

Painful erections in sickle cell disease (priapism)

Sickle Cell and Thalassemia Service

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Information for Patients

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What is priapism?

Most boys and healthy adult males have erections every day. It is common for boys and men to wake up with an erection. This type of erection is painless and fades away on its own.

Priapism is a long lasting painful erection of the penis. This happens without physical, mental or sexual stimulation. This is because blood gets trapped in the penis and cannot drain away. Most males with **sickle cell anaemia (Hb SS)** are likely to have priapism. It is not common in patients with other forms of sickle cell disease and thalassemia.

If you ignore priapism it may lead to problems like not being able to have normal erections.

What are the symptoms of priapism?

- Erections that last longer than 30 minutes.
- Hard erection without sexual stimulation.
- Pain or sensitivity in the penis.

What are the types of priapism?

There are 2 main types of priapism in sickle cell disease:

1. intermittent (stuttering)
2. acute (persistent)

These terms are explained on page 2.

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What is intermittent (stuttering) priapism?

This is the most common type. It is called intermittent because it happens again and again. This can last for 30 minutes to 1 hour. This gets better by itself but then happens again in a few minutes or within a few hours. Some episodes are not painful. But the longer it lasts, the more painful the erection becomes. This type often happens at night time and sometimes may not be painful. But the longer it goes on the more painful it can become. This type can become more severe like acute (persistent) priapism.

What is acute (persistent) priapism?

This happens when the vein running from the penis is blocked. This may lead to tissue damage. This type is a long lasting and painful erection. It may last for a few hours. It does not get better on its own. This is a major complication of sickle cell disease and will require medical attention.

Why does this happen in patients with sickle cell disease?

Priapism is a sickle cell crisis within the penis. Sickled red cells block the supply and flow of blood in the penis. The sickled red blood cells cause disruption to the normal flow of blood in the penis. There is less oxygen in the penis making it stay erect. This causes pain and tissue damage. Normal night time and early morning erections can be a common trigger.

What problems are caused by priapism?

The tissues in the penis can become scarred and damaged. These changes can become permanent the longer the priapism goes on. Scarring and damage to the tissue can disrupt the normal flow of blood into the penis. This may cause poor quality erections or no erections when one is desired (erectile dysfunction).

At what age is it likely to happen?

The average age to experience priapism is around 15 years old. But it can be experienced during early puberty. This is when a child's body begins to develop changes as they become an adult. We can have early talks about priapism and encourage your child to talk about this. Some patients experience priapism into their 30s or 40s.

What are the triggers?

- Alcohol and smoking.
- Certain drugs and treatment. Talk with your doctor about any new medications and treatments.
- Sexual intercourse. Some patients get priapism during sex.
- Normal early morning erections. This is often together with a full bladder.
- Dehydration and infection.
- Stress and cold environments.

How can I stop it from happening?

- Do not drink alcohol or use drugs. You can use what your doctor has prescribed.
- Drink plenty of water.
- Keep warm during cold weather.
- Do not use cannabis, tobacco or Viagra.

Priapism can happen even if you follow the above advice. Your doctor may ask you to take a medicine like etilefrin regularly to prevent further problems.

How do I manage it?

Each person will find different ways to manage their priapism. Some tips are:

- Go to the toilet just before you go to bed. This is to empty the bladder. Go to the toilet as soon as you wake up. This will make early morning erections less likely.
- Drink lots of fluids.
- Take simple pain killers such as paracetamol.
- Have a warm bath or shower and wear loose-fitting underwear.
- Go for a gentle walk, try gentle exercises such as squats or running on the spot.

Do not:

- Do not apply ice packs or cold water to your penis. This can make things worse.
- Do not have sex or masturbate. This will not make your erection go away.
- Do not drink alcohol.
- Do not smoke.

These strategies should help to take the problem away within 1 hour. You must report the episode to your haematology team as soon as possible. If it does not go away within **2 hours**, go to the Emergency Department (A&E) right away.

Going to hospital for treatment

When coming to the hospital you should wear baggy jogging bottoms or loose under garments. Tight garments may make the pain worse. If you are admitted to hospital we may give fluids into your vein (intravenously), oxygen and pain relief. The urology team may see you and recommend treatment to help reduce your erection, such as:

- **Medicine.** This can be etilefrin or pseudoephedrine. You can take these by mouth or by injection into the penis.
- **Drainage of blood from the penis.** The area is numbed with local anaesthetic.
- **Surgery to drain the blood through a thin cut.** We do this whilst you are asleep (under general anaesthetic).
- In some severe cases where these treatments have not worked, the haematology team may recommend a red cell exchange.

Call 999 or go to A&E if you have an erection that lasts more than 2 hours.

An erection that lasts this long requires hospital treatment to avoid permanent damage to your penis.

Useful contacts

Haematology Helpline (Adult): 0808 178 2212

UHL Medicines Information: Monday to Friday 8.30 am to 5.30 pm, call: 0116 258 6491

Sickle Cell Society:

www.sicklecellsociety.org

Phone: 020 8961 7795

email: info@sicklecellsociety.org or visit:

UK Thalassaemia Society

www.ukts.org

Phone: 020 8882 0011

Email: office@ukts.org

Sickle Cell and Thalassaemia Service

Leicester Royal Infirmary, Ground Floor, Osborne Building

Monday to Friday 9am to 5pm, call: 0116 258 6081

We are always pleased to hear from patients and carers. If you have any suggestions about how the service is run please contact us.

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Previous reference:

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