details.
**t:** 020 7188 8815  **fax:** 020 7188 5953

NHS Direct
Offers health information and advice from specially trained nurses over the phone 24 hours a day.
**t:** 0845 4647  **w:** www.nhsdirect.nhs.uk