Site Applicability

This guideline is for use in all inpatient areas, Sunny Hill Health Centre and the PICU at BC Children's Hospital

NOTE: This guideline is to be used in any Non-Critical Care area the "Pediatric End of Life Care High Dose Medication Infusion Policy" must be followed and a consultation to Canuck Place must occur.

Guideline Statements

This document is to be used as a resource during the provision of palliative or end-of-life care. It is not meant to be prescriptive but, rather, provide general principles, guidance and suggested doses for the bedside practitioner. The doses indicated below are suggested starting points and, often, very high doses are required to relieve pain and discomfort at the end of life.

Guidelines

Pain

Mild Pain	• Non-pharmacologic measures: massage, repositioning, distraction • Acetaminophen 15mg/kg PO/PR Q6H PRN or regular • Ibuprofen 10mg/kg PO Q6H PRN or regular • Ketorolac 0.3 mg/kg/dose IV Q6H PRN or regular
Moderate Pain	• Morphine 0.15-0.3mg/kg PO/SL Q4H PRN or regular, OR 0.05-0.1mg/kg IV Q4H PRN or regular • Hydromorphone 0.05-0.1mg/kg PO Q4H (<50kg) PRN or regular, OR 0.015mg/kg IV Q4H PRN or regular • Fentanyl 1-2mcg/kg/dose IV/IN, Q1-2H PRN (best for procedural/short-duration pain, for ages > 1 month)
Severe Pain	• Morphine 50mcg/kg/hr IV continuous infusion starting dose • Hydromorphone 10mcg/kg/hr IV continuous infusion starting dose • Fentanyl 1mcg/kg/hr IV continuous infusion starting dose • If breakthrough pain present, give bolus of equivalent of 1-hour's dose of opioid and increase infusion rate by 25% • In some cases, increases by up to 100% may be appropriate • Frequent re-assessment and nurse-led titration is necessary • Consider consult to Palliative Care Team (Canuck Place) or Acute Pain Service
Opioid Rotation	• Concurrent use of multiple opioids is not recommended • If intolerable side effects occur (myoclonus, itching, delirium, etc) occur, consider switching to another opioid • Equianalgesic doses: Morphine 1mg = Hydromorphone 0.15mg = Fentanyl 0.01mg • Start new infusion at 50% of calculated equianalgesic dose; reassess and bolus/increase as above

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Secretions

- Non-pharmacologic measures: fluid restriction, gentle suction, positioning for postural drainage, etc
- Glycopyrrolate 0.01-0.02mg/kg IV Q4-6H or 0.04-0.1mg/kg PO Q3-4H PRN or regular
- Atropine 0.01-0.02mg/kg PO (max dose 0.4mg) PRN or regular
- Consider decreasing or stopping enteral nutrition/hydration if secretions are difficult to manage

Dyspnea

- Non-pharmacologic measures: elevate the head of the bed, bedside fan, fluid restriction, gentle suction, etc
- Dyspnea refers to a subjective difficulty breathing, as experienced by the patient; this is different from “noisy” or “distressing” breathing observed by others around the time of death, although the two are not mutually exclusive
- When patients are unable to communicate discomfort or self-report dyspnea, health care providers and families must be diligent in their assessments of such distressing symptoms
- Administer oxygen as needed for comfort
- Morphine 0.15-0.3mg/kg PO/SL Q4H PRN or regular, 0.05-0.1mg/kg IV Q4H PRN or regular
- Can switch to hydromorphone if morphine is not well-tolerated
- Assess for anxiety related to dyspnea — may add Lorazepam 0.05mg/kg IV/PO Q6H PRN if needed

Agitation

- Non-pharmacologic measures: familiar people/objects, low lighting, soothing tones, music, decreased monitoring, etc
- Evaluate for pain versus anxiety, hypoxia, poor sleep and/or depression
- Lorazepam 0.05 - 0.1mg/kg/dose IV/PO Q1-2H PRN or regular
- Midazolam infusion 50mcg/kg/hr IV continuous infusion; if agitation persists, increase infusion by 25% and reassess frequently
- Clonidine 2-4 mcg/kg/dose PO Q4-6H PRN or regular
- Dexmedetomidine 0.1-1mcg/kg/hr IV continuous infusion

