



Information about priapism in a young person (over the age of 12) with Sickle Cell Disease

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Scottish Paediatric and Adult Haemoglobinopathies Network

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What is priapism?

Priapism is a medical term for a prolonged erection. It is not related to sexual intercourse or stimulation and is often painful. Patients with sickling disorders, particularly sickle cell anaemia (HbSS) are more likely to have this condition. It mostly affects teenagers and adults, but children can also suffer priapism.

Many young men with sickle cell disease (SCD) will have experienced an episode of priapism by the time they reach adulthood. Red blood cell sickling within the penis interferes with blood flow back to the body. This can cause swelling and pressure to build up. Very prolonged episodes of priapism may lead to problems getting an erection (erectile dysfunction). It is important to get medical help quickly to prevent this.

What are the types of priapism?

Stuttering

- Shorter episodes lasting from a few minutes up to three hours are described as stuttering priapism. This type of priapism can happen frequently. It's usually less serious, but it does increase the chance of having a more severe episode. If this is happening, you should always tell your Haematologist.
- Patients with frequent episodes may be given medication to control and prevent this.

Fulminant

- This is when an episode of priapism lasts **over three hours**.
- This is an emergency and if not treated promptly, permanent damage to the internal tissues of the penis can occur.

What triggers priapism?

Fatigue, cold, dehydration and infection all increase the chances of priapism. Priapism can occur along with a painful crisis.

What can I do to prevent it happening?

- Stay well hydrated.
- Empty your bladder before going to bed at night.
- Make sure you get enough sleep.
- Avoid alcohol, tobacco and recreational drugs like marijuana and cocaine, as these can all cause priapism.
- Use of sildenafil (also known as Viagra) can also increase the risk.
- Tell your doctor before starting new medicines.

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What do I do when I get priapism?

- · Take your usual pain relief medication.
- Try and empty your bladder.
- Increase your fluid intake.
- Do some gentle exercise, for example walking.
- Take a warm bath or shower.

Do not apply ice or use cold water, as this may make the priapism worse.

If you have done these things and your penis remains erect for more **than one hour**, go **IMMEDIATELY** to your nearest Accident and Emergency department or Haematology Unit for urgent assessment (see local contacts details below).

How is a priapism treated in hospital?

- You will be seen by a doctor and given pain relief and fluids.
- You may also be given medication to try and resolve the priapism.
- Blood samples will be taken.
- You may be given a blood transfusion.
- If the priapism continues, you may be seen by a specialist surgeon (Urologist).

Don't forget that:

- priapism is a common problem for people with SCD
- you should not feel embarrassed or ashamed if this happens to you
- it's very important for your Haematologist to know if you suffer from priapism. If you are asked about this, it's important to give an accurate answer so you can be properly treated
- you can ask your Haematologist for advice if you have any concerns

Local contact details

	Name	Contact number
Consultant Haematologist or		
Paediatrician		
Clinical Nurse Specialist		
A : 1 . 0 F		
Accident & Emergency		
Department		

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Further information

Can be found on the Scottish Paediatric and Adult Haemoglobinopathies Network (SPAH) website spah.scot.nhs.uk

If you require an alternative format, please contact nss.equalitydiversity@nhs.scot, telephone: 0131 275 600

British Sign Language, please contact Scotland BSL: <u>Contact Scotland</u> (<u>contactscotland-bsl.org</u>)