

Pain is the most common problem for people with sickle cell disease. It's important to know how you can try to prevent it starting and what you can do to manage pain at home. It's also important to know when and how to call the hospital if you are still in pain.

How can I prevent pain?

- Drink plenty of fluids – water is good, but a combination of the things you like (squash, tea, fruit juices, milk) is also effective.
- Stay warm, avoid sudden chilling, anticipate situations – always have something warm to put on after you have been exercising and an extra layer for when you go outside.
- Avoid getting wet and unable to get dry (such as wet feet on a rainy day at school)
- Try to avoid/manage stressful situations – allow yourself plenty of time (for homework, for travelling to appointments, for exam revision for example)

Even if you do all these things it is still possible to have a painful crisis, but paying attention to these measures will lessen the frequency of painful crises

I am in pain, what painkiller (analgesia) should I take?

The first choice of painkiller is Paracetamol. This should be taken as soon as you start getting pain. The correct dose for you will be on your latest clinic letter. Take it regularly (up to 4 times) the day the pain starts but don't have more than your recommended dose in a 24 hour period

What if this does not work?

The next step for many people is a group of medicines called NSAIDs (non steroidal anti-inflammatory drugs). These painkillers should generally not be taken long term as they can cause indigestion/stomach problems. They work by reducing swelling and inflammation and therefore pain. NSAIDs are especially effective for bony pain. They are **added** to paracetamol if you are still in pain 20-30 minutes later.

There are two common choices in this group, either **Ibuprofen** or **Diclofenac**.

Ibuprofen can be bought over the counter at chemists, (Nurofen) but we will provide it as a prescription in clinic and you can ask your GP to renew this prescription. The dose you take is on your latest clinic letter. It can be taken three times a day. Diclofenac is available only on prescription. Some people find it more effective than Ibuprofen. You can discuss this with the doctor at clinic if you would like to use it **instead of** Ibuprofen (these two must not be used together).

NSAIDs can cause stomach irritation and should not be taken on an empty stomach. NSAIDs may not be good for you if you have kidney problems and may cause fluid retention. Your doctor will not prescribe them for you if they would be bad for you. You should check with the clinic doctor before taking any of these painkillers if you have any stomach, heart, liver or kidney problems, asthma, or you may be pregnant.

Are there any other options?

If the pain is still not resolving you may be able to take Dihydrocodeine. This is for moderate to severe pain.

Dihydrocodeine is available only on prescription, and is not suitable for everybody. You can discuss with the clinic doctor if it might be helpful for you and you would like to try it. Constipation, nausea and dizziness are some of the possible side effects.

But I'm still in pain, what should I do?

Remember that none-drug treatments can help some people – relaxation, a warm bath, massaging the part that hurts and distracting yourself with a good DVD, game, music or a book can all add to the drug treatments. However, if you have done all this and you have taken your painkillers as above and you are still in pain it's time to call the hospital to arrange a review on Ward M3.

To arrange this call 0114 271 7000 and ask for the Haematology Doctor on call, or phone 0114 271 7322 (Ward M3). The Nursing staff there will take a note of your symptoms and ask the Haematology doctor to call you back to arrange a review.

Will I need morphine?

It's likely that we will need to use 'Opiate analgesia' (morphine or diamorphine). Opioids are the strongest painkillers available. They can be given by mouth, as a spray in your nose (fast acting but short lived) or into a vein (intravenous). The commonest side effects of this group of painkillers are: drowsiness, dizziness, nausea and vomiting (anti-sickness medications can be used to reduce this). One of the most important side effects of opioid painkillers is a reduced breathing rate, which can lead to low oxygen levels. Your breathing needs to be monitored closely especially if you have never had or rarely had this type of painkiller before.

When pain settles...

A painful episode may last several days. If strong opioids have been used it is necessary to taper these drugs over a few days rather than stopping abruptly since the body may become used to these strong painkillers. Sudden withdrawal may itself cause pain.

Information Leaflet number:
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757 (15/12/2014)
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Points to remember: -

- If your pain is persisting at home always seek medical advice.
- Never take more medication than prescribed or medication that has not been prescribed for you
- Strong opioid medication - such as Morphine should not be taken without careful monitoring so is best only to be used in hospital in Sickle Cell disease.

Managing Sickle Pain at Home

For further advice contact:

Main hospital number: 0114 271 7000

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The Children's Hospital
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www.sheffieldchildrens.nhs.uk

Review 2016

Our young patients are at the centre of everything we do and all our work is focused on providing them with the best facilities, equipment and experience possible, helping to provide a world-class facility that is positioned at the very forefront of paediatric care.

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