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Symptom Management for Children Near/At End-of-Life

EXPERT OPINION GUIDANCE FROM THE ONTARIO PEDIATRIC PALLIATIVE CARE STEERING COMMITTEE: 2023 UPDATE

Disclaimer

This document is for guidance only. Content in this document does not replace clinical judgement or dictate the treatment of individual patients. Furthermore, users of this document are reminded that medications and dosing strategies listed do not take into account drug-drug interactions. Caution must always be used when prescribing medications that providers are unfamiliar with.

Medication dosing strategies were based primarily on The Hospital for Sick Children (SickKids) Paediatric & Neonatal Formulary Database on Lexicomp. Any modifications to drug dosing strategies were based on expert opinion and consensus specifically in the context of End-of-Life. In the event of difficulties managing particular patients, or concerns about recommendations herein, we strongly suggest consultation with the referring physician or specialized pediatric palliative care team.

Many medications and dosing recommendations in this guide are 'off-label', meaning their use deviates from the dose, route of administration, patient age, or medical indications described in Health Canada-approved monographs. Off-label prescribing is very common in pediatrics; up to 80% of all medications currently prescribed in Canadian pediatric hospitals are administered 'off-label' (Hepburn et al., 2019). While off-label does not mean 'without evidence', prescribers must appreciate that the lack of rigorous studies to support the use of these medications in children receiving palliative care is not without risk. Since the recommendations contained in this guide were generated by clinicians experienced in pediatric palliative care and reviewed by external reviewers, they are in accord with practice. However, if the clinician is uncomfortable with any given recommendation, they should seek guidance from the regional pediatric palliative care team.

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In the event of any inconsistency between the content of a local copy and the online version of the *Symptom Management for Children Near/At End-of-Life*, the content of the online version shall be considered correct.

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Introduction

Symptom management for pediatric palliative care patients at the end-of-life requires an astute care team that is aligned to the status of the child[1] as well as the goals of care of the child and family.

The Provincial Pediatric Palliative Care Steering Committee convened a multidisciplinary working group comprised of pediatric palliative care experts (details and methods in Appendix B) to facilitate the review, and recommended updates, to the *2016 Pediatric Palliative Care: Approaching the End-of- Life Information for HealthCare Providers and Symptom Management Guide for Children Near/At End-of-Life* expert opinion guidance documents. This review was conducted to ensure currency and content of both documents accurately reflects current best practices for pediatric palliative care delivery and to facilitate inclusion of disclaimers on how or where to seek advice regarding care of children at or near end-of-life.

The information included in this document is based on standards of practice/experience from Ontario pediatric palliative care experts and serves as a basic approach to assisting those who provide care to pediatric palliative care patients at the end-of-life. The management strategies and medications listed in the following table are listed according to symptom and may be used for specific indications in pediatric patients approaching end-of-life. When no suggested dosing interval is provided, the decision to provide a medication regularly or "as needed" is up to the discretion of the treating team. Furthermore, goals of care should be discussed and kept in mind prior to initiating therapies.

Target Population

The target population consists of children and youth aged 0-18 years receiving pediatric palliative care. The target users are healthcare providers including physicians, nurse practitioners, nurses, pharmacists, and other healthcare providers who are concerned with the care of children receiving pediatric palliative care.

Patient-specific consultation with specialized pediatric palliative care providers at an associated pediatric academic health sciences centre is strongly recommended to determine which of the strategies may be most relevant and helpful.

[1] Throughout this document the terms 'child' and 'children' will be used to represent pediatric patients of any age, including infants, children, and youth.

1. PAIN

Management Strategies	Medications & Suggested Initial Doses
SOMATIC PAIN (Intermittent)	
A full pain assessment is imperative to effective pain management. Consider whether there is a neuropathic component or centralized chronic pain. Consider "Total pain" including contributing psychologic, emotional, social, and spiritual factors. Consider source control, such as radiotherapy for bony tumours. Consider integrative therapies such as massage, acupressure, acupuncture, TENS, music therapy, aromatherapy, meditation, guided imagery, biofeedback, hypnosis, etc. **Re: NSAIDs** Only 1 (one) NSAID (Ibuprofen, Naproxen, Ketorolac, Celecoxib) should be used at a time. NSAIDs can contribute to bleeding risk or gastritis. Consider parallel antacid therapy if NSAIDs are being used frequently. **Re: Opioids** It has been shown that appropriate opioid use does not hasten death but improves quality of life and may actually prolong life. There are no specific opioid dose limits. However, escalating doses without substantial or lasting improvements in pain should prompt consideration of alternate diagnoses that may require alternate treatment strategies including but not limited to severe neuropathic pain, chronic centralized pain/central hypersensitivity, anxiety, psychosocial distress, delirium, neuro-irritability, neurotoxicity, or opioid induced hyperalgesia. High doses of opioids can be related to neurotoxicity and hyperalgesia through accumulation of metabolites.	**EPISODIC MANAGEMENT (intermittent symptoms)** **FIRST LINE** **Acetaminophen (PO/GT)** • 15mg/kg Q4H PRN *(Dose Max: 1000mg; Daily Max: 75mg/kg, or 4000mg)* **Ibuprofen (PO/GT)** • <6mo: 5mg/kg Q6H PRN • >6mo: 10mg/kg Q6H PRN *(Dose Max: 400mg)* **Morphine (PO/GT, IV/SC, SL/B)** • PO/GT: 0.2-0.4mg/kg Q2H PRN *(Typical initial adult dose: 5-10mg)* • IV/SC, SL/B: 0.05-0.1mg/kg Q1H PRN *(Typical initial adult dose: 2-4mg)* • Titration: Increase by 33-50% if insufficient dose response. **SECOND LINE** **Naproxen (PO/GT)** • 5-10mg/kg Q12H PRN *(Dose Max: 500mg)* **Ketorolac (PO/GT, IV)** • PO/GT: >2y: 0.5mg/kg Q6H PRN *(Dose Max: 10mg)* • IV: >2y: 0.5mg/kg Q6H PRN *(Dose Max: 30mg, Daily Max: 60mg)* ○ *Note: Duration of treatment not to exceed 5 days. May be used in term infants, consult provider with experience prescribing ketorolac for infants*. **Hydromorphone (PO/GT, IV/SC, SL/B)** • PO/GT: 0.04-0.08mg/kg Q2H PRN *(Typical initial adult dose: 1-2mg)* • IV/SC, SL/B: 0.01-0.02mg/kg Q1H PRN *(Typical initial adult dose: 0.4-0.8mg)* • Titration: Increase by 33-50% if insufficient dose response. **THIRD LINE** **Consider adjuvant therapies.** **Celecoxib (PO/GT)** • 10mg/kg Q6H PRN *(Dose Max: 200mg, Daily Max: 400mg)* ○ *Note: Preferred NSAID if bleeding risk.* **Fentanyl (IV/SC, SL/B, IN)** • IV/SC: 0.25-0.5**mcg/kg** Q30min PRN *(Typical initial adult dose: 25**mcg**)* • SL/B, IN: 1.5**mcg/kg** Q30min PRN *(Typical initial adult dose: 25**mcg**)* • Titration: Increase by 33-50% if insufficient dose response. ○ *Note: Preferred opioid in renal failure, use with extreme caution in opioid-naïve.*

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1. PAIN

Management Strategies	Medications & Suggested Initial Doses
SOMATIC PAIN (Persistent)	

Management of persistent pain should include a maintenance plan *and* a breakthrough plan, both consisting of non-pharmaceutical +/- pharmaceutical therapies.
 	
Re: NSAIDs
Only 1(one) NSAID (Ibuprofen, Naproxen, Ketorolac, Celecoxib) should be used at a time. NSAIDs can contribute to bleeding risk or gastritis. Consider parallel antacid therapy in routine use of NSAIDs.
 	
Re: Opioids
It has been shown that appropriate opioid use does not hasten death but improves quality of life and may actually prolong life.
 	
Many patients begin on intermittent opioids. Continuous opioid dosing should be calculated from current intermittent opioid usage. If the patient is not currently receiving opioids, but continuous opioid therapy is indicated (such as following a surgery or severe injury), doses within this chart can be considered.
 	
