

How to manage your sickle cell pain in hospital

Information for children and young people

This information leaflet is for children and young people (CYP) from ages 11 to 16 years old. It provides a brief outline of what to expect when you arrive at King's Emergency Department (ED) and what happens if you need to be admitted or discharged.

The leaflet covers pain medications, pain tools used by medical staff, and cannulations. It also provides information about the nursing care you can expect to receive. If you have any other questions or concerns, please do not hesitate to speak to the doctors or nurses caring for you.

Confirming your identity

Before you have a treatment or procedure, our staff will ask you your name and date of birth and check your ID band. If you do not have an ID band we will also ask you to confirm your address. If we do not ask these questions, then please ask us to check. Ensuring your safety is our primary concern.

What happens during my admission to the Emergency Department (ED)?

When you come to the ED, the nurses will take your observations (your heart rate, your respiratory rate, your blood pressure and your oxygen levels), and ask you about your pain.

It might seem like there are lots of questions, but it is important for us to know what medication you have taken, what time it was taken and how much you have taken, so that we can make a plan to manage your pain.

The doctors will also come and speak to you. They will examine you, and they might need to take some bloods, or do some other tests.

The doctors in the ED will work together with the blood specialist doctors to come up with a plan for your treatment.

You should expect to receive pain relief within 30 minutes of being seen, and your pain should be reassessed within 30 minutes to 1 hour after you have had the medicine.

Sometimes we are really busy in the ED – if you are still in pain after this time and no one has come back to you, please do ask for more pain relief.

Do I need to prepare for my hospital admission?

Please bring all the medications you are currently taking to hospital.

What happens after my initial assessment in the ED?

At this point, the doctors and nurses from ED and the Haematology Team will make a decision whether to admit you to hospital, or discharge you home.

If they decide to admit you to a hospital bed, it may take some time to find a bed for you in the hospital. Until this point, you will be cared for in the ED.

If you are 16 years old or over, your bed may be on an adult ward. This will depend on whether you have already been transitioned to adult services.

How do we assess your pain?

One of the ways we assess your pain is by giving it a score. We will ask you to rate your pain on a scale of 0 to 10 or by using different faces to describe how you are feeling.

VA Score Pain: Faces: suitable for children between 3 and 18 years

Choose the face that shows the level of pain or hurt that you feel.



Paediatric Pain **FLACC** Score: suitable for children between 0 and 18 years:

Categories	0	1	2
Face	No particular expression or smile.	Occasional grimace or frown, withdrawn, disinterested.	Frequent to constant frown, clenched jaw, quivering chin.
Legs	Normal position or relaxed.	Uneasy, restless, tense.	Kicking or legs drawn up.
Activity	Lying quietly, normal position, moves easily.	Squirming, shifting back and forth, tense.	Arched, rigid or jerking.
Cry	No cry (awake or asleep).	Moans or whimpers, occasional complaint.	Crying steadily, screams or sobs, frequent complaint.
Consolability	Content, relaxed.	Reassured by occasional touching, hugging or being talked to, distractible.	Difficult to console or comfort.

Each category is scored on the 0-2 scale, which results in a total score of 0-10.

0: Relaxed and comfortable

1-3: Mild discomfort

4-6: Moderate pain

7-10: Severe discomfort or pain or both

Revised **FLACC** for **Special Needs**:

Categories	0	1	2
Face	No particular expression or smile	Occasional grimace or frown, withdrawn, disinterested. Appears sad or worried.	Frequent to constant frown, clenched jaw, quivering chin. Distressed looking face; expression of fright or panic.
Individual behaviours			
Legs	Normal position or relaxed. Usual tone, motion to all limbs.	Uneasy, restless, tense. Occasional tremors.	Kicking or legs drawn up. Marked increase in spasticity, contact tremors or jerking.
Individual behaviours			
Activity	Lying quietly, normal position, moves easily. Regular, rhythmic respirations.	Squirming, shifting back and forth. Tense or guarded movements; mildly agitated (for example, head back and forth, aggression); shallow, splinting respirations, intermittent sighs.	Arched, rigid or jerking. Severe agitation, head banging, shivering (not rigors), breath holding, gasping or sharp intakes of breath; severe splinting.

Individual behaviours			
Cry	No cry or verbalisation (awake or asleep)	Moans or whimpers, occasional complaint. Occasional verbal outburst or grunt.	Crying steadily, screams or sobs, frequent complaint. Repeated outbursts, constant grunting.
Individual behaviours			
Consolability	Content, relaxed	Reassured by occasional touching, hugging or being talked to, distractible	Difficult to console or comfort. Pushing away caregiver, resisting care or comfort measures.
Individual behaviours			

Adapted from Malviya et al. 2006

Consent

We must by law get written consent from you and/or parent/guardian to any operation and some other procedures beforehand. Nursing Staff will explain the risks, benefits before they ask you or your parents/guardians to sign a consent form. If you are unsure of any part of the treatment, please talk to your nurse or doctor.

What medicines will I be given?

At King's, we try to follow a pathway to manage your pain. We may start by giving paracetamol and ibuprofen, if you have not had this recently at home.

If your pain persists, we will give you morphine.

How do I take this medication?

It is important that while you are in pain you take all of your medications regularly, even if this means waking up at night-time. This stops the pain building up while you are asleep and being unmanageable when you wake up.

It also means taking the simple medications like paracetamol and ibuprofen regularly too. We know that stronger medicines will work better if you are taking simple ones too.

Paracetamol can be taken by mouth or given into your vein every 6 hours.

