

# Fifteen minute consultation: Practical pain management in paediatric palliative care

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## ABSTRACT

Pain and distress in the paediatric palliative care population can be very difficult to manage.

Clinical scenarios range from the acute management of cancer-related pain at the end of life to the ongoing long-term support of children with complex multimodal pain related to progressive neurological conditions. Understanding the child's underlying condition, possible causes of pain and their preferred mode of communication are important to the delivery of holistic care. Modification of environmental factors, basic care consideration and non-pharmacological measures have a large role to play, alongside conventional analgesics. Medication may also need to be delivered by novel routes such as transdermal patches, continuous subcutaneous infusion of multiple drugs or transmucosal breakthrough analgesic doses. Two cases are used to illustrate approaches to these clinical problems.

## INTRODUCTION

Pain in paediatric palliative care is rarely due to a single cause, and frequently occurs in children who are preverbal, non-verbal or losing the ability to communicate as a result of progressive illness. A child presenting in distress may of course not only be in pain, and it is important to consider causes of primary agitation, frustration and anxiety alongside physical pain.<sup>1</sup> Despite this, it is important to try to ascertain the intensity and quality of pain, the potential underlying causes, as well as triggers that may cause, contribute or exacerbate it. In general, the following types of physical pain should be considered: somatic pain, neuropathic pain, bone pain (due to cancer), headache (related to raised intracranial pressure) and visceral pain (eg, bowel or bladder).<sup>2</sup> When treating pain, a comprehensive approach that incorporates both non-pharmacological and

pharmacological interventions is needed. The main objectives are to prevent pain from occurring and to treat pain rapidly; this is usually achieved by the use of regular analgesia with additional doses in place for breakthrough pain, or incident pain related to the delivery of care. It may be helpful to think more widely in terms of 'total pain',<sup>3</sup> including social, emotional and spiritual elements of the child and family's situation in the face of pain, as failing to address these will reduce the chance of effective pain relief (see [figure 1](#)) Failing to provide timely and effective relief from pain can prevent children from being looked after in their chosen place of care by leading to unnecessary emergency hospital admissions.<sup>4</sup> This can be disempowering for the child and family, as well as carrying resource implications for healthcare services.<sup>2</sup>

## Case 1: complex cancer-related pain

*Martha's case is made up of a combination of real-life experiences of children with neuroblastoma, receiving end-of-life care*

Martha is a 5-year-old girl with a recent diagnosis of relapsed neuroblastoma. She is cared for at home, and initially only requires simple analgesia to manage her pain, which occurs particularly when she is tired. After a few weeks, she begins to experience episodes of pain which do not respond to simple analgesia, and her family describe her as increasingly grumpy. On further questioning, this meant to them that she was more unsettled. You are asked to review her at home by her Paediatric Oncology Outreach Nurse. She weighs 15 kg.

## What might you do?

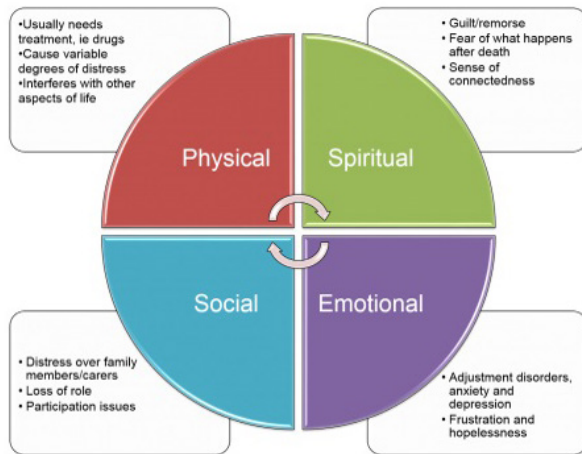
You introduce relatively low-dose morphine by as a standard release liquid, so as to titrate her requirement. As Martha's grumpiness may indicate background pain, you suggest that the family



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## Best practice



**Figure 1** Total pain is a concept defined by Dame Cicely Saunders, which encourages consideration of the wider aspects of the symptom that may prevent adequate symptom relief if left unaddressed.

use the morphine 100 mcg/kg 4 to 6 hourly, with extra administrations (at the same dose) if her pain breaks through. The outreach nurse keeps closely in touch with the family. After 48 hours, she informs you that that Martha has needed an average oral morphine dose of 9 mg per 24 hours (six doses at 1.5 mg each), and that with this she has been comfortable with no signs of opiate toxicity.

#### What might you do next?

You convert her morphine to a sustained release preparation, with an additional breakthrough dose of standard release morphine available to use as required.

A 9 mg oral morphine requirement in 24 hours is equivalent to 4.5 mg of a sustained release 12 hours preparation given twice a day.

Breakthrough is usually one-sixth of the background dose per administration, this would therefore be as follows: 9 mg divided by 6 giving an individual breakthrough dose of 1.5 mg.

A dose of 4.5 mg twice a day of sustained release morphine with a breakthrough dose of 1.5 mg is therefore prescribed.

It is also worth noting that morphine can be used at lower dose in paediatric palliative care to manage breathlessness (usually 30%–50% of the analgesic dose).