There are no specific opioid dose limits. However, escalating doses without substantial or lasting improvements in pain should prompt consideration of alternate diagnoses that may require alternate treatment strategies including but not limited to severe neuropathic pain, chronic centralized pain, anxiety, psychosocial distress, delirium, neuro-irritability, neurotoxicity, or opioid induced hyperalgesia. High doses of opioids can be related to neurotoxicity and hyperalgesia through accumulation of metabolites.
	MAINTENANCE MANAGEMENT (persistent symptoms)
	
	FIRST LINE
	
	Acetaminophen (PO/GT)
	• 15mg/kg Q6H *(Dose Max: 1000mg)*
	Ibuprofen (PO/GT)
	• <6mo: 5mg/kg Q6H
	• >6mo: 10mg/kg Q6H *(Dose Max: 400mg)*
	Morphine (PO/GT, IV/SC, SL/B) *(caution in renal failure)*
	• PO/GT: 0.2-0.4mg/kg Q4H *(Typical initial adult dose: 5-10mg)*
	  ○ Breakthrough: 10% of the total daily dose Q2H PRN
	• IV/SC, SL/B: 0.05-0.1mg/kg Q4H *(Typical initial adult dose 2-4mg)*
	  ○ Breakthrough: 10% of the total daily dose Q1H PRN
	• Continuous IV/SC infusion: 10-20**mcg/kg/h**
	  ○ Breakthrough: 10% of the total daily dose Q1H PRN
	• Titration: Increase based on breakthrough use and total daily dose.
	
	SECOND LINE
	
	Naproxen (PO/GT)
	• 5-10mg/kg Q12H *(Dose Max: 500mg)*
	Ketorolac (PO/GT, IV)
	• PO/GT: >2y: 0.5mg/kg Q6H *(Dose Max: 10mg)*
	• IV: >2y: 0.5mg/kg Q6H *(Dose Max: 30mg, Daily Max: 60mg)*
	  ○ *Note: Duration of treatment not to exceed 5 days. May be used in term infants, consult provider with experience prescribing ketorolac for infants.*
	Hydromorphone (PO/GT, IV/SC, SL/B) *(caution in renal failure)*
	• PO/GT: 0.04-0.08mg/kg Q4H *(Typical adult dose: 1-2mg)*
	  ○ Breakthrough: 10% of the total daily dose Q2H PRN
	• IV/SC, SL/B: 0.01-0.02mg/kg Q4H *(Typical adult dose 0.4-0.8mg)*
	  ○ Breakthrough: 10% of the total daily dose Q1H PRN
	• Continuous IV/SC infusion: 2-4**mcg/kg/h**
	  ○ Breakthrough: 10% of the total daily dose Q1H PRN
	• Titration: Increase based on breakthrough use and total daily dose.

1. PAIN

Management Strategies	Medications & Suggested Initial Doses
SOMATIC PAIN (Continued)	**THIRD LINE** *(also see Adjuvant Pain Therapies)* **Celecoxib (PO/GT)** • 10mg/kg Q12H *(Dose Max: 200mg)* ○ *Note: Preferred NSAID if bleeding risk.* **Fentanyl (IV/SC, transdermal)** • Fentanyl dosing should be derived from current opioid dosing. If not currently on opioids and a fentanyl infusion is indicated (e.g., severe consistent pain with allergy, renal failure), suggest consultation with provider with experience prescribing fentanyl to children. **Methadone (PO/NG, SL/B)** • Consider early introduction of methadone for children with expected progressive pain (e.g., cancer/bony pain). • Consult provider with experience prescribing methadone to children.

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1. PAIN

Management Strategies	Medications & Suggested Initial Doses
NEUROPATHIC PAIN	
Neuropathic pain may be peripheral (e.g., brachial plexus injury) or central (e.g., spinal cord injury, thalamic stroke). Neuropathic pain management should include a maintenance plan and a breakthrough plan, both consisting of non-pharmaceutical +/- pharmaceutical therapies. Consider source control, such as radiotherapy for bony tumours. Consider integrative therapies such as massage, acupressure, acupuncture, TENS, aromatherapy, meditation, guided imagery, biofeedback, hypnosis, etc. Consider topical options including creams containing lidocaine, NSAIDs, etc. Breakthrough options for neuropathic pain include: • Acetaminophen • NSAIDs • Opioids • Methadone (advanced prescribers) • Clonidine • Cannabinoids (advanced prescribers) • Ketamine (advanced prescribers)	**MAINTENANCE MANAGEMENT** **FIRST LINE** **Gabapentin (PO/GT)** • Initiation: 2-4mg/kg TID *or* 5-10mg/kg QHS *(Typical starting adult dose: 100mg TID or 300mg QHS)* then increase by 5-10mg/kg/day every 2-4 days until reaching 20-30mg/kg/day divided equally TID or 25% of the total daily dose QAM, 25% QMidday, and 50% QHS (particularly if nighttime symptoms and sleep disturbance are prevalent). • Titration: Increase by 5-10mg/kg/day every 7days PRN *(Daily max: 75mg/kg or 3600mg, Higher doses may be possible but would warrant specialist consultation).* ○ *Note: Give half of total daily dose QHS if symptoms occur mostly in evening/overnight.* **Pregabalin (PO/GT)** • Initiation: 1mg/kg QHS x 3 days *(Typical starting adult dose: 75mg QHS),* then 1mg/kg BID • Titration: Increase by 1mg/kg/dose every 7days PRN *(Daily Max: 12mg/kg/day or 600mg/day).* **SECOND LINE** **Clonidine (PO/GT)** • Initiation: 1-2**mcg/kg QHS** x 3-5 days, then increase to BID *(Dose max: 100***mcg***)* • Titration: May Increase dose (to 4**mcg/kg**) or frequency of dosing (to QID) every 2-4days as needed depending on time and severity of symptoms *(Daily max: 16**mcg/kg** or 400**mcg/day** (Higher doses may be possible but would warrant specialist consultation.)* **Amitriptyline (PO/GT)** • 0.2mg/kg *(Typical adult starting dose: 10mg)* • Titration: May increase 0.2 mg/kg Q4-5days as needed *(Daily Max: 2mg/kg or 50 mg).* **Opioids** see *Somatic Pain (persistent)* **THIRD LINE** **Methadone (PO/NG, SL/B)** • Consider early introduction of methadone for children with expected progressive neuropathic pain (e.g., cancer/bony pain). • Consult provider with experience prescribing methadone to children. **Cannabinoids (PO/NG, SL/B)** • Consult provider with experience prescribing cannabinoids to children. See *Adjuvant Pain Therapies*

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1. PAIN

Management Strategies	Medications & Suggested Initial Doses
SEVERE NEUROPATHIC PAIN	

Many of the above therapies take time to be effective. In the scenario of acute severe neuropathic pain, consultation with palliative care/pain experts is strongly recommended.	In addition to initiating/optimizing above measures above, consider:
	• **Methadone (PO/NG, SL/B)**
	  ○ Consult provider with experience prescribing methadone to children.
	• **Ketamine (IV/SC infusion)**
	  ○ Consult provider with experience prescribing ketamine to children.
	• **Dexmedetomidine (IV/SC infusion)**
	  ○ Consult provider with experience prescribing dexmedetomidine to children.
	• **Lidocaine (IV infusion)**
	  ○ Consult provider comfortable prescribing IV lidocaine to children.

ADJUVANT PAIN THERAPIES	
Interprofessional and multi-specialist collaboration is critical to the management of advanced pain.	**LOCALIZED PAIN** • **Consider Local/Regional Anesthetics** ○ Consult provider with experience providing local/region blocks to children.

	BONY PAIN
	• **Alendronate (PO/GT)**
	  ○ 1mg/kg/week, rounded to nearest 10mg *(Weekly Max: 70mg)*
	• **Pamidronate, Zoledronic Acid**
	  ○ Consult provider with experience prescribing bisphosphonates to children.

	CANCER PAIN
	• **Dexamethasone (PO/GT, IV/SC)**
	  ○ 0.01mg/kg BID-TID *(Max daily dose: 12mg/day)*
	  ○ *Note: Use in 2-3 day pulses. Consider concomitant antacid therapy. May use higher doses in certain clinical emergencies and would warrant specialist consultation.*
	• **Prednisone (PO/GT)**
	  ○ 0.5-1mg/kg Q12H *(Dose Max: 40mg)*
	• **Radiotherapy**
	  ○ Consult Radiation Oncology provider.

