

The ROYAL MARSDEN

NHS Foundation Trust

Taking pain relief medicines

Children and Young People's Unit

**Information for parents and carers
of those under 18 years of age**



NHS

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Introduction

At diagnosis and during treatment your child may experience pain due to the side effects of their chemotherapy, radiotherapy, investigations, procedures or from the cancer itself.

The information in this booklet explains The Royal Marsden's guidelines for taking pain relief medicines for children. We may need to use a combination of different types of medicine to relieve different types of pain.

How is pain measured?

Children may have difficulty in describing the intensity or type of pain. Certain information about your child's pain can help us manage it.

- What does the pain feel like?
- When does the pain occur?
- Where is the pain?
- Does anything make the pain worse or better, for example walking or resting?

Teach your child how to measure pain

Children can learn to tell you how bad their pain is. For young children, use simple language that is familiar to them, such as "Is it a big hurt or a little hurt?" Older children (usually 7 years or older) can rate the intensity of the pain on a scale of 0 to 10 with 0 being 'no pain' and 10 being 'the worst pain'. Through this, you will have a better understanding of what the pain feels like for your child and that will help decide what to do next, such as the decision to give paracetamol or morphine medicine for the pain.

To help us measure pain, we use pain rating scales (see page 11) to help your child to report its intensity. Pain rating scales are available as separate factsheets. Please ask if you would like one.

These pain rating scales also help us understand whether the pain relief medicines are working or whether there is a need to change the dose or use a different pain-relieving medicine.

Aims of pain relief

Everyone experiences pain differently and our aim is to reduce your child's pain and to improve their function so that they can continue with routine day-to-day activities.

Types of pain

Acute pain (related to procedures)

Some procedures that your child has during their treatment may be uncomfortable or painful. Some examples are central line insertion and removal, bone marrow tests or lumbar punctures. This pain, depending upon the procedure, may last for a few hours or up to two to three days. We will assess your child's pain before they are discharged home and will prescribe appropriate pain relief medicines for them to take with them.

Persisting pain

Persisting pain is any pain that is not related to a procedure or investigation. It can be constant but it can also come in waves.

Chronic pain

Chronic pain is a pain that continues beyond three months even after the injury has healed.

Neuropathic pain

Neuropathic pain is caused by damage or injury to the nerves that transfer information between the brain and spinal cord from the skin, muscles and other parts of the body. The pain is usually described as a burning, stinging sensation and affected skin areas can be sensitive to touch.

What pain medicine can my child have?

Paracetamol

On treatment: Paracetamol, also known as Calpol in liquid form, can be used whilst receiving chemotherapy or radiotherapy treatment, if your child experiences pain after a test or procedure, but is otherwise well.

- Only use it if your child's neutrophil (part of the total white blood cells) count is above 0.5. Please speak to your healthcare team if in doubt.
- At home, paracetamol can be repeated every four to six hours for a maximum of **four** doses every 24 hours and up to a maximum of **three** days.
- Check your child's temperature before giving them paracetamol to ensure that it is 37°C (normal) or less.

If after three days of using paracetamol your child is still in pain, please call your local shared care hospital for advice.

Regular and long-term use of paracetamol is not recommended because it may conceal a fever which is an important sign of infection.

After treatment: It is important that the healthcare team is aware of the regular use of paracetamol for persisting pain, as the team will need to monitor this.

Non-Steroidal Anti-Inflammatory Drugs (NSAIDs)

NSAIDs will only be prescribed with your child's oncologist's agreement if they are receiving chemotherapy. NSAIDs such as ibuprofen (for example, Nurofen) can be considered for mild or moderate pain as they have an anti-inflammatory effect. As with paracetamol, there are concerns that NSAIDs may conceal a fever, which is a key sign of infection.

NSAIDs are known to cause stomach bleeds if taken long-term, which may be made worse if your child is also taking steroids such as Dexamethasone.

Your child's platelet count may need to be regularly checked and a stomach protectant drug, such as Lansoprazole or Ranitidine will also be prescribed.

Codeine

It is now recommended by the Department of Health that Codeine should not be prescribed for children due to previous known adverse events affecting children.

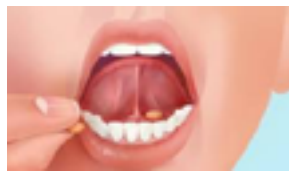
Opioid pain relief medicines

Opioid painkillers are a group of medicines resulting from morphine and morphine-like medicines that are used to treat moderate to severe pain. Strong opioids include morphine, oxycodone and fentanyl. These can be given by various methods, including:

- Injection
- Liquid
- Buccal (between the cheek and gum)
- Tablets
- Topical patch
- Sublingual (under the tongue)
- Intranasal (into the nose).



Buccal



Topical patch



Intranasal



Sublingual

A stronger pain relief medicine should be considered for any child who experiences severe or persisting pain for longer than three days that does not respond to regular paracetamol.

Opioid painkillers are controlled under medicines law due to the possibility of misuse. Parents may find the thought of their child taking these medicines uncomfortable for many reasons; fear of addiction, concern over side effects, long term effects or withdrawal. If opioids are given for pain at the prescribed dose under the supervision of a doctor or nurse, then addiction and withdrawal should not occur. Please speak to your keyworker if you have any concerns.