Nausea and Vomiting

- Non-pharmacologic measures: avoid noxious foods or smells, position with head of bed elevated or lying on right side, etc
- Ondansetron 0.15mg/kg/dose PO/IV Q8H PRN or regular
- Metoclopramide 0.1-0.2mg/kg/dose PO/IV Q6H PRN or regular
- Dimenhydrinate 0.5-1mg/kg/dose PO/IV Q4-6H PRN or regular
- Dexamethasone 6mg/m^2 PO/IV Q6H PRN or regular

Additional Resources

1. Canuck Place can be consulted to support end of life symptom management as well support staff (medical, nursing and support staff) and provide support and bereavement services to the family. Canuck Place can be consulted to support the clinical team even if the family would not like to meet with them. Please contact them through paging.
2. Canuck Place Symptom Assessment Guideline

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Canuck Place Symptom Assessment

3. WHO guidelines on the pharmacological treatment of persisting pain in children with medical illnesses; http://www.who.int/medicines/areas/quality_safety/guide_perspainchild/en/
4. End of life care for infants, children and young people with life-limiting conditions: planning and management; NICE guideline; https://www.nice.org.uk/guidance/ng61
5. Fraser Health Hospital Palliative Care Symptom Guidelines; https://www.fraserhealth.ca/health-professionals/professional-resources/hospice-palliative-care/
6. Pediatric Hospice Palliative Care Guiding Principles and Norms of Practice; Canadian Hospice Palliative Care Association & Canadian Network of Palliative Care for Children; http://www.chpca.net/media/7841/Pediatric_Norms_of_Practice_March_31_2006_English.pdf
7. Basic Symptom Control in Paediatric Palliative Care; Together for Short Lives; https://www.togetherforshortlives.org.uk/resource/basic-symptom-control-paediatric-palliative-care/
8. A Care Pathway to Support Extubation with a Children's Palliative Care Framework; Association for Children's Palliative Care (ACT); https://www.togetherforshortlives.org.uk/wp-content/uploads/2018/01/ProRes-Extubation-Care-Pathway.pdf

Patient & Family Engagement/Education

Educational resources for the family (caregivers) may be found by searching 'end of life' on ePOPS (http://policyandorders.cw.bc.ca/).

References

1. WHO Definition of Palliative Care; http://www.who.int/cancer/palliative/definition/en/
2. BCCH Policy CC.17.04 – Pediatric End of Life Care High Dose Medication Infusion Exception Policy
3. Algorithms for End-of-Life Care in Anticipated Pediatric Deaths; Pediatric Palliative Care Team, C.S. Mott Children's Hospital University of Michigan; https://open.umich.edu/sites/default/files/downloads/code_cards_december_2013.pdf

Definitions

Palliative care is a model of care that improves the quality of life of patients and families facing life-threatening illness, through the prevention and relief of suffering. This includes the assessment and treatment of pain and other physical, psychosocial and spiritual issues. The delivery of palliative care may begin at birth or at the time of diagnosis of a life-threatening or life-limiting condition, and may continue for as long as is necessary. *End-of-life care* is an extension of palliative care principles designed to relieve suffering and provide comfort when death is imminent. It is important to note that patients can pursue both curative medical care and palliative care concurrently — there is no need to choose one at the exclusion of the other.

The ***principle of double effect*** seeks to resolve the moral dilemma when one action will have both a good (intended) and bad (unintended but known) effect. In healthcare, this principle is most commonly applied to the administration of a medication to relieve pain, anxiety, or suffering, even though it may lead to the unintended consequence of hastening death. Interventions that may hasten death but are delivered with the intent to provide comfort or relieve pain are ethically appropriate in the setting of palliative and end-of-life care.

In the intensive care unit, patients are often receiving aggressive curative interventions at or around the time of death. When a decision is made to stop pursuing curative measures, it is referred to as a "*withdrawal of life-support*" — not a "withdrawal of *care*". This may include the discontinuation of inotropes or vasopressors, removal of extra-corporeal life support (ECMO, CRRT, etc), or a terminal ("one-way") extubation. Interventions to prevent or manage pain, agitation, dyspnea, secretions or nausea can be implemented prior to a withdrawal of life support.

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