



Sickle cell home management action plan

Information for parents

When your child is in pain, you will need to assess the severity of the pain to be able to give adequate or appropriate medication at home on a regular basis.

- Firstly, check your child's temperature. If their temperature is between 37.5°C to 38°C, give Paracetamol and remove some layers of clothing to help bring the temperature down.
- Check their temperature again after one to two hours. If it is greater than 38°C, contact the sickle cell nurse or Ifor ward staff for advice (See contacts below).

Spleen palpation (touch to check)

- If your child is below five years old and appears paler than normal and has abdominal pain, it might be necessary to palpate for the spleen as this can suddenly get very big and lead to worsening anaemia. The spleen can be felt just below the rib cage on the left side of the abdomen.
- The team would have shown you how to palpate for the spleen and encouraged you to familiarise yourself with how it feels when your child is well, so you will be able to tell when it is bigger than normal.

Mild pain (hurts a little)

If your child is:

- Easily distracted
- Miserable or moaning, but happy when distracted
- Moves reasonably freely, may be tense
- Sleeps for short periods
- Contented or slightly irritable

Give Paracetamol, and if there is no improvement, administer Ibuprofen. This can be given regularly. Give Paracetamol every four to six hours and Ibuprofen every six to eight hours.

Moderate pain (hurts more)

If your child is:

- Distracted for short periods
- Miserable, withdrawn, moaning, or crying
- Complaining of pain
- Reluctant to move
- Looks tense on moving and may be touching the painful area
- Unsettled, may be irritable or restless.

Give Paracetamol, Ibuprofen and Dihydrocodeine.



Severe pain (hurts a lot)

If your child is:

- Unable to be distracted
- Crying, screaming, or aggressive
- Complaining of pain
- Not moving freely, body looks rigid
- Guarding the painful area
- Unusually still
- Constantly awake, restless with exhausted sleep

Give Paracetamol, Ibuprofen and Dihydrocodeine, and contact the service for your child to be reviewed.

Paracetamol every 4 to 6 hours (maximum 4 doses in 24 hours)

3-5 months	60mg
6-23 months	120mg
2-3 years	180mg
4-5 years	240mg
6-7 years	240-250mg
8-9 years	360 – 375mg
10-11 years	480 – 500mg
12-15 years	480 – 750mg
16-17 years	500mg – 1gram

Ibuprofen every 6 to 8 hours (maximum 3 doses in 24 hours)

6-11 months	50mg
1-3 years	100mg
4-6 years	150mg
7-9 years	200mg
10-11 years	300mg
12-17 years	200-400mg

- Try other methods of pain relief such as distracting your child with storytelling, watching TV, or playing video games.
- Make sure they have adequate rest, a warm bath, a massage, heat rub or heat pads along with the above medication.
- It is important to encourage your child to drink plenty of fluids, so take more than normal.
- **If your child is still uncomfortable and pain not relieved, please contact the service using the method outlined in your emergency card.**

Potential or possible medical emergency

- The following are situations when your child needs to be seen by a doctor:

Fever

Temperature 38 degrees or higher.

Dehydration

Vomiting/diarrhea, unable to keep fluids down.



Neurological signs	Severe headaches, dizziness, double vision, stiff neck, change in behaviour, appearing confused or drowsy or unable to speak.
Fits/convulsion	Body spasms.
Weakness	May affect one side of the body or both and cannot walk.
Chest problems	Difficulty in breathing, severe cough, shortness of breath, chest pain and swelling.
Stomach discomfort	Severe abdominal pain and swelling.
Spleen	Sudden enlargement of the spleen.
Colour	Unusually pale palms, feet, lips and nail beds.
Priapism	Painful erection of penis lasting for more than an hour.

In an emergency you should call 999 for an ambulance and you will be taken to the nearest Emergency Department or our emergency unit.

- Always remember to administer Penicillin V twice a day as this can prevent serious infection.
- To reduce the chances of your child having a crisis you need to do the following:
 - Dress up warmly.
 - Take a lot of fluids.
 - Avoid fizzy drinks.
 - Eat healthily including five portions of fruits or vegetables a day.
 - Exercise without over exerting.

Contacting the hospital using your emergency card outside working hours

- Telephone the ward, ask to speak to the Nurse in charge and give your child's details.
- Discuss your child's symptoms with the Nurse, for example, where your child is feeling pain, how long they have had the pain, what pain relief you have given and what effect it has had.
- Talk to the Nurse about any other symptoms your child may have, such as shortness of breath, feeling drowsy, looking paler than usual, any diarrhoea or vomiting, or whether your child has a temperature.
- Following your discussion with the Nurse, a decision will be made for you to either bring your child to the ward or be referred to the Children's Sickle Cell Specialist Nurse who will then contact you to review your child.



Why you need to attend outpatient appointments

- Doctors and Nurses will check the development and health of your child.
- You can learn how to feel the spleen and take a temperature.
- Your child can be vaccinated against infections such as Pneumovax and Hepatitis B.
- You can discuss any schooling, housing or social problems and seek help from a multidisciplinary team of professionals.
- You can meet other parents/carers of children with Sickle Cell Disease and be part of the parent's support group meetings.
- You can learn about the latest developments in sickle cell management if applicable to your child.
- You can get one to two yearly blood tests – sometimes more often, as required by your child's condition.
- You can get medical advice and information about travel.
- You can obtain and update the emergency card.
- Information from the clinic is sent to your GP so your child's health records are complete.

We will try to:

- Arrange appointments for school age children during the holidays or book early appointments, so that your child can still attend school.
- See you only when necessary.

If you cannot attend appointments for any reason, please call and cancel well in advance so that an appointment can be offered to somebody else. If cancelling, remember to rebook your next appointment.

Contacts

Ifor ward	020 7288 5442
Roses Day Care Unit	020 7288 3769
Children Ambulatory Unit	020 7288 3560
Clinic 4D (Children's Outpatients)	020 7288 5882

Specialist nurses: Edith Aimiuwu / Emma Disu-Savie 020 7288 3017 / 07799 347 161
Hours of work: 10 am - 8 pm Monday to Friday



Healthwatch England

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Patient advice and liaison service (PALS)

If you have a compliment, complaint or concern please contact our PALS team on 020 7288 5551 or whh-tr.PALS@nhs.net

If you need a large print, audio or translated copy of this leaflet please email whh-tr.patient-information@nhs.net. We will try our best to meet your needs.

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Date published: 30/07/2024
Review date: 30/08/2024
Ref: CYP/PaedHaem/SCHMAP/03

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