

## Paediatric Sickle Cell Service

# Priapism and sickle cell disease in adolescents

## Information for adolescents, relatives and carers

### Introduction

This leaflet has been provided to help answer some of the questions you may have about **priapism and sickle cell disease in adolescents**. It is not meant to replace the consultation between you and your healthcare team, but aims to help you understand more about what you discussed together.

### What is priapism?

Priapism is a prolonged and painful erection of the penis. It is normal for the penis to become erect for short periods of time in boys, of all ages, although this should not normally be painful or last more than 30 minutes.

### What causes priapism?

It happens when sickled red blood cells block the flow of blood in the penis. This trapped blood causes an unusual hard erection. Because of lack of oxygen to the penis, damage may then occur which causes pain and, if prolonged and left untreated, may cause scarring of penile tissue, which can lead to loss of sexual function.

Priapism is mainly seen in teenagers and adults. It is less common in younger children but can still occur at almost any age. It is however rare in children under the age of two years. Priapism occurs in all forms of sickle cell disease, but is most common in HbSS disease. Most episodes occur for no obvious reason however it can occur as part of a more general episode of acute pain.

### Types of priapism

- **Stuttering priapism:** Episodes of reoccurring priapism, which lasts a few minutes to 2 hours, and can sometimes be painful.
- **Acute priapism:** A painful prolonged erection lasting for more than 2 hours. It can sometimes last from 6-10 hours or many days if left untreated.

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## What should I do if priapism occurs?

This is very embarrassing for children and teenagers but **it is vital that they tell someone**. The importance of telling a parent or their nurse, doctor or any responsible adult must be stressed from a young age. To help children, adolescents and parents talk about priapism you can always use this leaflet to show someone. **Patients with priapism must attend hospital if the symptoms have not disappeared after 2 hours.**

## Is there anything I can do to help?

- Seek treatment early.
- Treat priapism as a sickle cell crisis and drink extra fluids.
- Avoid getting too hot at night and empty your bladder at night –to avoid early morning erections.
- Walking around or gentle exercise.
- Having a warm shower or bath.
- Keeping warm improves the circulation.
- Avoid sexual activity during priapism.
- Take pain relief but if priapism is occurring regularly you need to talk to your doctor to discuss other treatments.
- Passing urine is sometimes easiest done in a warm bath.
- Avoid alcohol, cannabis, cocaine or Viagra, as these can potentially trigger priapism.
- Do not apply anything cold to the penis. This will make it worse as cold causes the blood vessels to constrict further.

## Will I need medication?

If short episodes of priapism occur frequently, medication may help to stop further problems occurring. Your doctor will discuss this with you, including side effects and benefits of treatment.

## What happens if I do not get treatment?

You must attend your nearest hospital for treatment and advice when priapism lasts for 2 hours or more. If you do not get treatment, there is a risk of developing loss of normal sexual function.

Treatment will normally be analgesia for the pain and intravenous fluids to help with the sickling. In some cases surgery will be needed which involves a small operation under general anaesthetic to wash the sickled blood out of the penis. This surgery can only be done in specialist centres.

## Whom can I contact for more information?

Clinical nurse specialist, Monday to Friday 9-5pm on **07795651153**

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Paediatric Haematology Registrar Monday to Friday 9-8pm and Saturday/Sunday 9-5pm via switchboard on **020 3313 6666**

You can talk to your consultant about this problem during outpatient visits.

## Further information and support

Sickle Cell Society, Tel: **020 8961 7795**. Email: [info@sicklecellsociety.org](mailto:info@sicklecellsociety.org).  
Website: [www.sicklecellsociety.org](http://www.sicklecellsociety.org)

## How can I make a comment about my treatment?

We aim to provide the best possible service and staff will be happy to answer any questions you may have. However, if your experience of our services does not meet your expectations and you would like to speak to someone other than staff caring for you, please contact the patient advice and liaison service (PALS) on **020 3313 3322** or **020 3133 0088** (Charing Cross and Hammersmith hospitals), or **020 3312 7777** (St Mary's Hospital). You can also email PALS at [pals@imperial.nhs.uk](mailto:pals@imperial.nhs.uk). The PALS team are able to listen to your concerns, suggestions or queries and are often able to help sort out problems on behalf of patients.

Alternatively, you may wish to express your concerns in writing to:

The chief executive  
Imperial College Healthcare NHS Trust  
Trust Headquarters  
The Bays, South Wharf Road  
London W2 1NY

## Alternative formats

This information can be provided on request in large print, as a sound recording, in Braille, or in alternative languages. Please contact the communications team on **020 3312 5592**.