Five weeks later, her pain has been reasonably controlled at home with sustained release morphine and the current dose is now 9 mg twice a day, complemented with standard release morphine 3 mg. This has crept up in relatively gentle increments, titrated against her use of background medication. She begins to get upset when she is cuddled or showered. This does not respond well to breakthrough medication, and Martha denies pain. She mentions that her legs feel like 'buzzy bees'. You are called to see her on

#### Box 1 Some examples of verbal children's descriptions of neuropathic pain

- ▶ Weird legs
- ▶ Fizzy pain
- ▶ Cloud on my shoulder
- ▶ Spade digging my head
- ▶ My head is a dinosaur
- ▶ My back is a tiger on fire
- ▶ I have got buzzy bees
- ▶ My pain is hot

the oncology day ward, where she is attending for review.

#### What might you consider?

You examine Martha to exclude spinal cord compression, and decide that she is likely to have neuropathic pain (see [box 1](#)). Her symptoms settle a few days later with the introduction of gabapentin.

A week after this, you review her during a home visit, requested by the community nursing team. Her abdominal girth has increased significantly, and she has developed a sharp pain in her right upper quadrant, which is worse on inspiration, her liver is tender and more easily palpable.

#### What might be the issue?

Martha has liver capsule pain from the increasing hepatomegaly. Her pain settles with dexamethasone.

Over the next couple of days, she becomes sleepier and struggles to take her oral analgesia. She has needed four breakthrough doses of her morphine in the last 24 hours. Her parents request admission to the hospice. She has an advance care plan in place stating this to be their preferred place of care, and confirming that resuscitation should not be attempted. Martha is responsive and perks up briefly on arrival, she responds socially to staff; her pupils are mid-size and responsive to light, and her respiratory pattern is normal. You feel that her reduced wakefulness is a result of her disease progression, rather than her increased need for analgesia. Her morphine dose is now 15 mg twice a day of sustained release morphine with a breakthrough dose of 5 mg.

#### What route of administration would help?

Subcutaneous infusion via syringe driver<sup>5</sup> (see [figure 2](#)).

#### How would you convert her medication regime?

First, her total oral morphine equivalent dose (per 24 hours) is calculated: two doses of 15 mg of the sustained release preparation, plus four breakthrough doses at 5 mg per dose making a total of 50 mg per 24 hours.



**Figure 2** A Mckinley T34 pump of the type often used for continuous subcutaneous infusions in the community.

This is then divided by two to convert to an equivalent subcutaneous dose of 25 mg per 24 hours by continuous infusion.

Ketamine can be added to the infusion to cover neuropathic pain (replacing gabapentin), and dexamethasone (for liver capsule pain) can also be combined. An antiemetic could be added if needed.

Martha settles comfortably, and is able to enjoy some periods of pain-free awake time, before dying peacefully 3 days later.

### Case 2: multimodal pain in progressive neurological illness

Jack is a real patient, and the story is told in the words of Katherine, Jack's mother, they are an extract from her account, 'Caring for Jack'<sup>6</sup>:

'As far as we were aware, Tay-Sachs did not cause pain. However, as the years passed, it was clear that Jack needed regular paracetamol. When Jack was about four, it was recognised, by members of his professional team, that his quality of life was being impaired by pain greater than routine paracetamol could cope with. The pain manifested itself through increased secretions, grumpiness, lines on his face, not wanting to be moved, and general unhappiness. It was felt there was no one single reason for his pain, but a combination of muscles being twisted by his scoliosis, sitting in a chair, not being able to move to a more comfortable position and the like.'

### How might you address Jack's pain?

After titration with low-dose standard release morphine, a low dose of transdermal buprenorphine was introduced. Buprenorphine is a good option when simple analgesia is no longer adequate in the face of chronic multifactorial pain in children with neurodisability.<sup>7</sup>

'Jack then had a buprenorphine patch that gave him a background level of pain relief. Initially he had a quarter patch changed weekly, but towards the end of his life he was on a whole patch changed every 6

### Box 2 Clues to neuropathic pain in a non-verbal child

- ▶ Biological plausibility
- ▶ Metabolic storage disease
- ▶ Mitochondrial disease
- ▶ Changes in behaviour
- ▶ Unexplained screaming
- ▶ Combative behaviour
- ▶ Difficulty with handling or delivering care
- ▶ Unable to enjoy cuddles

days. We saw an immediate improvement in Jack's concentration and engagement in life. It was great to have his smile back more often. We were lucky in Jack's later years to have access to a Paediatric Palliative Care Consultant. Prior to her first consultation with us and Jack, she had not only read his notes but talked to his carers in both the community and Helen & Douglas House hospice. As a result she felt that Jack was suffering from neuropathic pain. This was explained to us as nerves sending pain messages to the brain for no apparent reason. All the carers had noticed that Jack had days when he did not want to be touched or moved. All of us had developed strategies for minimising movement and handling of Jack on these days. On hand-over for respite we used to describe these days as Jack having a quiet day and we would sometimes discuss how much we missed having cuddles with him. The Consultant recognised this as a possible indicator of neuropathic pain for those that were non-verbal (see **box 2**). We quickly started Jack on medication to target this, and within a short space of time he was once again able to enjoy cuddles.'

