

Patient information

Sexual Health Advice for Patients with Haemoglobinopathy Disorders

Haematology Liverpool

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 your haematology doctors or the sickle cell nurse specialists.

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** – you can request an STI testing kit from your clinical nurse specialist

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 family doctor (GP) or local sexual health clinic (please see list of clinics on page 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 or their helpline on Tel: 0845 122 8690.

Free condoms are available from your clinical nurse specialist

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. This clinic is held in the Liverpool Women's Hospital.

Should you find yourself pregnant 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?

Axess Sexual Health Services (Liverpool, Knowsley, Warrington, Halton, Cheshire East, Wirral)

<https://www.axess.clinic/>

Specialist Haemoglobinopathy Team:

Consultant Haematologist

Lead Clinical Nurse Specialist

Two Clinical Nurse Specialists

Haematology Specialist Registrar (Rotational Position)

Clinical Psychologist

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:

Clinical Nurse Specialist

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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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