Ibuprofen can be taken by mouth every 6 hours, and diclofenac orally or via the bottom every 8 hours.

Morphine can be given in a lot of ways. We only give you morphine in hospital because it has a lot of side effects. If you are in severe pain, we can give you a fast-acting version that you sniff up your nose. It works quickly.

You can take your morphine by mouth every 4 hours.

If your pain is not managed this way, Morphine (or other opioid drugs) can be given by a "patient", or "nurse controlled" pump into a cannula. These are sometimes called a patient-controlled analgesia (PCA) infusion pump or a nurse-controlled analgesia (NCA) infusion pump.

A member of the pain team will explain how the PCA or NCA infusion pump works. The infusion pump has a button that can be pressed to deliver extra medicine, which will either be operated by yourself or a nurse.

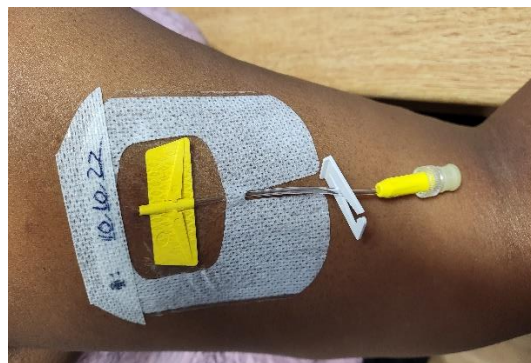
A PCA or an NCA can be delivered either into your vein (intravenous), or under your skin (subcutaneous) by a cannula (a small plastic tube).



PCA or NCA machine



Cannula



Subcutaneous

Benefits and side effects of medication

- The aim of medication is to reduce your pain.
- If pain is reduced, then you can heal quicker.
- There are very few risks with paracetamol, which is why we choose to give it first
- Ibuprofen and diclofenac are generally very safe too, but some people with medical conditions like stomach ulcers cannot take them. Ask a parent or medical staff if you think you can't have ibuprofen.
- Morphine is given commonly in hospital for young people with painful crises. There are some side effects however, including itching, feeling sick, constipation, tolerance (which means it doesn't seem to work as well), and in rare cases it can cause changes to your breathing.

What happens after I have taken my medication, when I am admitted to the ward?

- The nurses will check your heart rate, breathing rate, temperature, and the oxygen in your blood (observations). We will also check your pain score to make sure the medicine has worked.
- Depending on the type of medication you are on, they may check your observations and your pain score more regularly. This will mean they have to wake you up during the night.
- Your specialist teams will be round to see you regularly to check how you are doing. If you are experiencing any side effects from the pain medication, they will try to make those better.

What else can I do to help with my pain?

- We always encourage people to bring in hot water bottles from home, as sometimes these can help your pain. The hospital cannot provide these for you, but can provide the hot water.
- Physiotherapy can be helpful when your pain is affecting your movement. It is important to keep moving, even if you do not feel like it.
- The team will encourage you to regularly use a medical device called an 'incentive spirometry', which helps strengthen your lungs. This reduces the chance of the pain spreading to your chest and reduces the chance of you having breathing difficulties.
- Distraction or play therapy can be helpful to take your mind off the pain. Our play specialists can provide you with things to keep your mind occupied while you're in hospital, but you can also bring things in to keep you occupied too.
- We recognise that pain can affect your mental wellbeing. There are sickle cell specialist psychologists in the Haematology Team. We can refer you to them if you require further help and support to manage painful episodes or need further support in other aspects of your sickle cell care. Let your sickle cell team know if you would like to be referred to the psychology specialist team and this can be arranged as an outpatient or with your next clinic appointment.
- It is important that you continue to eat and drink, as this reduces the amount of time you spend in hospital.

Who else will be involved in my hospital stay?

- Haematology specialists
- Pain specialists
- Physiotherapists
- Ward staff (nurses, doctors and students)
- The play team
- Psychologists

When can I go home?

You will be able to go home when your pain has reduced to the point that you can manage it at home.

Who to contact?

If you or your parents have any queries or concerns about your stay in hospital, please ask the doctors or nurses on the ward you are staying, or contact the clinical nurse specialists.

Pain clinical nurse specialists: 020 3299 3273

Haematology clinical nurse specialists: 020 3299 1916 or 020 3299 4752

Sharing your information

We have teamed up with Guy's and St Thomas' Hospitals in a partnership known as King's Health Partners Academic Health Sciences Centre. We are working together to give our patients the best possible care, so you might find we invite you for appointments at Guy's or St Thomas'. To make sure everyone you meet always has the most up-to-date information about your health, we may share information about you between the hospitals.

Care provided by students

We provide clinical training where our students get practical experience by treating patients. Please tell your doctor or nurse if you do not want students to be involved in your care. Your treatment will not be affected by your decision.

PALS

The Patient Advice and Liaison Service (PALS) is a service that offers support, information and assistance to patients, relatives and visitors. They can also provide help and advice if you have a concern or complaint that staff have not been able to resolve for you. They can also pass on praise or thanks to our teams. The PALS office is located on the ground floor of the Hambleden Wing, near the main entrance on Bessemer Road - staff will be happy to direct you.

PALS at King's College Hospital, Denmark Hill, London SE5 9RS

Tel: 020 3299 3601

Email: kch-tr.palsdh@nhs.net

If you would like the information in this leaflet in a different language or format, please contact our Communications and Interpreting telephone line on 020 3299 4826 or email kch-tr.accessibility@nhs.net