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2. NEUROLOGICAL SYMPTOMS

Management Strategies	Medications & Suggested Initial Doses
NEURO-IRRITABILITY	
For children with neurologic conditions who demonstrate irritability of unclear origin, suggest consulting the American Academy of Pediatrics Clinical Report: Pain Assessment and Treatment in Children with Significant Impairment of the Central Nervous System. This approach focuses on identifying potential sources of pain or discomfort leading to irritability. Neuro-irritability is a specific phenomenon best defined as a state of global heightened sensitivity to external and internal stimuli leading to stimulatory overload and manifesting in irritability, often accompanied by pain behaviours such as hypertonicity, sleep disturbance, or mood/cognitive changes. Neuro-irritability is usually found in the context of biochemical or electrical changes in the brain (e.g., meningitis, post-anoxic or traumatic brain injury/diffuse axonal injury, intracranial hemorrhage, epileptic encephalopathy, end stage metabolic or neurodegenerative disease).	**MAINTENANCE MANAGEMENT** **FIRST LINE** **Gabapentin (PO/GT) or** *Pregabalin* **(PO/GT)** • See *Neuropathic Pain* **SECOND LINE** **Clonidine (PO/GT)** • *See Neuropathic Pain* **Phenobarbital (PO/GT, IV/SC)** • See *Seizures* **THIRD LINE** **Methadone (PO/NG, SL/B)** • Consult provider with experience prescribing methadone to children. **Cannabinoids (PO/NG, SL/B)** • Consult provider with experience prescribing cannabinoids to children. **Haloperidol (PO/IV)** • 0.01-0.02mg/kg TID • Titration: Increase by 0.5mg/day every 5-7 days as needed *(Daily Max: 0.15mg/kg or 15mg, Higher doses may be possible but would warrant specialist consultation)*. **BREAKTHROUGH MANAGEMENT** **FIRST LINE** **Clonidine (PO/GT)** • 2**mcg/kg** Q4H PRN *(Typical adult dose: 100**mcg**)* • Titration: Increase to 4**mcg/kg** if insufficient dose response *(Dose Max: 100**mcg**, Higher doses may be possible but would warrant specialist consultation).* **Lorazepam (PO/GT, SL/B, IV/SC)** • See *Anxiety* **SECOND LINE** **Midazolam (PO/GT, SL/B, IN, IV/SC)** • PO/GT: 0.2-0.5mg/kg Q2H PRN *(Typical initial adult dose: 5 mg)* • SL/B, IN, IV/SC: 0.1-0.2 mg/kg Q1H PRN *(Typical initial adult dose:* 2.5*mg)* • Titration: Increase by 33-50% if insufficient dose response. **Opioids** • See *Somatic Pain (persistent)* **Phenobarbital (PO/GT, IV/SC)** • 5-10 mg/kg Q12H PRN *(Dose Max: 200mg)*

2. NEUROLOGICAL SYMPTOMS

Management Strategies	Medications & Suggested Initial Doses
NEUROIRITABILITY (Continued)	**THIRD LINE**
	Haloperidol (PO/GT, SC) • See *Delirium* **Chloral hydrate** • Consult provider with experience prescribing chloral hydrate to children.

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2. NEUROLOGICAL SYMPTOMS

Management Strategies	Medications & Suggested Initial Doses
SEIZURES	
Seizures at end-of-life can be very distressing, and aggressive management is most often appropriate. If refractory, refer to continuous palliative sedation therapy section.	**EPISODIC/BREAKTHROUGH MANAGEMENT:** 1. If not resolving spontaneously (3-5min), give benzodiazepine of choice. 2. If no response after 5min, repeat benzodiazepine. 3. If no response, levetiracetam, phenobarbital, or phenytoin (as available). **Lorazepam (SL/B, IV/SC)** • 0.1mg/kg *(Dose Max 4mg)* **Midazolam (IN, SL/B, IV/SC, IM):** • IN: 0.2mg/kg *(Dose Max: 10mg, 5mg per nostril)* • SL/B: 0.5mg/kg *(Dose Max: 10mg)* • IV/SC: 0.1-0.2 mg/kg/dose *(Dose Max: 10mg)* • IM: 0.3mg/kg *(Dose Max: 10mg)* **Diazepam (IV, PR):** • IV: 0.3mg/kg *(Dose Max: <5y: 5mg, >5y: 10mg)* • PR: 0.5 mg/kg *(Dose Max: 20mg)* **Levetiracetam (IV)** • Loading dose: 60 mg/kg *(Dose Max: 4.5g)* **Phenobarbital (IV/SC)** • Loading dose: 20mg/kg over 10-20min *(Dose Max: 1g)* **Phenytoin (IV):** • Loading dose: 20 mg/kg over 20-30min *(Dose Max: 1.5g)*
Chronic epilepsy is best managed in consultation with neurologists. In the last weeks to days of life, several medications may be used to prevent seizures during the dying process.	**MAINTENANCE MANAGEMENT** **Levetiracetam (PO/GT, IV/SC)** • 2.5-5mg/kg BID • Titration: Increase by 5-10mg/kg/day every 7 days PRN *(Daily Max: 60mg/kg or 3000mg, Higher doses may be possible but would warrant specialist consultation).* **Phenobarbital (PO/GT, IV/SC)** • <10y: 2-3mg/kg BID or 4-6mg/kg QHS (*Dose Max: 200mg)* • >10y: 1-2mg/kg BID or 2-4mg/kg QHS (*Dose Max: 200mg)* • Titration: Increase by 20-33% of total daily dose every 2 days as needed *(Daily Max: 200mg).* **Phenytoin (PO/GT, IV)** • 1mo to 6y: 3mg/kg Q8H or 4mg/kg Q12H • 7-15y: 2.3mg/kg Q8H or 3.5mg/kg Q12H • >16y: 1.3-2mg/kg Q8H or 2-3mg/kg Q12H **Clobazam (PO/GT)** • 0.25mg/kg QHS or 0.125mg/kg/dose BID *(Max initial dose: 10mg)* • Titration: Increase by 25-33% every 2-3days as needed *(Daily Max: 1mg/kg/d or 80mg).*

2. NEUROLOGICAL SYMPTOMS

Management Strategies	Medications & Suggested Initial Doses
Chronic Epilepsy (Continued)	**Valproic acid (PO/GT/PR)** • 15mg/kg once daily or divided BID • Titration: Increase by 5-10 mg/kg/day every 7 days as needed *(Daily Max: 60mg/kg/day).* **Midazolam (IV/SC)** • See *Continuous Palliative Sedation Therapy* for refractory seizures near end-of-life.
SLEEP	
Ensure detailed sleep history (e.g., initial insomnia vs. waking vs. early rising). Consider status while awake (comfortable vs. distressed). **Treat underlying causes of sleep disturbance:** commonly pain, dystonia, delirium, reflux, anxiety, depression, nausea, itch, seizures, etc. Review sleep hygiene practices (e.g., bright lights, fresh air, activity during day hours, consistent bedtime routine and timing; dark, quiet environment during night; no screen time before bed, consistent morning routine and timing). Consider non-pharmacological interventions (e.g., weighted blankets, massage, meditation, etc.). **Melatonin is the first line pharmacologic treatment for sleep disturbance when no other obvious stimulating etiology (e.g., pain) is present.** Other agents should be considered as second line and chosen based on clinical features of sleep disturbance and co-morbidities. Other pharmaceutical options may be appropriate for your patient depending on their specific circumstances.	**MELATONIN SUPPLEMENTATION** **Melatonin (PO/GT, SL)** • <2y: 1mg QHS • 2-9y: 1-3mg QHS • >10y: 3mg QHS • Titration: Increase by 1-3mg every 7 days as needed *(Dose Max: 10mg).* **HYPEREXCITABILITY (including. drug induced, e.g., steroids, ADHD, Autism Spectrum Disorder)** **Clonidine (PO/GT)** • 2**mcg/kg** QHS *(Max initial dose: 100**mcg**)* • Titration: Increase by 2**mcg/kg** every 3-4 days as needed *(Dose Max: 4**mcg/kg** QHS or 200**mcg**, higher doses may be possible but would warrant specialist consultation).* **Gabapentin (PO/GT)** • 5mg/kg QHS • Titration: Increase by 5mg/kg every 3-5 days as needed *(Dose Max for sleep: 15mg/kg QHS).* **Hydrocortisone** • Consider physiological dosing of hydrocortisone for steroid-induced insomnia. **ANXIETY AND DEPRESSION** • See *Anxiety* and *Depression* **SEDATION** (only if no underlying cause can be found and sleep is profoundly affecting quality of life) **Zopiclone (PO/GT)** • 2.5-7.5mg/dose QHS *(Dose Max: 7.5mg)* **Trazodone (PO/GT)** • >12y: 25-50mg QHS • Titration: Increase by 25mg every 24hrs as needed *(Dose Max: 150mg).*

