



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 take off some of their clothes 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 for ward staff for advice. (See contacts below)

Spleen palpation

If your child is below 5 years old and appears pale with abdominal pain, it might be necessary to palpate for the spleen as this can suddenly get very big and lead to worsening anaemia. (The team would have shown you how to palpate for the spleen and encouraged you to familiarise yourself with how it feels when child is well to be able to tell when it is bigger, this can be felt just below the rib cage on the left side of the abdomen.

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- Miserable, withdrawn, moaning or crying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 if below 17 years of age.



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 painful area
- Unusually still
- Constantly awake, restless with exhausted sleep

Give Paracetamol, ibuprofen and dihydrocodeine if below 17 years of age, and codeine if above 17.

Paracetamol doses, four to six hourly (four doses in 24 hours only)

| | |
|---------------|-------------|
| 3-6 months | 60-120 mg |
| 1-5 years | 120mg-240mg |
| 6-12 years | 240mg-500mg |
| Over 12 years | 500mg-1gram |

Ibuprofen (Junifen®, Brufen®)

| | | |
|-------------|-----------|---------------|
| 1-2 years | 50mg | 8 hourly |
| 3-7 years | 100mg | 6 to 8 hourly |
| 8-12 years | 200mg | 6 to 8 hourly |
| 12-17 years | 200-400mg | 6 to 8 hourly |

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/diarrhoea, unable to keep fluids down

Neurological signs – severe headaches, dizziness, double vision, stiff neck, change in behavior, appearing confused or drowsy or unable to speak

Fits/convulsion – body spasms

Weakness – may affect one side of the body or both, as well as inability to 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, lips and nail beds

Penis – painful erection lasting for more than an hour



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 hours

Telephone the Ifor 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, such as shortness of breath, if they look paler than usual, any diarrhoea or vomiting, or whether your child has a temperature or is feeling drowsy.

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 check the development and health of your child.
- You can learn how to feel the spleen and take a temperature.
- Your child can be immunised against infections e.g. Pneumovax, 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 with children with sickle cell disease and be part of the parents 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 (CAU) 020 7288 3560
 Edith Aimuwu – Sick cell 020 7288 3017, mobile: 07799347161
 Specialist nurse (hours of work 10.00am-6.00pm Monday to Friday)
 Clinic 4D (Children's Outpatients) 020 7288 5882

Healthwatch England

Skipton House
 80 London Road
 London, SE1 6LH
 Telephone: 03000 683 000
 Fax: 01132 204702
 Email: enquiries@healthwatch.co.uk

Website: www.healthwatch.co.uk/Twitter: @HealthwatchE #thinkrights

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.whitthealthPALS@nhs.net

If you need a large print, audio or translated copy of this leaflet please contact us on
 020 7288 3182. We will try our best to meet your needs.

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