Priapism and sickle cell disease (SCD)
A guide for parents and carers
This leaflet offers further information about priapism in children with sickle cell disease, including what it is and what to do if your child experiences it. If you have any further questions or concerns, please contact us using the details given at the end of this leaflet.

What is priapism?
Most adult men and boys over the age of about 10 years will have three to four erections a day. Many will happen at night and it is normal for boys and men to wake up with an erection. Normal erections are not painful and go away as the person gets on with their day.

Priapism, however, is a persistent erection that:
- is painful
- does not go away within 30 minutes.

Priapism can occur in males of all ages and is common in sickle cell anaemia.

There are two types of priapism:

- **Stuttering priapism** – This is when a person has episodes of priapism several times during the course of a day. They last from a few minutes to an hour, but get better on their own without medicines.

- **Fulminant priapism** – This is a painful erection that lasts for more than an hour and may continue for hours to days unless treatment is given.

What causes priapism?
Most episodes of priapism in sickle cell anaemia happen for no obvious reason, although priapism may occur as part of a sickle cell pain crisis or another illness.

Misuse of prescription drugs, as well as alcohol and drug abuse can cause priapism in some cases.

What should I do if my child gets priapism?
It is important for children and teenagers to know about priapism and to tell their parents or carers if they get a prolonged, painful erection. They are often embarrassed by this and may not mention it to anyone. It is therefore useful to speak to your child about priapism before it happens.

The following things may help:
- drinking lots of fluids
- having a warm bath
- passing urine
• walking around or exercising
• taking painkillers such as ibuprofen or paracetamol.

Make sure to tell your doctor about any episodes of priapism at your next visit.

If the problem lasts more than two hours or keeps coming back you must seek medical help by attending your nearest A&E (emergency) department. In hospital the doctors will assess your child. This may include assessment by specialist doctors called urologists, who have in-depth knowledge of conditions affecting the urinary tract and the male reproductive organs. A number of treatments may be used, including:

• painkillers
• intravenous fluids
• blood transfusions
• surgery (if necessary). This will be performed under a general anaesthetic and will involve putting a needle in the penis to wash the blood out. This is usually a quick procedure and your child will be asleep throughout.

If your child has to come to the hospital for treatment of priapism, they will be monitored in the hospital until no episodes occur for at least 24 hours. They may be started on medicines to prevent further episodes of priapism.

If your child experiences an episode of priapism, it is important not to ignore it as it may lead to future problems, such as inability to have sexual intercourse.

Contact us

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<thead>
<tr>
<th>Department</th>
<th>Telephone number</th>
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<tbody>
<tr>
<td>Sickle cell counsellor</td>
<td>020 8812 6236</td>
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<td>Paediatric haematology secretary</td>
<td>020 8725 3921</td>
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<td>Freddie Hewitt Ward</td>
<td>020 8725 2081</td>
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</tbody>
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Additional services

Patient Advice and Liaison Service (PALS)
PALS can offer you on-the-spot advice and information when you have comments or concerns about our services or the care you have received. You can visit the PALS office between 9am and 5pm, Monday to Friday in the main corridor between Grosvenor and Lanesborough Wing (near the lift foyer). Tel: 020 8725 2453 Email: pals@stgeorges.nhs.uk

NHS Choices
NHS Choices provides online information and guidance on all aspects of health and healthcare, to help you make decisions about your health.
Web: www.nhs.uk

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