Morphine/Oxycodone

Morphine/oxycodone (either liquid or tablets) are prescribed for up to three days to provide pain relief for pain episodes that are expected during your child's treatment. These opioids act immediately and will be prescribed every four hours as required. The lowest start dose will be given based on your child's weight. We aim for your child to experience a reduction in their pain within 30 minutes of taking the medicine and for the pain relief benefit to last up to four hours. Your child's pain will be re-assessed between 24–48 hours after starting opioids, by a doctor or nurse to check whether the dose is relieving their pain. The dose may need to be increased slowly until the pain is improved or decreased slowly if the pain has improved.

If your child has pain beyond three days and still needs to take morphine or oxycodone, they will need to be reviewed by a doctor or nurse at their local shared care hospital or at The Royal Marsden. A longer acting morphine or oxycodone medicine (taken every 12 hours) or fentanyl topical patch may need to be prescribed. These provide continuous background pain relief, aiming to avoid your child experiencing episodes of breakthrough pain (see page 13 for the definition).

Fentanyl

Fentanyl is prescribed as a topical patch for application to dry skin. The patches are changed every 72 hours (three days). *Fentanyl patch for pain relief* is available as a separate factsheet if you would like further information.

What side effects could my child have from opioid medicines?

Opioids cause your child's gut to slow down and will always cause constipation, so a laxative will always be prescribed alongside the opioid medicine.

Other side effects can include:

- Drowsiness
- Itching
- Confusion
- Nausea and/or vomiting
- Slow breathing rate
- Jerky movements
- Reduced urine output.

Side effects are usually mild and resolve after a few days. Please seek **immediate** advice from your healthcare team if you are worried about your child and their opioid medicine, (please see contact details on page 9).

If your child is still experiencing moderate or severe pain despite the opioid medicine dose prescribed, please contact your local shared care hospital or The Royal Marsden.

If your child's breathing is slower, they have slurred speech, or they are drowsier than usual, then they should be reviewed **urgently** by a nurse or doctor.

Neuropathic pain medicines

(see page 2 for the definition of neuropathic pain)

Unlike most other types of pain, neuropathic pain does not usually get better with usual pain relief medicines, such as paracetamol and morphine, therefore other medicines are prescribed.

These medicines are given orally (by mouth) and are also used to treat other conditions, such as depression, epilepsy, anxiety or headaches. The main medicines prescribed for neuropathic pain include:

- Gabapentin or Pregabalin – used to treat certain types of epilepsy (fits) or headaches
- Amitriptyline – used for treatment of depression and migraines.

Ketamine

Ketamine is a short-acting anaesthetic medicine which has pain relieving properties when prescribed at low dose. It is used for nerve (neuropathic) pain and other complex pain. In some situations, it can be prescribed to reduce the need for opioids.

Ketamine is prescribed when:

- Pain is not relieved by other regular neuropathic pain medicines
- Pain is not relieved by morphine and morphine-like pain medicines alone
- The specialist consultant paediatrician in pain management is available to lead on this.

Ketamine may be given by mouth (oral), buccal, into the nose (intranasal) or by injection.

A separate factsheet, *Ketamine; medicine for pain relief*, is available if you would like further information.

Keeping medicines at home

- **All** medicines should be kept in a safe place that is out of sight and reach of children
- Opioid medicines should be locked away from children
- Opioid medicines should be kept in their original packaging showing the patient's name and date prescribed
- Always keep the 'patient information leaflet' to refer to.

Out of date opioid medicines

Medicine packaging should have a clear expiry date and it is important to be aware of this and regularly go through your medicine cabinet removing anything that is past its expiry date.

Once opened, a bottle of oral morphine liquid will have an expiry of 90 days.

Disposing of opioid medicines

- Any opioid medicine that has not been administered should be returned either to your local hospital or local pharmacy for disposal by a pharmacist
- Opioid medicines should not be flushed down the toilet or sink, or thrown away
- Empty bottles that have been washed out can be thrown away in your recycling or household waste
- Fentanyl patches should be folded sticky sides together and disposed of in your household bin. Keep away from pets.

Contact details

If you have any questions about the information in this booklet, please speak to your child's named Clinical Nurse Specialist, pharmacist, doctor or named nurse on the ward, day-care or out-patient department at The Royal Marsden.

The Royal Marsden's CYP Oak Centre 24 hour helpline:
020 8915 6248

**Children and Young People's Oncology Outreach
and Symptom Care Nurse Specialists (CYPOONS):**
020 8661 3625

FLACC Behavioural Rating Scale

This is recommended for young children who are not yet able to talk and those who are cognitively impaired.

