

Managing your sickle cell pain at home

Information for parents/carers and young people

Whether you're a parent, carer or young person, this leaflet for managing sickle cell pain at home will help you understand and handle different types of pain effectively.

Parents may prefer to read the leaflet themselves first and take time to understand the information before explaining it to their younger children.

While this leaflet provides valuable information, it's important to consult with your healthcare provider before making any changes to your pain management plan.

If you have any queries or concerns, please do not hesitate to speak to one of the healthcare team.

What is sickle cell pain management?

Managing your pain at home means knowing different ways to measure it and using methods other than medication to ease it. This leaflet gives you tips on how to manage pain effectively if you have sickle cell disease.

Why do I need this leaflet?

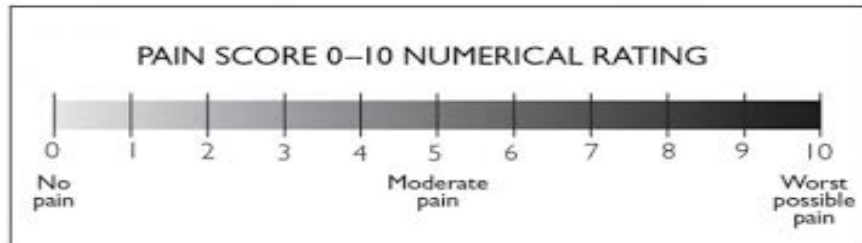
The aim is to assist you in better managing sickle cell pain. It provides tools to assess pain and non-drug methods to lessen it. Proper pain management can help prevent increased discomfort and complications.

It will provide information on:

- Using non-pharmacological methods to relieve pain.
- How you can accurately measure how much pain you're in.
- Improve communication with your healthcare team.

Types of pain and intensity

Understanding how pain feels and how strong it is helps us manage it better. Below are different ways to describe your pain — you don't need to use more than one, it's important to keep using the same one that fits the child's or young person's age group.



Numerical scale:

- Suitable from 7 years old plus. The numerical scale allows you to rate your pain on a scale from 0 to 10, where:
- **0**: Represents no pain.
- **10**: Represents the worst pain imaginable.

This scale helps you and your healthcare team understand how bad your pain is. It is important to be honest when rating your pain so you can get the right care.

0-10 NUMERIC PAIN RATING SCALE



Coloured numerical pain scale:

- Suitable from 7years+. This scale uses colours to show how intense your pain is. Each colour stands for a range of numbers (for example, **green** for **mild** pain, **yellow** for **moderate** pain, and **red** for **severe** pain). This can be especially useful for children or those who find it easier to understand pain levels through colours.

Wong-Baker FACES Pain Rating Scale



Wong baker faces scale:

- Designed for children (3 years+) and young people who have difficulty expressing pain with words, the Wong-Baker Faces Scale uses a series of faces ranging from smiling to crying. Patients pick the face that best shows how they feel.

Brief pain inventory

For children aged 12 and over. This short form helps understand how much pain your child is feeling and how it affects their daily life, like sleep, mood, or activities.

STUDY ID #: _____ DO NOT WRITE ABOVE THIS LINE HOSPITAL #: _____

Brief Pain Inventory (Short Form)

Date: ____ / ____ / ____

Time: _____

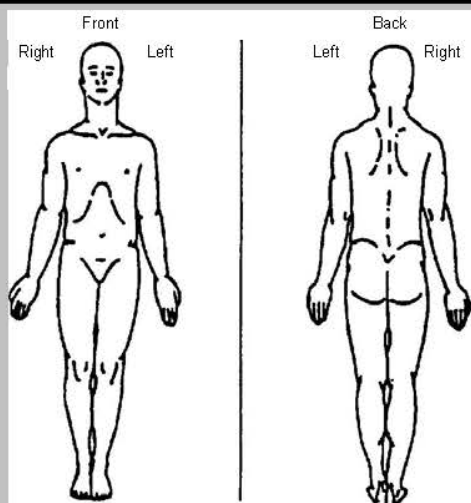
Name: _____
Last First Middle Initial

1. Throughout our lives, most of us have had pain from time to time (such as minor headaches, sprains, and toothaches). Have you had pain other than these every-day kinds of pain today?

1. Yes

2. No

2. On the diagram, shade in the areas where you feel pain. Put an X on the area that hurts the most.



3. Please rate your pain by circling the one number that best describes your pain at its worst in the last 24 hours.

0 1 2 3 4 5 6 7 8 9 10
No Pain Pain as bad as you can imagine

4. Please rate your pain by circling the one number that best describes your pain at its least in the last 24 hours.

0 1 2 3 4 5 6 7 8 9 10
No Pain Pain as bad as you can imagine

5. Please rate your pain by circling the one number that best describes your pain on the average.

0 1 2 3 4 5 6 7 8 9 10
No Pain Pain as bad as you can imagine

6. Please rate your pain by circling the one number that tells how much pain you have right now.

0 1 2 3 4 5 6 7 8 9 10
No Pain Pain as bad as you can imagine

STUDY ID #: _____

DO NOT WRITE ABOVE THIS LINE

HOSPITAL #: _____

Date: ____/____/____

Time: _____

Name: _____
Last First Middle Initial

7. What treatments or medications are you receiving for your pain?

8. In the last 24 hours, how much relief have pain treatments or medications provided? Please circle the one percentage that most shows how much relief you have received.

| | | | | | | | | | | |
|--------|-----|-----|-----|-----|-----|-----|-----|-----|-----|----------|
| 0% | 10% | 20% | 30% | 40% | 50% | 60% | 70% | 80% | 90% | 100% |
| No | | | | | | | | | | Complete |
| Relief | | | | | | | | | | Relief |

