Sexual health, contraception and preparing for pregnancy

North Central London Haemoglobinopathy Network jointly with Whittington Health, Royal Free London, and Luton and Dunstable NHS Foundation Trust

Joint Red Cell Unit
If you need a large print, audio, braille or translated copy of this booklet, please contact us on 020 3447 9638. We will do our best to meet your needs.

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This booklet explains more about sexual health, contraception and preparing for pregnancy and has been developed for patients with thalassaemia and sickle cell disease (SCD).

**Why is this important?**

Awareness of sexual health and contraception is important to all sexually active people. If you have SCD or thalassaemia, it is particularly important that you:

- prevent sexually transmitted infections and any unplanned pregnancies
- prepare for pregnancy, and
- understand the risk of having a child with a major haemoglobin disorder.

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

**Sexually transmitted infections (STIs)**

Sexually transmitted infections can affect anyone but it is particularly important that thalassaemia and SCD patients reduce their risk of getting them. This is because:

- your spleen, an important organ that helps to prevent infections, may not work (hyposplenia) or it may have been removed (asplenia)
- you may have excess iron in your blood due to regular transfusions, which can promote the growth of bacteria
- infections can trigger a sickle cell crisis.
These are the things you can do to reduce your risk:

• 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.

• Talk to your partner openly about STIs and prevention methods before sexual activity.

• Be aware that alcohol and drugs reduce your ability to make good decisions and make you less able to fully agree to any activity, including sex.

If you are unsure whether you may have an STI, don’t rely on symptoms – get tested.

Which type of contraception should I use?

You should always tell the health professionals looking after you that you have SCD or thalassaemia and of any problems you may have had with contraception in the past. You can also give them our contact details so we can discuss any concerns with them.

The full range of contraceptive choices is available to you. Here are some examples:

• Barrier contraceptives, such as condoms (male or female), protect against STIs and reduce the risk of unplanned pregnancy.

• Progesterone-only contraceptives for women are available in different forms, such as tablets, injections and implants.

• The combined oral contraceptive pill, known as ‘the pill’, contains both progesterone and oestrogen and is one of the most effective contraceptives. The concern regarding the high oestrogen content causing blood clots is now outdated with the new generation pill containing lower oestrogen levels.

• Intrauterine devices, such as the mirena coil, are also used successfully in women with SCD or thalassaemia.
Each of these methods of contraception has their own advantages and disadvantages – for more information please contact your haematology doctor, your GP or a local sexual health clinic. You can also request an appointment with a fertility consultant who sees patients in our Wednesday evening clinic. Please talk to your haematology consultant or clinical nurse specialist (CNS), or call the haematology advice line (contact details are listed on page 9).

**Emergency contraception**

The morning-after pill (emergency hormonal contraception or EHC) can be taken up to 72 hours after unprotected sex but works best the earlier it is taken. It is available free of charge from your GP and some chemists.

**Preparing for pregnancy in SCD and thalassaemia**

It is important that you are aware of some possible complications associated with pregnancy that can affect both you and your baby. These include severe crises in patients with SCD and premature birth in both thalassaemia and SCD patients.

Please also note that some of the medicines used to manage these conditions, such as hydroxyurea (hydroxycarbamide), bisphosphonates, deferasirox and deferiprone, may harm the developing foetus.

Your haematology doctor will give you more information. You can also ask for copies of our leaflets, *Thalassaemia and pregnancy* and *Sickle cell disease and pregnancy*. 
To reduce the risks to both you and your baby the following steps should be taken before you get pregnant:

1. Let your doctors in the sickle cell and thalassaemia clinic know that you are planning a pregnancy so they can ensure that
   • your partner has the appropriate screening tests.
   • both you and your partner are advised about the chances of your baby having SCD or thalassaemia, and the options available to you. You will be referred to the relevant clinic for this and you can be seen, with or without your partner, at a very short notice.

2. Your haematology team will also review all of your vaccinations and medicines, and stop any medicines that pose a risk to your baby. Some of these (for example hydroxyurea) should be stopped three months before conception.

3. If you are receiving regular transfusions, it is essential that your iron levels are optimised, particularly because chelation therapy will be stopped for the majority of pregnancy.

4. We will also carry out extra tests, such as your red cell antibody status. This is because some of the antibodies that may have developed after blood transfusions or previous pregnancies can be transferred to your baby’s blood.

If you get pregnant unexpectedly, it is important that you let both your haematology doctor and your GP know as soon as possible so we can ensure that the risks to both you and your baby are reduced as much as possible.
Once you become pregnant

• You will have a consultant-led care in the high-risk obstetrics clinic where you will regularly see a consultant obstetrician (a doctor who looks after pregnant women); you will also have an appointment with an anaesthetist with an interest in pregnancy.

• You will see your sickle cell or thalassaemia doctor monthly.

• If your doctor thinks you may be at a high risk of a thrombosis (blood clot) during pregnancy, you may see a different haematology doctor who specialises in this area.

• We will need to tell the transfusion department as the blood for your transfusions will be prepared slightly differently – it will have to be screened for cytomegalovirus (CMV), a virus that can be harmful to the unborn baby.

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

• Mortimer Market Centre
  Mortimer Market, Capper Street
  London WC1E 6JB

  www.mortimermarket.com

  Appointments: 020 3317 5100

  Health Advisor: 020 3317 5111

• British Pregnancy Advisory Service (BPAS)
  26-27 Bedford Square
  London WC1B 3HP

  www.bpas.org

  Telephone: 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  
  Telephone: 020 3317 3654  

• **Brook in Euston**  
  92-94 Chalton Street  
  London NW1 1HJ  
  www.brook.org.uk  
  Telephone: 020 7387 8700  
  Helpline: 0808 802 1234  

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

• **Family Planning Association**  
  www.fpa.org.uk/helpandadvice/contraception  
  Telephone: 0845 122 8690
Contact details

Haematology advice line (office hours, adults and children):
020 3447 7359

Adult haematology advice line (out of hours):
07852 220 900

Paediatric helpline (out of hours):
• nurse in charge 07961 081 645
• ward T11 south 020 3456 7890 ext. 71103 or 71143

Apheresis:
020 3447 1803

Address: The Joint Red Cell Unit
Department of Haematology
3rd Floor West, 250 Euston Rd
London NW1 2PG

Website: www.uclh.nhs.uk/JRCU

Haematology consultants:
Professor John Porter
Dr Sara Trompeter
Dr Perla Eleftheriou
Dr Emma Drasar
Dr Bernard Davis
Dr Farrukh Shah

Specialist nurses:
Bernadette Hylton (adults)
Nancy Huntley (apheresis)
Nina Gorman (children)
Where can I get more information?

**Sickle Cell Society**
Tel: 020 8861 7795  
Website: www.sicklecellsociety.org

**NHS Sickle Cell and Thalassaemia Screening Programme**
Website: www.gov.uk/guidance/sickle-cell-and-thalassaemia-screening-programme-overview

**UK Thalassaemia Society**
Tel: 020 8882 0011  
Fax: 020 8882 8618  
Email: office@ukts.org  
Website: www.ukts.org

University College London Hospitals NHS Foundation Trust cannot accept responsibility for information provided by external organisations.
Space for notes and questions