

Managing pain in sickle cell disease

Information for parents

What causes pain in sickle cell disease

Sickle cell disease is the name for a group of inherited conditions that affect the red blood cells. It includes HbSS, HbSC and HbSbeta thalassaemia. Pain is the most common symptom.

A painful episode (painful crisis) happens when the red blood cells sickle and block small blood vessels. This prevents blood from getting through to the tissues which are then deprived of oxygen and this causes pain in the affected part of the body.

These episodes of pain can start from 6 months of age. In this young age group it mainly involves the hands and feet (dactylitis) while in older children it often occurs in the back, chest, arms, legs or stomach. Pain can begin suddenly, lasting from several hours to days and can range from mild to severe.

How to manage pain at home

Most episodes of pain can be managed at home, reducing the need to attend the emergency department (A&E).

Sometimes it may be difficult to determine that your child is experiencing pain, particularly in young babies and toddlers. However, you will learn to identify when your child is unwell and develop the confidence to manage pain at home. As your child grows older, they become better at expressing when they are having pain and are also able to locate where the pain is.

Signs of pain in children

- Not behaving normally – may be withdrawn or not wanting to play.
- Fretting and looking miserable.
- Persistent crying.
- Crying when touched or moved.
- Swelling (inflammation) on the part which hurts and may also feel warm to touch.

Pain relief medication

It is a good idea to keep a stock of pain relief at home. You may give:

- Paracetamol (Calpol) every 4 to 6 hours (maximum 4 times a day)
- Ibuprofen every 6 to 8 hours (maximum 3 times a day)
- Dihydrocodeine 4 to 6 hours (over 1 year of age).

Important: read and follow the recommendations by your doctor or pharmacist written on the medicine bottle or box. **Do not give more** than the recommended dose.

In mild-moderate pain, ibuprofen helps relieve inflammation. It is safe to give together with paracetamol and may manage the pain better.

In more severe pain, dihydrocodeine can be added. It can be helpful to stagger the doses so they don't wear off at the same time.

Pain chart to use with your child



This is the worst pain I have had (8 to 10)



It hurts a lot (4 to 7)



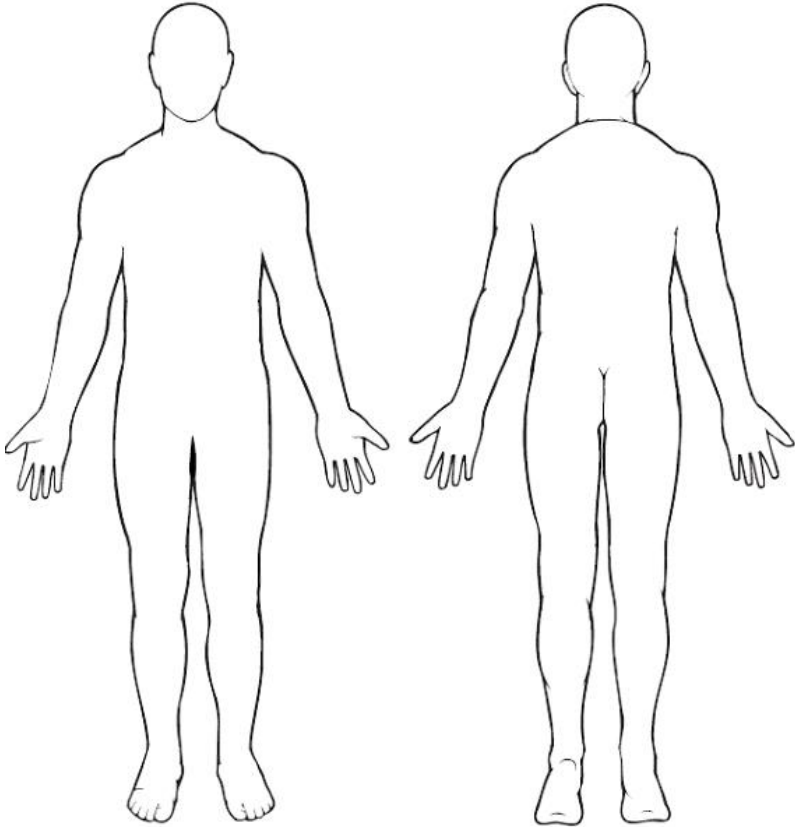
I have a little bit of pain (1 to 3)



I have no pain at all (0)

- If my pain score is **1-3** please give me paracetamol as prescribed.
- If my pain score is **4-7** please give me paracetamol and ibuprofen at the same time as prescribed.
- If my pain score is **8-10** please give me paracetamol, ibuprofen and dihydrocodeine, and call sickle CNS for advice. If you are really worried about me, call **999** for an ambulance.

Show me where it hurts



Front

Back

Other useful things to do

- Give extra fluids to drink – dehydration (less water in the body) is a common trigger for crisis pain.
- Warm moist towels – soak a flannel in warm water, wring out the excess water and use to massage the painful areas (please be sure not to leave the child wet and cold).
- Heat pads – always follow the manufacturer's instructions for safe use.
- Massage – use baby oil and gently massage the affected area. Touch can be very comforting.
- Distraction – for example reading a book, listening to music or playing games on a computer. This helps take the child's mind off the pain while the pain killers take effect.

When to seek medical advice

During working hours (9am to 5pm), you can call your nurse specialist if you are worried about anything.

You should contact your GP or take your child to the emergency department (A&E) if:

- They are still in pain after giving the medications and trying the other remedies above.
- Their pain becomes severe.
- They develop a fever of 38 degrees and above.
- They have severe chest or abdominal pain.
- They have sudden weakness or numbness (loss of feeling).

Contact us

Lead consultant for haemoglobin disorders, and consultant in haematology, phone: 020 7188 6203 (secretary), **email:** Dudhma.Banu@gstt.nhs.uk

Lead nurse, phone: 020 7188 9432 or 07918 338730
email: HaemoglobinopathyCNS@gstt.nhs.uk

Nurse specialist, phone: 07771 345847 or 07517 592436 **email:** HaemoglobinopathyCNS@gstt.nhs.uk

Research nurse, phone: 020 7188 6637 or 07517 592436

Specialist nurse – community, phone: 020 3049 5993 or 07880 781545

Therapy and psychology team, phone: 020 7188 9125 or 07817 905844

Sickle cell education video

<https://www.youtube.com/watch?v=wsykWgyXSKM>



More information and useful contacts

UK Thalassaemia Society (UKTS)

Educational material, counselling and support.

Call 020 8882 0011 or email info@ukts.org

www.ukts.org

Sickle Cell Society

Offering information, support and local services including mentoring and children's activities.

Call 020 8961 7795 or email info@sicklecellsociety.org

www.sicklecellsociety.org

The Sickle Cell and Thalassaemia Centre

Information, counselling support and local services

phone 020 7414 1363

Evelina London Medicines Helpline

If you have any questions or concerns about your child's medicines, please speak to the staff caring for them or contact our helpline.

phone: 020 7188 3003, Monday to Friday, 10am to 5pm

email: letstalkmedicines@gstt.nhs.uk

Your comments and concerns

For advice, support or to raise a concern, contact our Patient Advice and Liaison Service (PALS), **phone** 020 7188 8801 **email** pals@gstt.nhs.uk. To make a complaint contact the resolution department **phone** 020 7188 3514 **email** complaints2@gstt.nhs.uk

Language and accessible support services

If you need an interpreter or information about your care in a different language or format, please contact the department your appointment is with.

Leaflet number: 5079/VER2

Date published: October 2023

Review date: October 2026

© 2023 Guy's and St Thomas' NHS Foundation Trust