9. Circle the one number that describes how, during the past 24 hours, pain has interfered with your:

A. General Activity

| | | | | | | | | | | |
|-----------|---|---|---|---|---|---|---|---|---|------------|
| 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| Does not | | | | | | | | | | Completely |
| Interfere | | | | | | | | | | Interferes |

B. Mood

| | | | | | | | | | | |
|-----------|---|---|---|---|---|---|---|---|---|------------|
| 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| Does not | | | | | | | | | | Completely |
| Interfere | | | | | | | | | | Interferes |

C. Walking Ability

| | | | | | | | | | | |
|-----------|---|---|---|---|---|---|---|---|---|------------|
| 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| Does not | | | | | | | | | | Completely |
| Interfere | | | | | | | | | | Interferes |

D. Normal Work (includes both work outside the home and housework)

| | | | | | | | | | | |
|-----------|---|---|---|---|---|---|---|---|---|------------|
| 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| Does not | | | | | | | | | | Completely |
| Interfere | | | | | | | | | | Interferes |

E. Relations with other people

| | | | | | | | | | | |
|-----------|---|---|---|---|---|---|---|---|---|------------|
| 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| Does not | | | | | | | | | | Completely |
| Interfere | | | | | | | | | | Interferes |

F. Sleep

| | | | | | | | | | | |
|-----------|---|---|---|---|---|---|---|---|---|------------|
| 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| Does not | | | | | | | | | | Completely |
| Interfere | | | | | | | | | | Interferes |

G. Enjoyment of life

| | | | | | | | | | | |
|-----------|---|---|---|---|---|---|---|---|---|------------|
| 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| Does not | | | | | | | | | | Completely |
| Interfere | | | | | | | | | | Interferes |

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Non-pharmacological routes

- Sometimes, simple methods can really help with sickle cell pain with or without needing medication. Here are some effective techniques you can try:

1. Heat packs / Hot water bottle

- Applying heat can soothe pain and relax tense muscles.
- Use a heat pack or a hot water bottle wrapped in a towel on the painful area. Heat increases blood flow and can help ease discomfort.



Why cold packs are **NOT** recommended

- Using cold packs can create an environment that increases sickling of red blood cells. This can block small and large blood vessels, leading to reduced blood flow. Ultimately, this can cause tissue damage and serious complications in the affected limb.

2. Warm bath

- Taking a warm bath is not only relaxing but can also provide relief from pain. The warmth of the water helps to loosen muscles and joints, reducing the intensity of pain.

2. TENS machines (Transcutaneous Electrical Nerve Stimulation):

- TENS machines work by sending tiny electrical pulses through pads on your skin. These pulses can help lessen pain signals going to your brain and give you something else to focus on instead of the discomfort.



4. Gentle massage

- Massaging the sore area with gentle, circular motions can relax muscles and boost blood flow. Use a moisturising lotion or oil to reduce friction and make the massage more soothing.

5. Distraction

- Doing things that hold your interest can help take your mind off the pain. Try activities like playing games, solving puzzles, drawing, or doing crafts. This distraction can be especially useful for handling mild to moderate pain.

Pharmacological Routes

Green Zone (Pain Level 1-3)



Medications: Paracetamol or Ibuprofen.



Instructions: Follow recommended dose, follow package/provider instructions



Monitoring: Monitor pain level, if 1-3, continue to rest

Yellow Zone (Pain Level 4-6)



Medications: Combine Paracetamol & Ibuprofen, Diclofenac if prescribed.



Instructions: Take as directed, caution with NSAIDs, consult provider for dosing



Monitoring: Wait 1 hour, if pain persists or worsens, consider stronger medications

Red Zone (Pain Level 7-10)



Emergency Care: Seek immediate medical help.



Instructions: Severe pain may indicate crisis, do not delay



Monitoring: ED pain review and further medications

PAIN MANAGEMENT DIARY

| DATE | TIME | SYMPTOM DESCRIPTION | PAIN SCALE RATING | LOCATION OF PAIN | MEDICATION and DOSAGE NON-MEDICATION INTERVENTIONS | PAIN SCALE RATING 1 HOUR AFTER INTERVENTION | SIDE EFFECTS FROM MEDICATION |
|------|------|---------------------|-------------------|------------------|---|--|------------------------------|
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PAIN INTENSITY SCALE (from PAIN ASSESSMENT RATING SCALE SHEET)

| | | | | | | | | | | |
|---------|------|------|------|------|----------|----------|----------|--------|--------|-----------------------|
| 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| No Pain | Mild | Mild | Mild | Mild | Moderate | Moderate | Moderate | Severe | Severe | Worst Pain Imaginable |

Who to contact?

Haematology Clinical Nurse Specialists
Tel: **020 3299 1916** or **020 3299 4752**

MyChart

Our MyChart app and website lets you securely access parts of your health record with us, giving you more control over your care. To sign up or for help, call us on 020 3299 4618 or email kings.mychart@nhs.net. Visit www.kch.nhs.uk/mychart to find out more.

Sharing your information

King's College Hospital NHS Foundation Trust has partnered with Guy's and St Thomas' NHS Foundation Trust through the 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' hospitals. King's College Hospital and Guy's and St Thomas' NHS Foundation Trusts share an electronic patient record system, which means information about your health record can be accessed safely and securely by health and care staff at both Trusts. For more information visit www.kch.nhs.uk.

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 Hambleton 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 4618**

Email: [**kings.pals@nhs.net**](mailto:kings.pals@nhs.net)

If you would like the information in this leaflet in a different language or format, please contact our Interpreting and Accessible Communication Support on 020 3299 4618 or email [kings.access@nhs.net**](mailto:kings.access@nhs.net)**