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3. PSYCHIATRIC SYMPTOMS

Management Strategies	Medications & Suggested Initial Doses
ANXIETY	
Anxiety and fear are part of the human experience and expected for many children facing life-threatening/life-limiting conditions. Anxiety is our body's danger warning system and plays an important role in regulating behaviour to keep us safe and help us avoid harm and injury. However, anxiety can become detrimental in two ways. First, anxiety can become disproportional to the threat level (e.g., severe needle phobia). This can cause extreme distress for the patient and be detrimental to treatment plans. Second, the anxiety can be appropriate to the threat level, however, the threat cannot or should not be avoided (e.g., death-related anxiety, anxiety regarding impending amputation). Intervention for anxiety may be indicated when there is a significant change in a patient's baseline worries or anxiety that leads to significant interference in daily functioning or medical care. Early intervention of non-pharmacologic therapies and professional support is beneficial and may include therapies such as counselling, cognitive-behavioural therapy (CBT), meditation, guided imagery, hypnosis, yoga.	**MAINTENANCE MANAGEMENT** **FIRST LINE** **Sertraline (PO/GT) (if prognosis >1month)** • See *Depression* **Citalopram (if prognosis >1month)** • See *Depression* **Lorazepam (PO/GT, SL/B, IV/SC)** • 0.02-0.05mg/kg QHS-QID *(Max initial dose: 2mg)* • Titration: Increase by 0.02-0.05mg/kg per dose every 2-3 days as needed *(Daily Max: 8mg).* **Clonazepam (PO/GT)** • <30kg: 0.005-0.025mg/kg BID or 0.003-0.017mg/kg TID • Titration: Increase by 0.05mg/kg/day every 3 days as needed *(Daily Max: 0.2mg/kg).* • >30kg: 0.5mg PO TID • Titration: Increase by 0.5-1mg/day every 3 days as needed *(Daily Max: 12mg, higher doses may be possible but would warrant specialist consultation*). **SECOND LINE** **Olanzapine (PO/GT, SL)** • See *Delirium* **Quetiapine (PO/GT)** • See *Delirium* **Mirtazapine (PO/GT, SL)** • See *Depression* **THIRD LINE** **Trazodone (PO/GT)** • >12y: 12.4-25mg QHS • Titration: Increase dose (by 12.5-25mg/dose) and/or frequency to TID as needed and based on timing of symptoms *(Dose Max: 100mg, Daily Max: 200mg).* **Ketamine (PO/GT, IN, IV/SC)** • Consult provider with experience prescribing ketamine to children for psychiatric symptoms. **EPISODIC/BREAKTHROUGH MANAGEMENT (e.g., panic attacks, pre-procedural anxiety)** **FIRST LINE** **Lorazepam (PO/GT, SL/B, IV/SC)** • 0.02-0.05mg/kg, may repeat Q15min x3.

3. PSYCHIATRIC SYMPTOMS

Management Strategies	Medications & Suggested Initial Doses
EPISODIC/BREAKTHROUGH MANAGEMENT (Continued)	**SECOND LINE** **Olanzapine (PO/GT, SL)** • 4-9y: 1.25-2.5mg Q2H PRN, may repeat Q1H x3 • >10y: 2.5-5mg Q2H PRN, may repeat Q1H x3 **THIRD LINE** **Trazodone (PO/GT)** • >12y: 12.5-25mg, may repeat Q1H x3

DEPRESSION

Sadness and grief are a normal part of a child's palliative care journey. Depression occurs when a patient's sadness and grief become overwhelming and begin to consume their capacity to experience joy. Depressive symptoms are more common in children when diagnosis and health status are not disclosed. Five or more of the following symptoms are present for a contiguous 2-week period: 1. Depressed Mood* 2. Anhedonia* 3. Sleep disturbance 4. Weight change 5. Loss of energy/fatigue 6. Psychomotor retardation 7. Worthlessness, hopelessness, guilt 8. Inability to concentrate, indecisiveness 9. Suicidality or recurrent thoughts of death** ***Must include one of these 2 features.** ****Recurrent thoughts of death may be very normal for a patient facing their own mortality.** Non-pharmacologic interventions may include: open communication, non-judgmental and safe space for processing fears, worries, anger, and reactions to loss; opportunities for 'normal' childhood activities; discussions to support informed choices about therapeutic options; emotional and pragmatic support for the patient and family; cognitive behavioural therapy (CBT), mindfulness; meditation; interpersonal psychotherapy; group therapy; family therapy; relaxation skills training; journaling, acceptance and commitment therapy.	**FIRST LINE** **Sertraline (PO/GT) (if prognosis >1month)** • 6-12y: 12.5-25mg daily • >13y: 25-50mg daily • Titration: Increase by 12.5-50mg every 7 days as needed *(Daily Max: 200mg/day).* **Citalopram (if prognosis >1month)** • Initiation: ▪ 7-11y: 2.5-10mg daily, then increase by 2.5-5mg every 7-14 days to target 10-20mg/day ▪ >12y: 10mg daily, then increase by 5-10mg every 7-14 days to target 20-40mg/day **Methylphenidate (PO/GT)** • 2.5-5mg (immediate release) QAM +/- 2.5-5mg 4hrs later. • Titration: Increase by 2.5-5mg per dose every 24h as needed. *(Daily Max: 60mg).* ○ *Note: Once the appropriate dose is identified, can convert to long-acting formulation.* **SECOND LINE** **Dextroamphetamine/Mixed Amphetamine Salts (PO/GT)** • 2.5mg QAM, followed by 2.5mg 4hrs later • Titration: Increase by 2.5-5mg per dose every 24h as needed (Daily Max: 40mg). **Mirtazapine (PO/GT, SL)** • <12y: 3.75mg QHS • >12y: 7.5mg QHS • Titration: Increase by 7.5 - 15mg weekly as needed *(Dose Max: <12y: 22.75mg, >12y: 45mg).* ○ *Note: Mirtazapine is activating at higher doses, if prescribed solely for sleep, consider a lower dosing range.* **THIRD LINE** **Ketamine (PO/GT, IN, IV/SC)** • Consult provider with experience prescribing ketamine to children for psychiatric symptoms.

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3. PSYCHIATRIC SYMPTOMS

Management Strategies	Medications & Suggested Initial Doses
DELIRIUM	
Consider looking for reversible cause (e.g., low sodium, high calcium, steroids, chemotherapy, opioids, benzodiazepines, etc., though at end-of-life at times those medications cannot be reduced). • Attempt to help orient the child. • Comforting social interactions may be helpful with familiar visitors. • Minimize noise and avoid unnecessary stimulation. • Be calm and reassuring at the bedside. • Remind child gently where they are and what time of day it is. • Provide familiar things such as a favourite blanket, stuffed animal, family pictures, or comforting music. • Do not argue with a confused child. • Distract child with happy thoughts or images. • Provide glasses if needed. • Help keep child safe during agitation. • Encourage being awake during the day and getting out of bed if medically allowed. • Encourage longer stretches of sleep at night. • Explain to child later if they have questions or remain upset about confusion or hallucinations. If patient is in hospital or has regular nursing care at home, it is helpful for healthcare providers to use the Pediatric Confusion Assessment Method for the ICU (pCAM-ICU) or the Preschool Confusion Assessment Method for the ICU (psCAM-ICU) and fill this out every shift to monitor delirium symptoms.	**FIRST LINE** **Haloperidol (PO/GT, SC)** • 2mo-3y: 0.01-0.02mg/kg Q6-8H *(Initial Dose Max: 0.5mg)* • 3-12y: 0.025-0.05mg/kg Q6-8H *(Initial Dose Max: 1.5mg)* • >12y: 0.5-1.5mg Q6-8H • Titration: Increase by 33-50% daily as needed *(Daily Max: 2mo-3y: 0.15mg/kg, 3-12y: 10mg, >12y: 30mg).* **Quetiapine (PO/GT)** • <7kg: 0.5mg/kg/day • 7-19kg: 6.25-12.5mg QHS to BID • 20-39kg: 18.75 QHS to BID • 40-59kg: 25mg QHS to BID • >60kg: 25-50mg QHS to BID • Titration: Increase by 50% daily as needed *(Daily Max: >7kg: 6mg/kg, 7-19kg: 200mg, 20-59kg: 300mg, >60kg: 600mg).* **Olanzapine (PO/GT, SL)** • <30kg: 1.25mg QHS to BID • 30-60kg: 2.5mg QHS to BID • >60kg: 5mg QHS to BID • Titration: Increase by 50-100% every 7 days as needed *(Daily Max: <30kg: 5mg, 30-60kg: 10mg, >60kg: 20mg).* **SECOND LINE** **Risperidone (PO/GT)** • <10kg: 0.05-0.1mg QHS to BID • 10-20kg: 0.125-0.25mg QHS to BID • 20-60kg: 0.25-0.5mg QHS to BID • >60kg: 0.5-1mg QHS to BID • Titration: Increase by 50% daily as needed *(Daily Max: <10kg: 0.1mg/kg, 10-20kg: 2mg, 20-60kg: 3mg, >60kg: 4mg).* **Aripiprazole (PO/GT)** (consider in children with autism) • <2y: 0.5mg daily • 2-6y: 1-2mg daily • >6y: 2-5mg daily • Titration: Increase by 50-100% every 2 days (initially) then every 14 days *(Daily Max: <2y: 1mg, 2-6y: 5mg, >6y: 15mg).*

3. PSYCHIATRIC SYMPTOMS

Management Strategies	Medications & Suggested Initial Doses

DELIRIUM (Continued)	**THIRD LINE**
	• **Dexmedetomidine (IV/SC infusion)**
	  ○ Consult provider with experience prescribing dexmedetomidine to children.
	• **Methotrimeprazine/Levomepromazine (PO/GT, IV/SC)**
	  ○ Consult provider with experience prescribing methotrimeprazine to children.

