

Sexual health, contraception and preparing for pregnancy

Information for patients with thalassaemia and sickle cell disease

Why is this important?

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

As the genetic makeup of sickle cell and thalassaemia syndromes is such that two abnormal genes are present in affected people, any child you have will be a carrier.

This means that if you have an unplanned pregnancy with someone who is a carrier of an abnormal haemoglobin there is a 50 per cent chance you may have a child affected by sickle cell or thalassaemia.

In women, the presence or absence of periods should not be taken as an indicator of your ability to conceive. Use appropriate contraceptives for prevention of pregnancy. If you want to start a family please discuss this with your doctors as this may require some pre-pregnancy assessment or treatment to help ensure you are well enough to go through a pregnancy safely.

In men, fertility may be normal or subnormal and it may also vary according to the state of your health over time. It is not correct to assume you cannot get a partner pregnant. If you want to start a family please discuss your plans with your doctors.

Sexually transmitted infections (STIs)

Sexually transmitted infections can occur in 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.
- Communicate openly 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 sickle cell and thalassaemia. You should always tell your doctor that you have sickle cell disease or thalassaemia and of any problems you may have had.

Barrier contraceptives such as condoms (for male or female) 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) are also a good option for pregnancy prevention in women.

The combined oral contraceptive pill is one of the most effective contraceptives and is safe to use in women with sickle cell and thalassaemia.

Intrauterine devices such as the Mirena® coil are also used successfully in women with sickle cell 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 discuss with us or contact your GP or local sexual health clinic.

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.

Preparing for pregnancy in sickle cell and thalassaemia

In sickle cell disease and thalassaemia, pregnancy can be associated with complications to both the mother and baby. This includes increased sickle cell crises in patients with sickle cell disease and premature birth in both groups.

It is also important to be aware that some of the medicines used to manage these conditions may harm a developing baby such as:

- hydroxyurea (hydroxycarbamide)
- bisphosphonates (e.g. Pamidronate)
- deferasirox and deferiprone
- Angiotensin converting enzyme (ACE) inhibitors (e.g. Ramipril)
- Certain pain killers known as non-steroidal anti-inflammatory drugs (NSAIDs) e.g. ibuprofen and diclofenac) -

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 know that you are planning a pregnancy
- **Partner screening:** You can both be counselled about the chances of your baby having sickle cell or thalassaemia and what options are available to you.
- **Review all of your medicines:** Stop taking medicines that pose a risk to your baby. Some of these (e.g. hydroxyurea) have to be stopped three months before conception.
- **Vaccination status:** Check that you are up-to-date with recommended vaccinations.
- **Optimise iron levels:** If you are receiving regular transfusions then it is extremely important that your iron levels are optimised as chelation will be stopped for the majority of your pregnancy.
- **Red cell antibody status:** Some of the antibodies that may have developed after blood transfusions can be transferred to the baby's circulation.

Once you become pregnant you will be followed up in the monthly specialist obstetrics clinic which is run by a consultant obstetrician (a doctor who looks after pregnant women) and you will also see your sickle cell or thalassaemia doctor monthly.

What to do should you find yourself pregnant unexpectedly

It is important you let both your haematology doctors and your GP know as soon as possible so we can implement measures to reduce the risk to both you and your baby.

Your haematology and paediatric consultants are:

- Dr Farrukh Shah (lead consultant, Thalassaemia)
- Dr Bernard Davis (lead consultant, Sickle Cell Disease)
- Dr Ali Rismani (consultant haematologist)
- Dr Andrew Robins (lead consultant, Paediatrics)
- Dr Sara Hamilton (deputy lead consultant, Paediatrics)

Your specialist nurses are:

- Emma Prescott and Niamh Malone-Cooke (Thalassaemia)
- Matty Asante-Owusu (community matron)
- Edith Aimiuwu (paediatrics)

If you or your family have any other questions please do not hesitate to contact any of the above medical team at Whittington Health.

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

BPAS London Central

26-27 Bedford Square

London

WC1B 3HP

www.bpas.org

020 7612 0200 (London Central); 0845 730 4030 (Contact Centre)

Camden Health Bus
4th Floor, West Wing
St Pancras Hospital
4 St Pancras Way
London
NW1 0PE
020 3317 3654.

Free confidential health advice service for people at a range of sites and events around Camden. Information and advice on how to maintain a healthy lifestyle and access local services including sexual health, contraception, pregnancy, relationships, growing up, drugs, diet, exercise, smoking, and mental health.

Brook in Euston
92-94, Chalton Street
London
NW1 1HJ
www.brook.org.uk
020 7387 8700, 0808 802 1234 (Helpline)

Margaret Pyke Centre
44 Wicklow Street
London
WC1X 9HL
www.margaretpyke.org
020 3317 3737

Mortimer Market Centre
Capper Street (off Tottenham Court Road)
London
WC1E 6JB
www.mortimermarket.com
Appointments 020 3317 5100; Health Advisor 020 3317 5111

Family Planning Association
www.fpa.org.uk/helpandadvice/contraception
0845 122 8690

NHS111
Offers advice from a highly trained advisor, supported by healthcare professionals over the phone 24 hours a day.
Tel: 111
www.nhs.uk/NHSEngland/AboutNHSservices/Emergencyandurgentcareservices/Pages/NHS-111.aspx

Patient advice and liaison service (PALS)

If you have a question, compliment, comment or concern please contact our PALS team on 020 7288 5551 or

whh-tr.whitthealthPALS@nhs.net

If you need a large print, audio or translated copy of this leaflet please contact us on 020 7288 3081. We will try our best to meet your needs.

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