

# Priapism: information for people with sickle cell disease

This leaflet provides information about priapism – what it is and how to manage it. If you have any further questions or concerns, please speak to a member of the team using the contact details listed towards the end of this leaflet.

#### What is priapism?

Priapism is a long-lasting, usually very painful erection of the penis. It occurs in 40% of men with sickle cell disease.

Priapism occurs because the blood in the penis is trapped and unable to return to the circulation. It occurs in conditions where blood is thicker or where red blood cells lose their flexibility (for example in sickle cell disease). It is not necessarily related to sexual stimulation or desire.

If it is not treated, priapism can lead to scarring and being permanently unable to get an erection (erectile dysfunction or impotence). Priapism can occur in males of all age groups. It is less common in younger children but it can occur at almost any age (although it is very uncommon in boys under the age of two).

# **Types of priapism**

*Stuttering priapism* – this occurs where the erection typically lasts for less than one hour, on several occasions, and gets better without medical treatment.

Acute priapism – this is a painful erection which lasts for more than one hour and may continue for days unless treatment is given.

If a person has several episodes of stuttering priapism he is more at risk of having acute priapism. It is vital that you seek treatment after two hours and not leave it for days. Priapism must be treated **as early as possible**. You should also tell your doctor if you have episodes of stuttering priapism without developing acute priapism.

# Getting help for priapism

Men sometimes feel embarrassed by these episodes and therefore do not mention them to anyone, not even to their doctor. It is important to know that doctors will understand that this is a painful problem that may require urgent treatment.

# Management at home

#### The following actions are sometimes helpful:

- Taking painkillers
- Having a warm bath
- Passing urine
- Walking or other exercise (jumping up and down, walking up stairs)
- Avoid using ice packs around the penis.

# What should I do if the priapism lasts for longer than two hours?

You will need to seek urgent medical attention. Please come to the Emergency Department (A&E). Once there you will be assessed by the emergency staff who will ask the urology doctors – doctors who specialise in conditions of the genital and urinary systems - to come and see you as well as your haematology team.

# IF THE PRIAPISM LASTS FOR LONGER THAN TWO HOURS PLEASE COME AT ONCE TO THE ACCIDENT & EMERGENCY DEPARTMENT

#### Treatment

The doctor will ask you some initial questions to make a diagnosis of the priapism. He or she will ask about medication, medical history, and possibly about non-prescription drugs such as marijuana, cocaine and ecstasy. This is because some of these drugs can cause priapism.

The doctor will then examine you. The physical examination will probably show a hard penis with a soft glans (the head of the penis). Once a diagnosis is made, it is important to get treatment as soon as possible.

Effective pain relief should be given to you. This may include morphine or similar drugs. You may also be given fluids via a drip to ensure you are hydrated. The urology doctor may try medication (tablets) to relieve the priapism or try removing (aspirating) some of the blood from the penis with a needle. This would be done in combination with a local anaesthetic.

Occasionally surgery is needed to allow the urologists to wash out the blood from the penis or to inject it with medication. This would involve a general anaesthetic. Sometimes blood transfusions are also used to help with priapism. The urologists will discuss this with you.

# What happens after an episode of priapism?

If you have required hospital treatment you will need to stay in until the priapism is better. You may be given tablets to stop further episodes. You will be given an appointment for the urology clinic.

If you have concerns or questions about sexual function or sexual activity following priapism please talk to your doctor. You (and your

partner if you wish) are welcome to have further discussions with the haematologist, urologist or psychologist.

The following video may be helpful for younger people experiencing priapism:

Priapism » Sickle Cell Society

# Contact us

If you have any questions about your condition, please discuss with a member of the red cell haematology team at your next appointment or using the details below.

Dr Elizabeth Rhodes (sickle cell and thalassaemia consultant) Tel: 020 8725 0885

Dr Julia Sikorska (lead sickle cell and thalassaemia consultant) Tel: 020 8725 0885

Dr James Masters (sickle cell and thalassaemia consultant) Tel: 020 8725 0885

EnaAbena Akomah-Barnier (clinical nurse specialist) Tel: 07825 978812, Email: haemoglobinopathy.nurses@stgeorges.nhs.uk

Nazik Osei (clinical nurse specialist) Tel: 07825 978812, Email: haemoglobinopathy.nurses@stgeorges.nhs.uk

Sickle cell and thalassaemia secretary Tel: 020 8725 0885 For more information leaflets on conditions, procedures, treatments and services offered at our hospitals, please visit <u>www.stgeorges.nhs.uk</u>

#### Additional services

#### Patient Advice and Liaison Service (PALS)

PALS can offer you advice and information when you have comments or concerns about our services or care. You can contact the PALS team on the advisory telephone line Monday, Tuesday, Thursday and Friday from 2pm to 5pm.

A Walk-in service is available: Monday, Tuesday and Thursday between 10am and 4pm Friday between 10am and 2pm.

The Walk-in and Advisory telephone services are closed on Wednesdays.

Please contact PALS in advance to check if there are any changes to opening times.

PALS is based within the hospital in the ground floor main corridor between Grosvenor and Lanesborough wings.

Tel: 020 8725 2453 Email: pals@stgeorges.nhs.uk

#### NHS UK

The NHS provides online information and guidance on all aspects of health and healthcare, to help you make decisions about your health. **Web:** <u>www.nhs.uk</u>

#### NHS 111

You can call 111 when you need medical help fast but it's not a 999 emergency. NHS 111 is available 24 hours a day, 365 days a year. Calls are free from landlines and mobile phones. **Tel:** 111

#### AccessAble

You can download accessibility guides for all of our services by searching 'St George's Hospital' on the AccessAble website (www.accessable.co.uk). The guides are designed to ensure everyone – including those with accessibility needs – can access our hospital and community sites with confidence.



Reference: CLH\_PSCD\_LP\_03 Published: February 2025 Review date: February 2027