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4. RESPIRATORY SYMPTOMS

Management Strategies	Medications & Suggested Initial Doses
SECRETIONS	

If child is unable to clear own secretions, reposition on side for postural drainage. Give frequent mouth care.
 	
Consider side effects: thickened, difficult to clear secretions, dry mouth, and drowsiness.
 	
Suctioning can cause irritation and increased secretions and should be avoided if possible.
 	
Most effective treatment, with fewest side effects, is to reduce total fluid intake (via enteral tube or IV). Titrate to comfort.
 	
Anticholinergics, which may be considered, reduce production of saliva and are of minimal benefit when secretions are pulmonary in origin.
	FIRST LINE
	1% ophthalmic Atropine (SL/B)
	• *Note: Can be diluted to 0.25% or 0.5%*
	• 1-4 drops Q2H to Q4H PRN
	SECOND LINE
	Scopolamine (Transdermal, IV/SC)
	• Transdermal:
	  ▪ <2y: ¼ patch Q3days
	  ▪ 2-5y: ½ patch Q3days
	  ▪ 6-11y: ½ to 1 patch Q3days
	  ▪ >12y: 1 patch Q3days
	  ▪ Titration: Increase by initial dose every 3 days to reach desired effect
	  ○ Application: Remove only the portion of the backing required for the dose OR place Tegaderm dressing on the child's skin under the unwanted portion of the patch.
	  ○ *Note: The patch takes 24 hours to reach steady state. Do not use in an acute setting.*
	• IV/SC:
	  ▪ <50kg: 6**mcg/kg** Q6H PRN
	  ▪ >50kg: 0.3mg Q6H PRN
	Glycopyrrolate (PO/GT, IV/SC)
	• PO: 40-100 **mcg/kg/dose** TID-QID *(Dose Max: 3000**mcg**)*
	• IV/SC: 4-10 **mcg/kg/dose** Q3-4H *(Dose Max: 200**mcg**)*
	Salivary Botox
	• Consult Ear, Nose and Throat (ENT)/Interventional Radiology.

4. RESPIRATORY SYMPTOMS

Management Strategies	Medications & Suggested Initial Doses
SECRETIONS (Continued)	**THIRD LINE**
	Ipratropium bromide (INH) • MDI: ▪ <6 years: 1 puff (20**mcg**) Q4H PRN ▪ >6 years: 1-2 puffs (20-4**0mcg**) Q4H PRN • Nebulized: ▪ <6 years: 125 to 250**mcg** Q4H PRN ▪ >6 years: 250 to 500**mcg** Q4H PRN **Ductal Ligation** • Consult Ear, Nose and Throat (ENT)

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Management Strategies	Medications & Suggested Initial Doses
DYSPNEA (Episodic)	
Try deep breathing and distraction. A fan blowing on the face and/or an open window may be effective for decreasing the sensation of breathlessness. Using oxygen to bring Oxygen Saturation (SpO2) up to 98-100% is not necessary to treat dyspnea. However, if oxygen is felt to be beneficial by the patient (whether psychologically or due to the flow of air) it may be utilized as a part of a dyspnea management plan. PRN doses may be provided pre-exertion to prevent exertion-related dyspnea. Opioids are used for the relief of dyspnea. Benzodiazepines may treat dyspnea primarily but may also improve anxiety related to the dyspnea (cause or effect).	**EPISODIC MANAGEMENT, SLOW ONSET (mild to moderate symptoms)** **FIRST LINE** **Morphine (PO/GT)** • 0.1-0.2mg/kg q2h PRN *(Typical initial adult dose: 2.5-5mg)* • Titration: Increase by 33-50% if insufficient dose response. **SECOND LINE** **Hydromorphone (PO/GT)** ▪ 0.02-0.04mg/kg q2h PRN *(Typical initial adult dose: 0.5-1mg)* • Titration: Increase by 33-50% if insufficient dose response. **Lorazepam (PO/GT, SL/B)** • 0.03-0.05mg/kg q4h PRN *(Typical initial adult dose: 0.5-1mg)* • Titration: Increase by 33-50% if insufficient dose response *(Dose Max: 2mg).* **EPISODIC MANAGEMENT, RAPID ONSET (moderate to severe symptoms)** **FIRST LINE** **Morphine (IV/SC, SL/B)** ▪ 0.05-0.1mg/kg q1h PRN *(Typical initial adult dose: 1-2mg)* • Titration: Increase by 33-50% if insufficient dose response.

4. RESPIRATORY SYMPTOMS

Management Strategies	Medications & Suggested Initial Doses
DYSPNEA (Episodic) (Continued)	**SECOND LINE** **Hydromorphone (IV/SC, SL/B)** ▪ 0.01-0.02mg/kg q1h PRN *(Typical initial adult dose: 0.2-0.4mg)* • Titration: Increase by 33-50% if insufficient dose response. **THIRD LINE** **Fentanyl (IV/SC, SL/B, IN)** ▪ 0.125-0.25**mcg/kg** q30min PRN *(Typical initial adult dose: 12.5**mcg**)* • Titration: Increase by 33-50% if insufficient dose response. **Midazolam (IV/SC, SL/B, IN)** • IV/SC: 0.05mg/kg q30min PRN (Typical initial adult dose: 2.5mg) • IN: 0.1mg/kg q30min PRN *(Typical initial adult dose: 2.5mg)* • Titration: Increase by 33-50% if insufficient dose response.

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Management Strategies	Medications & Suggested Initial Doses
DYSPNEA (Persistent)	
Try deep breathing and distraction. A fan blowing on the face and/or an open window may be effective for decreasing the sensation of breathlessness. Using oxygen to bring Oxygen Saturation (SpO2) up to 98-100% is not necessary to treat dyspnea. However, if oxygen is felt to be beneficial by the patient (whether psychologically or due to the flow of air) it may be utilized as a part of a dyspnea management plan. PRN doses may be provided pre-exertion to prevent exertion-related dyspnea. Opioids are used for the relief of dyspnea. Benzodiazepines may treat dyspnea primarily but may also improve anxiety related to the dyspnea (cause or effect).	**MAINTENANCE MANAGEMENT (for persistent symptoms)** **FIRST LINE** **Morphine (PO/GT, IV/SC, SL/B)** • PO/GT: 0.1-0.2mg/kg Q4H *(Typical initial adult dose: 2.5-5mg)* ○ Breakthrough: 10% of the total daily dose Q2H PRN • IV/SC, SL/B: 0.05-0.1mg/kg Q4H *(Typical initial adult dose: 1-2mg)* ○ Breakthrough: 10% of the total daily dose Q1H PRN • Continuous IV/SC infusion: 5-10**mcg/kg/h** ○ Breakthrough: 10% of the total daily dose Q1H PRN • Titration: Increase based on breakthrough use and total daily dose. **SECOND LINE** **Hydromorphone (PO/GT, IV/SC, SL/B)** • PO/GT: 0.02-0.04/kg Q4H *(Typical initial adult dose: 0.5-1mg)* ○ Breakthrough: 10% of the total daily dose Q2H PRN • IV/SC, SL/B: 0.01-0.02mg/kg Q4H *(Typical initial adult dose 0.2-0.4mg)* ○ Breakthrough: 10% of the total daily dose Q1H PRN • Continuous IV/SC infusion: 1-2**mcg/kg/h** ○ Breakthrough: 10% of the total daily dose Q1H PRN • Titration: Increase based on breakthrough use and total daily dose.

4. RESPIRATORY SYMPTOMS

Management Strategies	Medications & Suggested Initial Doses
DYSPNEA (Persistent) (Continued)	**THIRD LINE** **Fentanyl (IV/SC, transdermal)** • Fentanyl dosing should be derived from current opioid dosing. If not currently on opioids and a fentanyl infusion is indicated (e.g., severe consistent dyspnea with allergy, renal failure), suggest consultation with provider experienced in prescribing continuous fentanyl to children. **Midazolam (IV/SC infusion)** • 0.25**mcg/kg/min** *(Max initial dose: 1.5mg/h)* ○ Breakthrough: 10% of the total daily dose Q1H PRN • Titration: Increase based on breakthrough use and total daily dose.

