



Priapism for patients with sickle cell disorder

Information for patients

What is it and who is affected?

- Priapism is a persistent and often painful erection that lasts for several hours.
- Priapism can occur in males of all ages, including newborn babies and is common in sickle cell anaemia.
- Most boys over the age of about 10 years and healthy adults will have at least three to four erections a day. Many will happen at night, and it is normal for older boys and men to wake up with an erection.
- Normal erections are not painful and fade away as the person gets on with other activities.

How does an erection happen?

- The artery to the penis opens wider and blood rushes into the penis.
- Veins carrying blood away from the penis shut down.
- Blood then becomes trapped inside the penis, making it hard and erect.
- An erection subsides when the veins open up and allow blood to flow out of the penis.

How do I recognise the problem?

- If the erection is painful, or if it does not fade away after about 30 minutes this is called priapism.
- Priapism is very common in boys and men with sickle cell anaemia and needs to be treated seriously.
- If it is ignored it may lead to future problems.
- At worst, the man may not be able to have normal erections.

Types of priapism

- There are two types of priapism:
 - **Priapism associated with low blood flow**
This occurs when the vein running from the penis is blocked, and results in a high risk of damage to the tissues.
 - **Priapism associated with high blood flow**
This occurs after injury to the penis, when the cavernosal artery (vessel leading to the penis) ruptures. This is unusual in sickle cell disorder.
- The erection can occur as repeated short episodes (known as stuttering priapism), which can last from a few minutes to several hours; or it can last for four hours or more (known as fulminant priapism).



Other causes of priapism

- Priapism can also be caused by damage to the nervous system and injury to the penis or genital area. Priapism may occur in:
 - Sickle cell disease
 - Thalassaemia
 - Leukaemia
 - Multiple myeloma
 - Fabry disease (a rare genetic disease that affects the metabolism)
 - Through use of illegal drugs and alcohol
- Priapism can be caused or made worse by alcohol and the use of illegal drugs, including:
 - Marijuana
 - Cocaine
 - Ecstasy

Can I do anything to prevent it?

- Reduce the use of any of the above-named drugs.
- Keep well hydrated.
- Sometimes priapism may happen despite these precautions.

What can I do about it when it happens?

- Do the following things immediately:
 - Drink lots of fluids
 - Some patients find jogging or other exercise helps
 - Take simple pain killers such as paracetamol
 - Try to ejaculate
- This may take the problem away within the next hour.
- If this works, you should then report the problem within the next few days to the Haematology medical team caring for you.
- **If the problem does not go away, you must go to the Whittington Hospital Emergency Department (A&E). You may be referred and/or transferred to University College London Hospital (UCLH) for treatment.**
- Show them this factsheet and ask them to follow the instructions for dealing with this problem.
- The plan will include a series of steps which includes a referral to a Urologist.
- In most cases, a sample of blood will be taken from the penis using a very small needle to check how much acid and oxygen is in the blood. This procedure is done by numbing the penis first using local anaesthetic and is crucial for saving future penile function.
- Other steps may include:
 - Drainage of some blood from the penis.
 - Medicines such as Etilerfrine or Pseudoephedrine which are usually given by mouth or may be given by injection into the penis.
 - Exchange blood transfusion.
 - In some cases, a different drug which stops erections by lowering testosterone is used
 - In severe cases, you may need an operation performed by a specialist urology team at UCLH. There are several types of operation, and these will be discussed with you.



If you are worried about anything you have read in this leaflet, please ask your consultant to arrange to see you for support and advice relating to any of your concerns.

Contact details

- Your consultant team is:

Dr Emma Drasar
 Dr Ryan Mullally
 Dr Ana Ortuno-Cabrero
 Dr Ali Rismani
 Dr Zara Sayar
 Dr Annabel McMillan
 Dr Prabal Mittal
 Dr Janine Younis

- Adult departmental contacts:

whh-tr.haematologyteam@nhs.net Haematology Administration Team

whh-tr.adultsicklecons@nhs.net Adult Sickle Cell Clinical Nurse Specialist (CNS) team

ncl.redcellteam@nhs.net Community link (Sickle cell, Thalassaemia and Rare Anaemia)
 0203 316 8853 Community phone number

emma.prescott@nhs.net Whittington Thalassaemia CNS

niamh.malone-cooke@nhs.net Whittington Thalassaemia CNS

- Network website:

<https://www.uclh.nhs.uk/theredcellnetwork/subscribe>

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

Patient advice and liaison service (PALS)

If you have a compliment, complaint or concern please contact our PALS team on 020 7288 5551 or whh-tr.PALS@nhs.net

If you need a large print, audio or translated copy of this leaflet please email whh-tr.patient-information@nhs.net. We will try our best to meet your needs.

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