Pain Management for Adult sickle cell disease patients: Information for patients, relatives and carers

Why you should read this leaflet

This leaflet will give you the information necessary to manage your painful crisis with the most suitable pain relief. If you have questions related to pain management please seek advice from your doctor, clinical nurse specialist or community nurse specialist.

What is a painful crisis?

A painful crisis occurs when the red blood cells change into a sickle shape due to various triggers; infection, stress, changes in weather temperature and dehydration. It makes the red blood cells more sticky, hard and brittle; when sickle shaped they cause blockage in the blood stream resulting in pain and swelling in the affected area.

How to manage a painful crisis?

- Drink plenty of fluids, up to 3 litres daily to prevent dehydration.
- Keep warm always, but do not over heat and avoid being too hot or too cold.
- Take oral pain relief for at least 12-24 hours when the pain is mild to moderate.
- If pain is not settling seek medical attention as soon as possible. Any delay can lead to further complications and increase in pain which in turn could result in a longer stay in hospital.

What type of pain do I have?

There are different types of painful crisis which require different pain relief:; acute, chronic and neuropathic pain..

Acute: is short-acting pain; it can vary in each individual lasting a few hours, days or weeks, caused by tissue or bone damage. The pain can be severe at first but with treatment can settle quickly.

Chronic: is a long-lasting pain (lasting over 3 months) occurring on a daily basis. Sometimes it is not clear why chronic pain occurs and it can be difficult to treat therefore it is difficult to completely relieve this pain. Chronic pain can cause distress, tiredness, irritability, disturbed sleep patterns and can affect relationships. We may advise that you see the chronic pain team for further specialist advice.

Neurological (nerve) type pain is different to other pains and can be acute or chronic causing problems with nerve signals. Symptoms include; burning, stabbing, and shooting, like a mild electric shock or sensitivity to touch.

What medications are advised?

Mild to moderate pain:

● Paracetamol up to four times a day

● Ibuprofen or Naproxen up to three times a day (**Do not take these two together**)

● *Weak opioids:* Codeine Phosphate/ Dihydrocodeine up to three times a day or Tramadol three times a day

Moderate to Severe pain:

Strong opioids:

- Sevredol, Oramorph, morphine sulphate, Diamorphine, MST or MXL
- Oxynorm or oxycontin,
- Fentanyl,
- Buprenorphine,
- Methadone
- Pethidine is only used in expectational circumstances such as allergy to other opioid medication

Strong opioids are usually only given in a hospital where you can be monitored and cared for safely.

See your prescription for dosing and instructions on how to take the medication. For further information discuss with your doctor and pharmacist.

If the above medications do not give enough pain relief we may advise adding a **neurological pain relief** such as pregabalin or gabapentin, taken up to three times a day.

Opioids usually relieve pain and make it more manageable for short periods but this varies with each individual and depends on the type of opioid taken. If limited benefit is experienced after first use then the dose can be increased after a medical review.

The overall aim is to limit long-term use of medications, reduce pain and prevent side-effects.

During the acute phase it is not advisable to use **entonox continuously for 60 minutes or over and not for long-term use.** Overuse of entonox can lead to acute chest problems due to the risk of lowering oxygen levels and reducing production of red blood cells. This can prolong a painful crisis.

Alternative pain management techniques

There are many other ways to manage your pain instead of using medication or in conjunction with medication; cognitive behavioural therapy (CBT), acupuncture, massage, transdermal nerve electrode stimulation (TENS) and lidocaine patches. Discuss with your doctor, nurse or psychologist.

How will injectable opioids be given and for how long?

During the acute phase of the painful crisis, when you are in hospital, we will give you either injectable opioids subcutaneously (under the skin) as required or via a continuous patient controlled analgesia (PCA) pump subcutaneously or intravenously, according to your individual treatment plan.

A PCA is a simple mechanical pump which enables you to control the amount of pain medication you receive, within safe limits, to control your pain. We advise not to use the intravenous route (into the veins). If the intravenous route is used it may delay you receiving effective pain relief and damage your veins from repeated puncturing, reducing the number of usable veins you have over time.

During the painful crisis we advise that you use injectable opioids for a short time only, up to 5-7 days maximum, but according to your clinical need. Convert to oral pain relief 12-24 hours before discharge from hospital to prevent rebound crisis and withdrawal symptoms. Continue your oral pain relief until your pain is suitably controlled.

While on injectable opiates or PCA you must remain on the ward for monitoring of potential side-effects. If you leave the ward area and side-effects occur we may not be able to help you.

Summary of main side-effects (read medication information supplied with packaging)

At least 80% of patients taking opioids will experience some adverse side-effects:

Paracetamol: Skin rash, unusual bruising and potential liver impairment with overdose.

Ibuprofen/ Naproxen: Nausea and vomiting, blood in your vomit or stools, unusual bruising, unexplained bleeding, heartburn, indigestion, liver or kidney impairment, unexplained wheezing or difficulty in breathing. Avoid this medication if you have renal disease or asthma and only take under medical advice.