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5. GASTROINTESTINAL (GI) SYMPTOMS

Management Strategies	Medications & Suggested Initial Doses
ACID REFLUX & REGURGITATION	
Reflux/regurgitation is common in children with neurologic impairment secondary to dysmotility and a driver of aspiration and progressive respiratory disease. Feeding regimes should be re-assessed. Smaller volumes more frequently are better tolerated. Medications and constipation may be contributors to slow motility and resulting reflux/regurgitation. Can confirm acid suppression with gastric residual pH tests in tube-fed children, best performed on empty stomach prior to antacid administration. Target pH >4.	**ACID REFLUX/GASTRITIS/ESOPHAGITIS** **Omeprazole (PO/GT)** • 1m-2y: 1-3mg/kg once daily or divided BID • >2y: 0.7-2.5mg/kg once daily or divided BID *(Typical adult dose: 40mg/day)* • Titration: Increase by 1mg/kg/day *(Daily max: 3.5mg/kg/day or 80mg/day).* **Lansoprazole (PO/GT, SL/B)** • <10kg: 7.5mg once daily • 10-29kg: 15mg once daily • >30kg: 30mg once daily • Titration: Increase by 7.5mg/day *(Daily Max: 1.6mg/kg or 30mg/day).* **Pantoprazole (IV)** • 1-1.5mg/kg once daily or divided BID *(Typical adult dose: 40mg/day)* • Titration: Increase by 0.5mg/kg/day *(Daily Max: 80mg)* **Famotidine (PO/GT, IV/SC)** • IV/SC: ▪ <3mo: 0.25mg/kg/dose IV Q24H ▪ >3mo: 0.25-0.5mg/kg/dose IV Q12H *(Daily Max: 40mg)* • PO/GT: ▪ <3mo: 0.5-1mg/kg/dose Q24H ▪ >3mo: 0.5-1mg/kg/dose Q12H *(Typical adult dose: 40mg Q12H)* **REGURGITATION** **Domperidone (PO/GT)** • 1.2-2.4mg/kg/day divided TID or QID *(Daily Max: 30mg/day)* **Cisapride (PO/GT)** • Consult provider with experience prescribing cisapride to children. **Consider post-pyloric feeds**

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5. GASTROINTESTINAL (GI) SYMPTOMS

Management Strategies	Medications & Suggested Initial Doses
NAUSEA & VOMITING	
Determination of etiology should guide treatment and medication modalities. Control smells and noise in the home, good oral hygiene, monitor for constipation. Visualization, distraction, and relaxation have also proved effective. Rapid weight loss may lead to Superior Mesenteric Artery (SMA)-syndrome and partial obstruction. Consider whether feeding is still providing net benefit to the child. Is feeding intolerance a symptom of the dying process?	**BROAD SPECTRUM** **Ondansetron (PO/GT, SL/B, IV/SC)** • 0.1-0.15mg/kg/dose Q8H PRN *(Typical adult dose: 4-8mg; Daily Max: 24mg)* **Dimenhydrinate (PO/GT, IV)** • 1-1.25mg/kg/dose Q6H PRN *(Typical adult dose: 25-50mg)* **Haloperidol (PO/GT, SC)** • 0.01-0.02mg/kg Q8H *(Initial Dose Max: 1mg)* **Olanzapine (PO/NG, SL/B)** • 10-19kg: 1.25mg daily to BID • 20-29kg: 2.5mg daily to BID • 30-39kg: 3.75mg daily to BID • >40kg: 5mg daily to BID **Nabilone (PO/GT)** • <6y: Consult provider experienced in prescribing cannabinoids to children. • >6y: 0.5-2mg BID • Titration: Increase dose (by 0.25-0.5mg/dose) and/or frequency (up to QID) every 2-3 days as needed. **CHEMOTHERAPY** • See *POGO guidelines* **VESTIBULAR** **Dimenhydrinate (PO/GT, IV)** • See Nausea & Vomiting *Broad Spectrum*. **Scopolamine (transdermal, IC/SC)** • See *Secretions* **INCREASED INTRACRANIAL PRESSURE** **Dexamethasone (PO/GT, IV)** • Initial: 0.2-0.4mg/kg *(Dose Max: 10mg)* • Maintenance: 0.075mg/kg Q6H *(Dose Max: 4mg)* ○ *If needed for >48hrs, consult provider experienced in prescribing dexamethasone for increased intracranial pressure to children.* **Acetazolamide (PO/GT, IV)** • Initial dose: 5-10mg/kg Q12H *(Typical initial adult dose: 500mg BID)* • Titration: Every 2-4 days, increase by 25-50% total daily dose, divided BID-QID, as needed *(Daily max: 4000mg).*

5. GASTROINTESTINAL (GI) SYMPTOMS

Management Strategies	Medications & Suggested Initial Doses
NAUSEA AND VOMITTING (Continued)	**ANXIETY**
	• See *Anxiety*
	ACID REFLUX
	• See *Acid Reflux*
	DYSMOTILITY/GASTROPARESIS/ILEUS
	• See *Regurgitation* • ***Note:*** While metoclopramide is commonly used in many settings, domperidone is used in pediatrics for its decreased CNS side effect profile.

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Management Strategies	Medications & Suggested Initial Doses
CONSTIPATION	

Manage proactively when administering opioids.
 	
Many children will not disclose that they are constipated so must be asked specifically about bowel habits.
 	
Note: Prolonged use of stimulant laxatives can cause dependence. However, children with dysmotility (often related to neurologic impairment) who have recurrent constipation despite achieving soft (or even liquid stools) with osmotic laxatives may require routine administration of stimulant laxatives to compensate for bowel dysmotility.
	OSMOTIC LAXATIVES (stool softeners)
	Polyethylene glycol 3350 (PO/GT)
	• 0.5-1g/kg daily or divided BID *(Daily Max: 34g)*
	  ○ *Note: Titrate dose to optimal effect (soft, formed stool q24-48h); May increase to 100g for clean out if >34kg and failing to respond*
	Lactulose (PO/GT)
	• 5-10mL daily *(Max: 30mL/day)*
	Magnesium (PO/GT)
	• *Comes in a variety of formulations. If uncomfortable, seek experienced provider.*
	STIMULANT LAXATIVES
	Senna (PO/GT)
	• 2-5years: 5.1- 8.6mg (3-5mL) QHS PRN
	• 6-11y: 8.6-17.2mg (5-10mL) QHS PRN
	• >12y: 8.6-34.4mg QHS PRN
	• Titration: Increase to twice daily as needed
	  ○ *Note: May be used routinely in dysmotility with recurrent failure of osmotic monotherapy.*
	Bisacodyl (PO/GT)
	• 16-30kg: 5mg
	• 30-50kg: 10mg
	• >50kg: 10-15mg
	  ○ *Note: Do not crush or chew tablets; must swallow whole.*
	Consider consultation with GI (Prucalopride, Cisapride)

5. GASTROINTESTINAL (GI) SYMPTOMS

Management Strategies	Medications & Suggested Initial Doses
CONSTIPATION (Continued)	**LOCAL (RECTAL) THERAPIES**
	Glycerin Suppository (PR) **Fleet enema (PR)** **Bisacodyl (PR):** • 2-5y: 5mg Q12H PRN • >6y: 10mg Q12H PRN
	OPIOID INDUCED CONSTIPATION:
	Methylnaltrexone (SC) • 150 **mcg/kg** Q2days PRN *(Dose Max: 18mg)* **Naloxegol (PO/GT)** • 0.5 mg/kg/dose enteral Q2days PRN *(Dose Max: 25mg)*
BOWEL OBSTRUCTION	
Signs of bowel obstruction include bloating, abdominal pain, bilious vomiting, bilious aspirates in g-tube, or post-pyloric feeds found in stomach (via g-tube) or mouth (spit up or vomit).	**OBSTRUCTION**
	• Discontinue all feeds. • Discontinue all prokinetics/stimulant laxatives. • Review each enteral medication. Hold those than can be held. Some critical medications with proximal gastrointestinal (GI) absorption might be continued. Consider consultation with pharmacy, surgery, and/or pediatric palliative care specialist. • Ensure acid suppression (See *Acid Reflux*).
	For symptomatic relief, consider:
	Octreotide (IV/SC) • 1-2**mcg/kg**, then 1-2**mcg/kg/h** infusion • Titration: increase by 1**mcg/kg/h** (Max rate: 4**mcg/kg/h**) **Scopolamine (transdermal, IV/SC)** • *See Secretions* **Hyoscine butylbromide (IV)** • 1mo-5y: 0.3mg/kg/dose q6h PRN • 6-11y: 5-10mg IV q6h PRN • >12y: 10-20mg IV q6H PRN **Dexamethasone (IV)** • 1-2mg/kg x1, then 1-1.5mg/kg/d divided Q6-Q12H *(Daily Max: 16mg)*

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5. GASTROINTESTINAL (GI) SYMPTOMS

Management Strategies	Medications & Suggested Initial Doses
DIARRHEA	
Consider: infection, malabsorption, diet, medications, and treatment. Decrease laxatives and titrate as needed. Maintain hydration.	Consider pharmacologic treatment with caution. May wish to consult GI or infectious disease specialist. **EPISODIC MANAGEMENT (near end-of-life):** **Loperamide (PO/GT)** • 2-5y: 1mg with loose stools PRN *(Daily Max: 3mg)* • 6-8y: 2mg with first loose stool, then 1mg PRN *(Daily Max: 4mg)* • 9-11y: 2mg with first loose stool, then 1mg PRN *(Daily Max: 6mg)* • >12y: 4mg with first loose stool, then 2mg PRN *(Daily Max: 8mg)*

