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Haematology Department

**Sickle Cell Management – Managing the Pain**

Information for parents and carers

**Introduction**

This leaflet aims to provide you with general information about the signs and symptoms your child may have when they are having a sickle cell crisis. If you are ever worried about your child please contact your Sickle Cell Team or take your child to the Accident and Emergency Department.

**What will I do once I have my child’s pain score?**

****Once you have got your child’s pain score, give them pain medication according to that score. If the pain score is seven or more, ring the hospital for advice or bring your child to the Accident & Emergency Department.

**What medication do I need to give?**

Look at the chart below. Find your child’s pain score and give them the pain medication in the column next to it.

|  |  |
| --- | --- |
| PAIN SCORE | PAIN MEDICATION |
| 1 - 2  Mild Pain | **Paracetamol** Give every four to six hours  (Do not give your child more than four doses in 24 hours) |
| 3 - 4  Moderate Pain | **Paracetamol**  Give every four to six hours  (Do not give your child more than four doses in 24 hours)  **Plus**  **Ibuprofen** Give every four to six hours  (Do not give your child more than four doses in 24 hours) |
| 5 - 6  Moderate to Severe Pain | **Paracetamol** Give every four to six hours  (Do not give your child more than four doses in 24 hours)  **Plus**  **Dihydrocodeine / oral morphine** Give every four to six hours  (Do not give your child more than four doses in 24 hours. Dihydrocodeine is only suitable for children over 12 years)  **Plus**  **Ibuprofen** Give every four to six hours  (Do not give your child more than four doses in 24 hours) |
| 7 OR MORE  SEVERE PAIN | **Give your chid the medicine as for Pain Score 5 - 6 and bring your child to hospital for review** |

**How much medicine should I give my child*?***

The doses of medicine for your child will depend on their age and weight. Follow the instructions written on the bottle of medicine you have been given by the hospital, chemist or your GP.

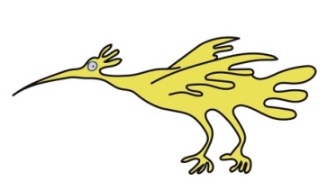
**Never give more medicine than instructed** as this will not help, and may harm your child.

**Why do I need to give more than one pain medicine?**

Different pain medicines work in different ways. There are three main groups of pain medicines –

* Mild analgesics paracetamol (Calpol, Disprol).
* Moderate analgesics (Ibuprofen, Diclofenac, Naproxen).
* Strong analgesic (Codeine Phosphate, Dihydrocodeine, Oral morphine, Morphine, Fentanyl).

It is important to give only **one pain medicine from each group**. Giving more than one medicine from each group will not relieve the pain any better but can increase side effects. Pain relief will be improved if you use a medicine from each group as they all reduce pain in a different way.

****Some 'over the counter' preparations contain a combination of two different pain medicines e.g. Paracetamol and Codeine, so check what is in medicines before you give it to your child. Codeine should not be given to children under 12 years of age.

**What should I do once I given my child their pain medicine?**

Once you have given your child their pain medicine it is important to check that it is working.

30 - 60 minutes after you have given the medicine, do your child’s pain score again. If the pain is better then you should continue giving the same medication. If the pain isn’t any better, or has become worse then give the medicines on the next pain score. Make sure that you do not give your child any medication that they have already had.

If your child's pain is increasing or their pain score is seven or more seek medical advice.

Ring your Sickle Cell Team or bring your child to Accident and Emergency Department.

**How often should I give my child their pain medicine?**

Once your child’s pain is under control continue to give the pain medicines regularly (as instructed on the bottle). If you don’t do this the pain may come back again. It can be helpful to stagger giving the different medicines so that they don’t wear off at the same time although research strongly recommends that Paracetamol and Dihydrocodeine/oral morphine are given together for best effect.

When your child seems to be improving, stop giving them one of the medicines. Don’t stop all of them at the same time. If the pain comes back, restart the medicine that you have stopped. If the pain doesn’t come back, gradually stop all pain medicines.

There is a page in your child’s Crisis Diary to record the time you gave your child their pain medicine. This allows you to keep track of when you gave the medicine and when you can give it again. When your child is in pain it is easy to forget when you last gave them some pain medication.

Do not give your child Ibuprofen regularly if they are not eating or drinking as this can cause stomach upset. However a single dose can do no harm. Contact the hospital for advice.

**Can I manage my child’s pain at home?**

Yes. Your Sickle Cell Team will encourage you to manage your child’s painful crisis at home.

Be sure to check the "When to bring your child to hospital" leaflet for the symptoms you must bring your child to hospital for.

If you are worried about your child then ring your Sickle Cell Team for advice or bring them to the hospital for review.

**What else should I be doing to manage my child’s pain at home?**

* **Prevent Dehydration**:

Not having enough fluid makes the blood flow more slowly and the red cells stickier so a crisis is more likely to occur. Giving your child extra fluids when they have a crisis can help to thin out their blood and unclog the sickled blood cells.

There is a page in your child’s Crisis Diary to record the amount of fluid you have given your child. This will help you to keep track of exactly how much fluid they have taken during the day.

* **Observe**

Keep assessing your child regularly to make sure that they are not getting worse*.*

**If you are doing all of these things and your child is still in pain or they develop any other symptoms then you must bring them to the hospital for review**.

**What should I do if I am unsure of what to do at home?**

If you are unsure what to do at home or want some advice about pain management, ring your Sickle Cell Team. If it is out of hours (before 8am or after 5pm) or at a weekend you can contact the on-call Haematologist who will be happy to give you advice. Telephone Alder Hey Hospital on

0151 228 4811 and ask to speak to the on-call Haematologist.

**Where can I get more pain medicine from?**

You can get pain medicines from the hospital or your GP. Paracetamol and Ibuprofen can be brought from your local chemist and most supermarkets.

**It is essential you keep a supply of pain medicines at home and get a new supply before you run out. You should always have pain medicines available should your child start a painful episode.**

**Further information**

If you have any questions or want any further information please contact your Sickle Cell Team on 0151 252 5070.

***Useful websites***

[www.alderhey.co.uk](http://www.alderhey.co.uk)

[www.sicklecellsociety.co.uk](http://www.sicklecellsociety.co.uk)

www.mychildisinpain.org.uk

Alder Hey Children's NHS Foundation Trust is neither liable for the contents of any external internet site listed, nor does it endorse any commercial product or service mentioned or advised on any of the sites.

****This leaflet only gives general information. You must always discuss the individual treatment of your child with the appropriate member of staff. Do not rely on this leaflet alone for information about your child’s treatment.

This information can be made available in other languages and formats if requested.

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