Weak opioids: Codeine/Tramadol/Co-codamol/Co-dydramol/Co-proxamol

Strong opioids: Sevredol, Oramorph, Oxynorm, Fentanyl, buprenorphine, morphine sulphate/diamorphine /pethidine;

***Short term side effects*:** Drowsiness, tiredness, constipation, nausea and vomiting, itching, dry mouth, confusion, hallucinations, breathing changes, low blood pressure or dizziness, sweating, bruising, twitches, shakes and problems sleeping.

***Long-term side-effects: (these are side effects that may occur if using opioids regularly long-term*)**

- Reduced fertility, low sex drive, irregular periods, male erectile dysfunction and hormonal changes.
- Increased risk of infection,
- Increased levels of pain,
- Muscle weakness,
- Weight loss,

- Headaches,
- Small pupils
- Mood changes.

For more information read the ***British Pain Society (2010) leaflet called 'Opioids for persistent pain: information for patients'*** and discuss with your hospital doctor or clinical nurse specialist.

Pregabalin/Gabapentin: Dizziness, blurred vision, drowsiness, constipation, mood changes, convulsions, liver or kidney disease, increased appetite, confusion or irritability.

All medications have a risk of causing an *allergic reaction*: skin rash, tongue/facial swelling, and shortness of breath, itching and anaphylactic shock (severe allergic reaction).

Recent research and guidance indicates that long term use of opioids can be dangerous and you will require stringent monitoring for safe use.

Common problems with taking opioids long term

Tolerance: If you have been taking opioids over a long time your body will get used to them and they will become less effective over time. Therefore higher doses are required to achieve the same pain relieving effect. The time-scale of this process varies considerably. Tolerance means that your body has developed a dependence on opioids and it is important to slowly wean off opioids to prevent withdrawal and long-term side-effects. If opioids are stopped suddenly or the dose is lowered too quickly you can experience **withdrawal symptoms**; these include sweating, shaking, runny nose, stomach cramps, diarrhoea or muscle cramps.

Addiction/Dependence is a pattern of substance misuse and continued drug-use causing harm to the person.

Pseudo-addiction is behaviours such as drug hoarding, attempts to obtain extra supplies and increase your doses to obtain better pain relief without medical advice.

Dependence is being dependent on a substance to prevent physiological withdrawal symptoms.

Warning: Patients, who develop addiction/pseudo-addiction or dependence choose to take opioids due to craving, feeling out of control or have a psychological need such as depression or anxiety. If you develop depression or anxiety there is a chance you could become dependent on opiates.

If you experience any of the above side-effects please seek urgent medical attention.

General advice while on opioids

Driving: You can drive while on opioids. You are responsible for ensuring you are fit to drive. It is not advisable to drive if on injectable opioids or if you're oral prescription has changed or you feel unsafe.

You should inform the Driving and Vehicle Licensing Authority (DVLA) that you take opiate medication. This is a legal requirement under UK law; Drug driving offence and screening (2013). If you are stopped by the police you will be screened to assess impairment. Check

https://www.gov.uk/government/publications/drug-driving-offence-and-drug-screening-devices-faq/drug-driving-offence-and-drug-screening-devices-background-information for further information and www.dvla-driving-licence/co.uk.

Work and activity: If you take opioids for chronic pain on a regular basis at a steady dose you should be able to work and do other activities. Please inform your work place occupational health department to check if you are fit to work while taking opioids.

Alcohol/ Illegal drugs: It is advisable to avoid alcohol/illegal drugs while taking opioids due to an increased risk of dehydration, drowsiness and poor concentration. This can increase your chance of developing a painful crisis. It may be dangerous and cause overdosing and bad interactions with your prescribed medications and these additional items may cause serious side-effects.

Pregnancy: It is advisable to limit the amount of opioids you need during a painful crisis. Your baby might experience breathing difficulties or opioid withdrawal symptoms at birth and may require specialist intensive medical care. **Medications to avoid during pregnancy are tramadol, Ibuprofen, naproxen, pregablin or gabapentin due to problems with the baby's development and possible effects at birth.** Talk to your doctor, clinical nurse specialist, obstetrician or midwife.

Storage: Store in a safe, dry and lockable place out of reach of children. Keep the medication in their original package with clear labelling and keep the original instructions.

Unused medications: All medication should be returned to a pharmacy for safe disposal. Do not flush them down the toilet or throw them away.

It is important to note that your prescriptions are for your use only and it is strongly advised not to share prescription medications.

Travel advice:

- You must obtain a letter or discharge summary, from your prescribing doctor confirming your medications.
- Before travelling abroad check the country's law about opioids importation or use of medical opioids. Also visit the Home Office website for further information; www.homeoffice.gov.uk/drugs/licensing.
- Before you travel check hand luggage restrictions regarding volume of liquids allowed through Customs. If you exceed the limit your liquids including medications and fluids will be taken from you.
- Oral medications can be carried in hand luggage but only in their original packaging.

Who can I contact for more information?

Contact your consultant haematologist, clinical nurse specialist or GP. **For repeat prescriptions your consultant will advise your GP to continue your medications or it will be managed in the outpatient clinic if appropriate.**