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6. MISCELLANEOUS SYMPTOMS

Management Strategies	Medications & Suggested Initial Doses
PRURITUS	
Consider allergy and review medications. Pruritus can be a side effect of opioids due to histamine-releasing properties, which usually resolves within a few days of treatment initiation or increased dosage. Some opioids result in less pruritus than others; itch may respond to opioid rotation (hydromorphone, fentanyl).	**HISTAMINE MEDIATED** **Cetirizine (PO/GT)** • 6m-1y: 2.5mg daily • 2-5y: 2.5-5mg daily • >6y: 5-10mg daily *(Daily Max:* 20mg/day) **Diphenhydramine (PO/GT, IV)** • 1-1.25mg/kg Q6H PRN *(Typical adult dose: 25-50mg Q6H PRN)* **Hydroxyzine (PO/GT)** • 0.5mg/kg Q6H PRN *(Typical adult dose: 25mg Q6H PRN)* **Consider topical or systemic steroids** **OPIOID-INDUCED** **Naloxone (IV infusion)** • Initial: >3y: 2**mcg/kg/h** • Titration: Every few hours, increase by 0.5**mcg/kg/h**

6. MISCELLANEOUS SYMPTOMS

Management Strategies	Medications & Suggested Initial Doses
PRURITUS (Continued)	**NON-HISTAMINE MEDIATED (e.g., neurogenic, renal failure)**
	Gabapentin (PO/GT) or Pregabalin (PO/GT) or Amitriptyline (PO/GT) • See *Neuropathic Pain* **Ondansetron (PO/GT, IV/SC, SL) or Aprepitant (PO/GT)** • See *Nausea and Vomiting* **Mirtazapine (PO/GT)** • See *Anxiety*
	LIVER FAILURE (in addition to above)
	Cholestyramine • <10y: 240mg/kg/d divided into 2 or 3 doses. Give 1-2 doses in AM, and another dose at lunch PRN *(Daily Max: 4g/day)* • >10y: Initial: 4g/d, divided into 2 or 3 doses. Given 1-2 doses in AM, and another dose at lunch PRN (Daily Max: 16g/day) ○ *Higher doses may be possible but would warrant specialist consultation.* **Rifampin (PO/GT)** • 5mg/kg BID • Titration: Increase by 33-50% ever 2-4 weeks *(Daily Max: 20mg/kg/day or 600mg/day)*
URINARY RETENTION	
Look for reversible causes. Providing a warm bath and encouraging the child to pass urine in the water is often effective for opioid induced retention. Consider opioid rotation. Catheterization may be necessary to relieve discomfort. It is recommended with the use of drugs at the end-of-life that may cause urinary retention to have catheterization supplies in the event the child is unable to void, and cause is not reversible.	**NON-OBSTRUCTIVE**
	Bethanechol (PO/GT) • 0.05mg/kg *(Typical initial adult dose: 5-10mg).* Repeat hourly until desired effect *(Max total: 50mg)* • Maintenance: Use effective dose *(Dose Max: 50mg)* TID-QID *(Daily Max: 200mg)* **Nalbuphine (IV/IM/SC)** • 0.05-0.1 mg/kg Q6H PRN *(Dose Max: 20 mg)*
	OBSTRUCTIVE
	Catheterization +/- discussion with urology

***** Medication dosing strategies were based primarily on The Hospital for Sick Children (SickKids) Paediatric & Neonatal Formulary Database on Lexicomp. Any modifications to drug dosing strategies were based on expert opinion and consensus specifically in the context of End-of-Life. In the event of difficulties managing particular patients, or concerns about recommendations herein, we strongly suggest consultation with the referring physician or specialized pediatric palliative care team.

6. MISCELLANEOUS SYMPTOMS

Management Strategies	Medications & Suggested Initial Doses
BLEEDING	
Have dark towels on hand. If bleeding does not respond to medication/transfusion, and/or is excessive, consider continuous palliative sedation therapy to decrease associated anxiety.	**ANY SITES**
	Tranexamic acid (PO/GT) • PO/GT: 10-25 mg/kg Q8H PRN *(Dose Max: 1.5g)* • IV: 10mg/kg Q6H PRN *(Dose Max: 1g)* • Note: May be used routinely as prophylaxis for known high risk of bleeding.
	MUCOSAL/EXTERNAL
	Tranexamic acid (topical or mouthwash) • Soak gauze in 100mg/mL inj. solution and apply directly to bleeding area as needed. • Dissolve 500mg tablet in 5-10 mL of water, rinse mouth for 2min and spit out, repeat PRN. **Epinephrine (topical)** • Soak gauze in 1mg/mL (1:1000) inj. solution and apply directly to bleeding area. **Fibrin Glue (topical)** • Apply to area.
	GI BLEEDING
	Consider conservative management near end-of-life for lower GI bleeding. **Pantoprazole (IV)** • 5-15kg: 2mg/kg x1, then 0.2mg/kg/h infusion • 16-40kg: 1.8mg/kg x1, then 0.18mg/kg/h infusion • >40kg: 80mg x1, then 8mg/h infusion **Octreotide (IV)**
	Other considerations (Hospital/Clinic use only)
	Correction of laboratory abnormalities with transfusions: **Platelets:** • 10mL/kg IV if bleeding and Platelets <50 **Vitamin K:** • 2-5mg/dose PO/IV **Fresh Frozen Plasma (FFP):** • 10mL/kg IV **Cryoprecipitate**: • Consultation with hematology recommended.

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7. CONTINUOUS PALLIATIVE SEDATION THERAPY

Management Strategies	Medications & Suggested Initial Doses
CONTINUOUS PALLIATIVE SEDATION THERAPY	
Use for management of refractory symptoms at the very end-of-life, in accordance with local policy and guidelines for Continuous Palliative Sedation Therapy (CPST). Prognosis for expected survival should be less than 2 weeks and symptoms deemed refractory to usual management, as determined in consultation with a Palliative Medicine physician. When provided in accordance with specific guidelines, palliative sedation does not hasten death. The objective is to treat the refractory symptom to achieve comfort until natural death occurs from progression of the underlying illness. Suggest choosing the sedative agent that targets the most problematic/refractory underlying symptom. Sedation should be titrated to the level needed to achieve comfort. Deep sedation is not always necessary to achieve comfort. Palliative sedation can happen in conjunction with (but is not always necessary with) withdrawal of artificial nutrition and hydration.	**FIRST LINE** **Midazolam (IV/SC)** (general use, seizures, neuro-irritability) • Induction: ▪ <25kg: 0.1mg/kg ▪ 25-50kg: 2.5-5mg ▪ >50kg: 5mg ▪ Repeat q5min until sedate • Continuous IV/SC infusion rate: 0.5-2**mcg/kg/min** (or 0.03-0.12**mg/kg/h**) ○ *Note: If patient required +++ loading, consider 25-33% of cumulative loading dose as hourly infusion rate* • Breakthrough dose: Give 1hourly rate as a bolus dose Q10min PRN (e.g., 2mg/hr infusion with 2mg PRN) • Titration: Increase based on breakthrough use and total daily dose. **Methotrimeprazine/Levomepromazine (IV/SC)** (delirium, nausea/vomiting, tolerant to benzodiazepines) • Induction: ▪ <25kg: 0.1-0.3mg/kg q8h ▪ 25-50kg: 6.25-12.5mg q8h ▪ >50kg: 12.5-25mg q8h ▪ Repeat Q1H until sedate • Breakthrough dose: As above Q1H PRN • Titration: Increase based on breakthrough use and total daily dose. **Ketamine (IV/SC)** (pain) • Induction: 0.5mg/kg IV over 5-10min, repeat q10min until sedate • Continuous IV/SC infusion: 5-10**mcg/kg/min** • Breakthrough dose: Give 1 hourly rate as a bolus dose Q15min PRN (e.g., 2mg/h infusion with 2mg PRN) • Titration: Increase based on breakthrough use and total daily dose **SECOND LINE** **Consider alternative First Line agent** **Phenobarbital (IV/SC)** (seizures, neuro-irritability) • Induction: 20 mg/kg over 10-20 minutes • Continuous IV infusion: 1mg/kg/h • Breakthrough dose: 1mg/kg Q1H PRN • Titration: Increase based on breakthrough use and total daily dose. **Dexmedetomidine (IV/SC)** (pain, delirium, neuro-irritability, autonomic storms) • Consult provider with experience prescribing dexmedetomidine to children.

