

Sexual Health and Contraception: information for patients with thalassaemia and sickle cell disease

This leaflet offers more information about sexual health and contraception. If you have any further questions or concerns, please speak to a member of the team using the contact details listed towards the end of this leaflet.

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 (STIs) and prevent unplanned pregnancy.

While most contraceptive methods allow you to choose when and whether you want a baby, only condoms (male or female) protect you from sexually transmitted infections. Condoms are recommended in addition to any other method you are using to prevent pregnancy in order to protect you and your partner's health.

Sexually transmitted infections (STIs)

Sexually transmitted infections can occur to all people from all walks of life. 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 right way.
- **Limiting the number of sexual partners** you have reduces the chances of 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 consent fully to any activity, including sex.

Which type of contraception should I use?

The full range of contraceptive choices can be offered to men and women with SCD and thalassaemia. Examples of these include:

- Barrier contraceptives such as condoms (male or female). These are a good option as they protect against STIs as well as reducing the risk of pregnancy.
- Progesterone only contraceptives, which are available in different forms (tablets, injection, and implant). These are 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 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 details at the end of this leaflet).

Emergency contraception

The morning after pill (Emergency Hormonal Contraception or EHC) can be taken up to 72 hours after unprotected sex but works better the earlier

it is taken. It can be obtained from your GP, a sexual health clinic and some chemists.

Pregnancy in sickle cell and thalassaemia

In SCD and thalassaemia pregnancy can be associated with 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 hydroxycarbamide (formerly known as hydroxyurea), bisphosphonates, deferasirox and desferrioxamine may harm the developing foetus.

Before getting pregnant you should take the following important steps to reduce the risk to you and your baby:

- You should let your haematology doctors know that you are planning a pregnancy so that they can ensure you are offered the opportunity to have your partner screened and be 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 your medicines and stop the ones that pose a risk to your baby. Some of these (for example, hydroxycarbamide) 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 the doctors will also carry out extra tests, such as your iron level and red cell antibody status.
- Once you become pregnant you will be followed up closely by your specialist obstetrics and haemoglobinopathy teams. These include a consultant obstetrician and a consultant haematologist as well as midwives with expertise in looking after women with SCD and thalassaemia through pregnancy.

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

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

Sexual health services are available in many different places, including GP surgeries, sexual health and family planning clinics, pharmacies and young people's services. They are free and are available to everyone regardless of sex, age, ethnic origin and sexual orientation. You are welcome to attend any of these clinics or any outside your local area if you prefer. Some run specialist services for young people and gay men.

For further information on sexual health and up to date information on services across Wandsworth, Merton and Richmond please look at

Sexual Health South West London <https://shswl.nhs.uk/>

You can also contact the Family Planning Association for more information: <http://www.fpa.org.uk/help-and-advice/contraception-help>

Helpline: 0300 123 7123

Contact us

If you have any questions about your condition, please discuss with a member of the red cell haematology team at your next appointment or using the details below.

Dr Elizabeth Rhodes (sickle cell and thalassaemia consultant)

Tel: 020 8725 0885

Dr Julia Sikorska (lead sickle cell and thalassaemia consultant)

Tel: 020 8725 0885

Carol Rose (clinical nurse specialist)

Tel: 07825 978812

Sickle cell and thalassaemia secretary

Tel: 020 8725 0885

For more information leaflets on conditions, procedures, treatments and services offered at our hospitals, please visit www.stgeorges.nhs.uk

Additional services

Patient Advice and Liaison Service (PALS)

PALS can offer you on-the-spot advice and information when you have comments or concerns about our services or the care you have received. You can visit the PALS office between 9.30am and 4.30pm, Monday to Friday in the main corridor between Grosvenor and Lanesborough wings (near the lift foyer).

Tel: 020 8725 2453 **Email:** pals@stgeorges.nhs.uk

NHS Choices

NHS Choices provides online information and guidance on all aspects of health and healthcare, to help you make decisions about your health.

Web: www.nhs.uk

NHS 111

You can call 111 when you need medical help fast but it's not a 999 emergency. NHS 111 is available 24 hours a day, 365 days a year. Calls are free from landlines and mobile phones.

Tel: 111

AccessAble

You can download accessibility guides for all of our services by searching 'St George's Hospital' on the AccessAble website (www.accessable.co.uk). The guides are designed to ensure everyone – including those with accessibility needs – can access our hospital and community sites with confidence.



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