### What therapy might you have considered for Jack's neuropathic pain?

Gabapentin can be very effective for the management of neuropathic pain in children.<sup>8</sup> The difficulty can be recognising the possible indicators of neuropathic pain in non-verbal children. Gabapentin is also effective in improving the quality of life in children with dystonia in the context of complex neurodisability, something which may frequently co-exist with neuropathic pain in the group of patients.<sup>9</sup>

'Over time Jack lost the ability to wee spontaneously, and this caused him great pain and distress at times. It was sometimes possible for us to assist him to pass urine by massaging and palpating, but this was not a long-term solution and one memorable few days it became impossible for us to help Jack pass urine until his bladder had been overfull for many hours and as the time passed he was in agony. We were advised to take him to A&E and despite what to us was very evident distress and pain (indicated by his facial expression, lines on his brow, shortened breath,

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**Box 3 Factors to consider in assessing pain**

- ▶ Underlying condition, disease process or likely biological mechanism
- ▶ Developmental level (cognition, communication, motor function)
- ▶ Usual means of communication (verbal or non-verbal)
- ▶ Caregiver's view
- ▶ Impact of concurrent illness
- ▶ Differential diagnosis (other distress, complex pain, dystonia)

clammy and utter concentration on not moving, even though he could barely move due to his condition, interspersed with involuntary jerks) we were not believed by either the junior doctor or the paediatrician (see [boxes 3 and 4](#)).<sup>7</sup>

**What might be affecting Jack's ability to pass urine?**

Jack had developed a neuropathic bladder and was distressed as a result of visceral pain, this required a physical solution. He also went on to develop significant constipation as a result of neuropathic bowel function.

'As soon as urology saw his 48 hours chart of liquids in/urine out, they knew there was an issue and from then on Jack was intermittently catheterised. It gradually became more difficult to catheterise Jack intermittently, and despite this previously being described to us as the 'gold standard' of catheterisation by his urology nurse, she persuaded us that with disease progression we had no choice but to move him to an in-dwelling catheter permanently. For Jack, being catheterised liberated him from a lot of pain and discomfort, and significantly reduced the number of UTI's he had from an early age.'

Jack continued to require a combination of non-pharmacological, physical and pharmacological approaches to manage his pain and other distressing symptoms (see [box 5](#)). He died peacefully at the age of 7.

**Box 4 Possible hidden causes of pain in non-verbal patients with neurodisability**

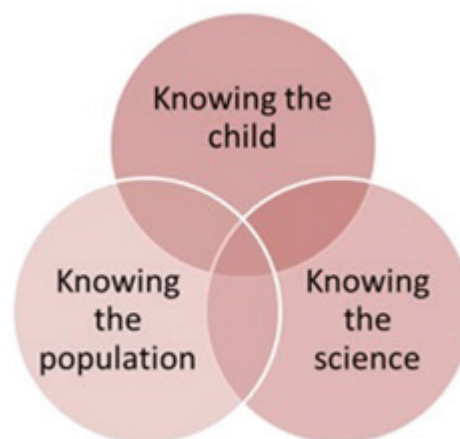
- ▶ Spasticity or dystonia
- ▶ Constipation
- ▶ Gastro-oesophageal reflux
- ▶ Headaches
- ▶ Back or hip pain (musculoskeletal)
- ▶ Urinary tract infection
- ▶ Dental pain

**Box 5 Approach to management of pain or distress**

- ▶ Basic care considerations: clean nappy or pad, well fed, warm, comfortable position, reassured.
- ▶ Environmental measures: noise levels, light levels, calm atmosphere.
- ▶ Non-pharmacological measures: distraction, stories, DVDs, music, pleasurable activities (including use of warm bath or hydrotherapy pool).
- ▶ Pharmacological treatments of pain: consider the likely source of pain, include background analgesia as well as breakthrough and escalation plan.
- ▶ Consider the mode of delivery: enteral versus transdermal, subcutaneous or transmucosal (if not able to absorb via gut).

**CONCLUSION**

As illustrated by the cases above, the management of pain in paediatric palliative care is a vast subject to cover; indeed we have barely scratched the surface in this practically focused article (see [figure 3](#)).<sup>10</sup> The Association of Paediatric Palliative Medicine produces a formulary specifically to support prescribing in the evidence-poor area of palliative care for children.<sup>11</sup> Together for Short Lives have also produced several practical resources, including the Rainbow's Hospice Basic Symptom Control Manual<sup>12</sup> and numerous helpful pathways.<sup>13</sup> Additionally, National Institute for Health and Care Excellence has recently produced evidence based national guidance on end-of-life care for infants, children and young people.<sup>3</sup> It remains to say just how challenging assessment of pain can be in paediatric palliative care. Standardised pain scales are rarely adequate for the purpose, indeed in this context to measure pain only with a number, would be to define music only by its volume.



**Figure 3** Making an assessment of pain/distress in a non-verbal child.

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**Competing interests** None declared.

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**Author note** Dedicated to the memory of Jack Pierre Pixton, who taught us all a thing or two.

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