7. CONTINUOUS PALLIATIVE SEDATION THERAPY

Management Strategies	Medications & Suggested Initial Doses
CONTINUOUS PALLIATIVE SEDATION THERAPY (Continued)	**THIRD LINE**
	Propofol (IV) • Consult provider with experience administering propofol to children

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Appendix A: Abbreviations

Abbreviation	Definition
BID or b.i.d.	Twice a day
GI	Gastrointestinal
IM	Intramuscular(ly)
IN	Intranasal(ly)
INJ	Injection
IV	Intravenous(ly)
IV/SC	Intravenous(ly) or Subcutaneous(ly)
mcg	Micrograms
mcg/kg	Micrograms per kilogram
mcg/kg/h	Micrograms per kilogram per hour
mg	Milligrams
mg/kg	Milligrams per kilogram
mg/kg/d	Milligrams per kilogram per day
mg/kg/h	Milligrams per kilogram per hour
mg/kg/week	Milligrams per kilogram per week
NSAID or NSAIDs	Nonsteroidal anti-inflammatory drug(s)
PO	By mouth or orally
PO/GT	By mouth or Gastrointestinal Tube (G-Tube)

Abbreviation	Definition
PO/NG	By mouth or Nasogastric
PR	Per rectum
PRN	As often as necessary, as needed
Q	Every
QAM	Once a day in the morning
QHS	Once a day at bedtime or Before bed
QMidday	Once a day, midday
Q30min	Every 30 Minutes
Q1H	Every One Hour
Q2H	Every Two Hours
Q4H	Every Four Hours
Q6H	Every Six Hours
Q8H	Every Eight Hours
Q12H	Every Twelve Hours
SC	Subcutaneous(ly)
SL/B	Under the tongue or in the cheek
TID	Three times a day

Appendix B: Methods, Working Group Members, External Reviewer, and Steering Committee Members

Methods

End-of-Life Symptom Management Working Group Constituents

An interdisciplinary Working Group of healthcare providers with expertise in pediatric palliative care was assembled. The working group included a specialized pediatric palliative care nurse practitioner, pediatric palliative care physicians, pediatricians, and a pediatric pharmacist. Working group selection was based on expertise and experience in management of pediatric palliative end-of-life care in children. The group was assembled by the Pediatric Oncology Group of Ontario (POGO) and the Provincial Council for Maternal and Child Health (PCMCH) to advise the Ontario Provincial Pediatric Palliative Care Steering Committee on updating the end-of-life formulary and symptom management guide to facilitate delivery of pediatric end-of-life care to children by community care providers in their homes and local community hospitals.

General Approach to Expert Opinion Guidance Development

Key working group responsibilities included: identifying opportunities to streamline pediatric palliative care end-of-life expert opinion guidance documents; reformatting content to improve clarity and support knowledge transfer; drafting appropriate disclaimers for community-based providers on how or where to seek advice of specialized pediatric palliative care providers; and, providing recommendations to the Provincial Pediatric Palliative Care Steering Committee on how to maintain and disseminate the expert opinion guidance documents. From June 2020 to June 2022, the working group had several meetings, which included seven healthcare providers with expertise and experience in pediatric palliative care from across Ontario. There were several communications and reviews done via email.

The process for the update included several steps. The update was triggered by the date of version 1, to ensure currency of recommended interventions and guidance in both documents: (1) information and (2) formulary document. A multidisciplinary working group of pediatric palliative care experts was created. Working group members reviewed version 1 of the documents. Members were assigned specific sections and responsibility for reviewing and updating assigned sections based on current clinical practice and expert opinion and consensus.

The completed updated sections of both documents were compiled, and the working group reviewed all content in its entirety. Draft working group revisions were reviewed by the Co-Chairs of the Ontario Provincial Pediatric Palliative Care Steering Committee and their feedback was integrated into the update. The draft then went to the Ontario Pediatric Palliative Care Steering Committee for review, feedback, and approval and the updated version of the document was finalized in August 2023. The working group members were provided with an opportunity to provide final comments in August 2023 prior to finalizing both documents in September 2023.

Expert and external reviewers were actively engaged in the review and updates to the formulary document, in addition to assigning reviews of specific sections of the formulary guide to working group members. All medication regimens and dosing recommendations were reviewed based on expert opinion and input from Ontario practicing pediatric palliative care subspecialty providers and by experts consulted in the review of the formulary document – e.g., to review symptom management recommendations, including medications, drug dosing guidance, recommended guidance on when to consult subspecialty pediatric palliative care experts/care teams. Recommendations from additional external clinical expert reviewers were discussed at working group meetings and/or shared via email. The disclaimers for when and how to consult pediatric palliative care experts/services for particular children were reviewed by the Co-Chairs of the Ontario Provincial Pediatric Palliative Care Steering Committee and final revisions to the symptom management guide were distributed to working group members in August 2023 prior to finalizing updates to both the (1) information and (2) symptom management guide in September 2023.

End-of-Life Symptom Management Working Group Members

- **Dr. Dave Lysecki, MD, FRCPC (Chair),** Medical Director and Pediatric Palliative Care Physician, Quality of Life & Advanced Care (QoLA Care), McMaster Children's Hospital, Hamilton Health Sciences; Medical Director, Keaton's House Children's Hospice, Kemp Care Network; Associate Professor and Division Head, Division of Palliative Medicine, Department of Pediatrics, McMaster University
- **Dr. Dawn Davies, MD, FRCPC,** Pediatric Palliative Care Physician, Roger Neilson House and Children's Hospital of Eastern Ontario; Associate Professor, Department of Pediatrics, University of Ottawa
- **Dr. Leonie Herx, MD PhD CCFP (PC) FCFP,** Palliative Care Physician, Kingston Health Sciences Centre; Division Chair and Associate Professor of Palliative Medicine, Queen's University
- **Rebecca Williams, NP, RN,** Nurse Practitioner, Paediatric Advanced Care Team, The Hospital for Sick Children
- **Dr. Taheera Ramji, MD,** Community Pediatrician, Trillium Health Partners

- **Dr. Jitin Sondhi, HBSc, MD, CCFP(PC),** Regional Clinical Co-Lead for the South West Hospice Palliative Care Network; Co-Lead Physician for Oxford Palliative Outreach Team, Sakura House Hospice
- **Dr. John Wiernikowski, BScPhm, PharmD, FISOPP, FCAPhO**, Clinical Pharmacist, Paediatrics, Paediatric Haematology/Oncology, McMaster Children's Hospital; Clinical Assistant Professor of Paediatrics, McMaster University

Additional Section Authors include:

- **Dr. Joanna Humphreys, MD, FRCPS,** Pediatric Palliative Care Physician, McMaster Children's Hospital; Assistant Professor, Division of Palliative Medicine, Department of Pediatrics (Secretions, Sleep)
- **Dr. Gregorio Zúñiga-Villanueva, MD, MSc,** Pediatric Palliative Care Physician, McMaster Children's Hospital; Assistant Professor, Division of Palliative Medicine, Department of Pediatrics (Continuous Palliative Sedation Therapy, Seizures)

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Provincial Pediatric Palliative Care Steering Committee Members

- **Dr. Mark Greenberg, OC, MB, ChB, FRCPC, Co-Chair,** Senior Clinical Lead, Strategic Initiatives, Pediatric Oncology Group of Ontario
- **Dr. Adam Rapoport, MD, FRCPC, MHSc, Co-Chair,** Medical Director, Paediatric Advanced Care Team, The Hospital for Sick Children; Medical Director, Emily's House; Co-Chair, Toronto Regional Implementation Working Group
- **Susan Blacker, MSW, RSW,** Provincial Clinical Co-Lead, Ontario Palliative Care Network
- **Deanna Bryant, MPA,** Group Manager (A), Secretariat, Ontario Palliative Care Network
- **Dr. Robert Connelly, MD, MBA, FRCPC;** Head, Department of Pediatrics, School of Medicine, Queen's University; Co-Chair, Kingston Regional Implementation Working Group

- **Sanober Diaz, MSc, CHE,** Executive Director, Provincial Council for Maternal and Child Health
- **Julie Drury,** Parent Partnership Advisor
- **Cathy Hecimovich, MEd,** Member-at-Large, Chief Executive Officer, Ontario Retirement Communities Association
- **Lynanne Mason,** Director of Paediatric Emergency, Inpatients & Ambulatory Care and Children's Hospital Capital Specialist, Children's Hospital, London Health Sciences Centre
- **Valerie McDonald,** Patient Member, Partnership Advisory Committee, Ontario Palliative Care Network
- **Bruce Squires, MBA,** President, McMaster Children's Hospital, Hamilton Health Sciences; Co-Chair, Hamilton Regional Implementation Working Group
- **Megan Wright, MSN,** Director, Palliative Care, Children's Hospital of Eastern Ontario; Executive Director, Roger Neilson House; Co-Chair, Ottawa Regional Implementation Working Group

Additional Acknowledgements

Reviewed and endorsed by**:**

- **Pediatric Oncology Group of Ontario**
  - **Jill Ross,** CEO, Pediatric Oncology Group of Ontario
  - **Dr. David Hodgson,** Medical Director and POGO Chair in Childhood Cancer Control, Pediatric Oncology Group of Ontario
- **Provincial Council for Maternal and Child Health**
  - **Sanober Diaz,** Executive Director, Provincial Council for Maternal and Child Health