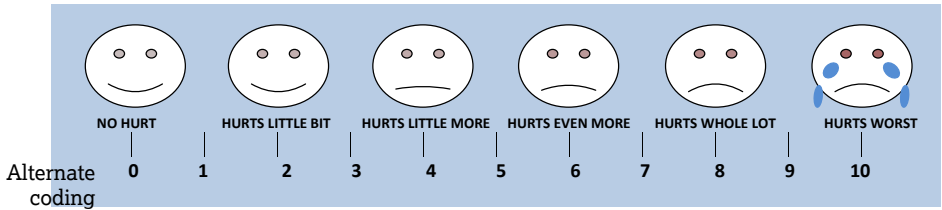
	Individual behaviour score		
	0	1	2
Face	No particular expression or smile	Occasional grimace or frown, withdrawn, disinterested <i>Appears sad or worried</i>	Frequent to constant quivering chin, clenched jaw <i>Distressed-looking face, expression of fright or panic</i>
Legs	Normal position or relaxed. <i>Usual tone and motion to limbs</i>	Uneasy, restless, tense <i>Occasional tremors</i>	Kicking, or legs drawn up <i>Marked increase in spasticity, constant tremors or jerking</i>
Activity	Lying quietly, normal, position moves easily <i>Normal rhythmic respirations</i>	Squirming, shifting back and forth, tense <i>Mildly agitated such as head back and forth, aggression; shallow, splinting respirations, intermittent sighs</i>	Arched rigid or jerking <i>Severe agitation, head banging, shivering (not rigors), breath holding, gasping or sharp intake of breaths, severe splinting</i>
Cry	No cry (awake or asleep)	Moans or whimpers: occasional complaint <i>Occasional verbal outburst or grunt</i>	Crying steadily, screams or sobs, frequent complaints <i>Repeated outbursts, constant grunting</i>
Consolability	Content, relaxed	Reassured by occasional touching, hugging or being talked to, distractable	Difficulty to console or comfort. <i>Pushing away care giver, resisting care or comfort measures</i>

Relaxed and comfortable = 0	Mild discomfort = 1-3	Moderate discomfort = 4-6	Severe pain or discomfort/or both = 7-10
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- Rate each of the 5 assessment scales (0, 1, 2)
- Add them together and record the total score out of 10
- Assess activity in children with spinal cord disease or injury at a level above injury, for example if paralysed below the waist, assess above the waist
- If your child has weakness down one side of their body (hemiplegic), assess them on the unaffected side.

Faces Pain Rating Scale

This is recommended for 4–7 year old children.

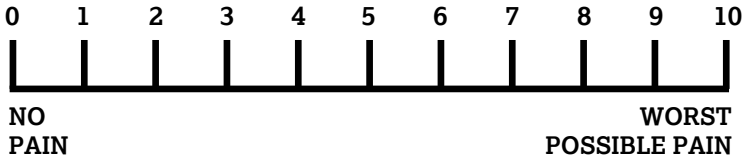


The Wong Baker faces pain scale combines pictures and numbers to allow pain to be rated by the parent, carer or healthcare practitioner. It is trustworthy and used with children over the age of four years. The faces range from a smiling face to a sad, crying face. A numerical rating is assigned to each face.

- Explain to your child that each face is for a child who feels happy because they have no pain (no hurt), or sad because they have some pain or a lot of pain (hurts worst)
- Point to each face using the words to describe the pain intensity
- Ask your child to choose the face that best describes their own pain (hurt)
- Listen to what words your child uses to describe their pain and use these same words when they are hurt
- Record on the chart the number of the face your child has chosen.

Numerical Pain Rating Scale

This is recommended for children 7 years old and above.



- At first, a child unfamiliar with pain may be unable to quantify pain by numbers – this can change with the experience of pain and pain relief with the use of medicines
- Numerical pain rating scales can help to quantify pain using numbers, sometimes in combination with words
- This is suitable for children who are able to count from one to 10
- They also need to understand the concept of big and small, that is, the size of the numbers
- Instruct your child to choose a number from 0 to 10 that best describes their current pain. 0 would mean ‘no pain’ and 10 would mean the ‘worst possible pain’.

Glossary of pain terms

Persisting pain

Persisting pain is any pain that is not related to a procedure or investigation.

Chronic pain

Chronic pain is a pain that continues beyond three months even after the injury has healed.

Breakthrough pain

This can occur when pain 'breaks through' a reasonably stable and controlled **background** pain. It may feel like the **background** pain and be at the same site. The pain can be severe and can start quickly or gradually build up and limits a child's ability to function.

There are two main types of breakthrough pain:

Predictable (incident) pain is an escalation of pain caused by weight-bearing and/or movement (including swallowing, having bowels open, coughing or nursing procedures such as wound care). It is typically of rapid onset and limits a child's ability to function.

Spontaneous pain is unrelated to movement or activity such as stabbing pain related to nerve injury or colic.

End of dose pain

This occurs close to the next planned long acting opiate which is due to be given.

Notes and questions

References

This booklet is evidence based wherever the appropriate evidence is available, and represents an accumulation of expert opinion and professional interpretation.

Details of the references used in writing this booklet are available on request from:

The Royal Marsden Help Centre

Telephone: Chelsea 020 7811 8438 / 020 7808 2083

Sutton 020 8661 3759 / 3951

Email: patientcentre@rmh.nhs.uk

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Should you require information in an alternative format, please contact The Royal Marsden Help Centre.

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