**Pediatric Palliative Care**

**Medication Dosing & Common Phrase Guide**

**What is pediatric palliative care?**

Palliative care no longer means helping children die well, it means helping children and their families to live well and then, when the time is certain, to help them die gently.\(^1\)

Palliative care is patient and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering. Palliative care throughout the continuum of illness involves addressing physical, intellectual, emotional, social, and spiritual needs to facilitate patient autonomy, access to information and choice.\(^2\)

**Spectrum of Palliative Care for Children**

Palliative care is available concurrently or independent of curative or life-prolonging therapy.

**Common Myths about Palliative Care**

1. **Child must be terminally ill or at the end of life**: Palliative care, as a philosophy and specialty, is recommended at any point in the patient’s journey as an extra layer of support.

2. **Palliative care = giving up hope**: PPC can be provided while families continue to hope for cure, but it can also support families as they consider other hopes and goals for quality.

3. **Child must have a ‘DNR’ to have palliative care**: Resuscitation should be treated like any other intervention with regards to its benefits and burdens.

4. **Must abandon all disease directed treatment**: Good palliative care often includes disease directed therapies (eg. chemotherapy, radiation, or even surgery). These forms of treatment are not only useful for maximizing quantity of life, but they also have a role in maximizing quality as well.

5. **Administering opioids causes respiratory depression and quickens death**: When titrated appropriately, the risk of opioid related toxicity causing significant respiratory depression and hastening death is negligible. If toxicity does occur, there will be a number of sequential warning signs such as drowsiness, confusion, and loss of consciousness prior to any significant respiratory compromise.\(^4,5\)

Helpful Phrases in Palliative Care

Finding the words to communicate difficult news can be very stressful. However, it is known that honest discussions are desired. Below are some suggestions for how to begin these difficult conversations. Over time you will find your own words. Social workers and Child Life Specialists can be very helpful in discussing many of these complex issues.

Communicating a new non-curable prognosis

• Disclosure: For some families they need to hear the word ‘die’ in order to understand the magnitude of this discussion, and for others, this word seems too harsh. Often starting with gentle terms, and clarifying with the word ‘die’ if they do not seem to understand is most appropriate.
  ○ We have always hoped that we could make this disease go away and never come back, but your (child’s) disease is proving to be resistant to all of our effective medicines and treatments; meaning that they are not working. Among children whose disease is resistant like yours/your child’s we know that eventually this disease will take your (child’s) life.
  ○ I am so sorry to have to tell you this news, but your child’s disease has progressed to the point that (s)he cannot be cured and will die of his/her disease.

• Shifting focus: At this point, families typically need some time to absorb that news. They often then ask “Is there nothing we can do – is there really no hope?!?” – and while they usually mean cure, it is helpful to reframe at this juncture.
  ○ We don’t have any options for treatment/medicines to make this go away, but that doesn’t mean there is nothing to do or hope for. We will work hard to make sure that you/your child feels as well as possible as this disease progresses. What other things do you/your family hope for? What matters most to you?

Introducing pediatric palliative care (PPC)

• Where PPC services are available:
  ○ In our hospital, when a child is diagnosed with a serious condition, we have the opportunity to bring in a special team of experts to provide an additional layer of support for you and your family. This team is called ‘Palliative Care’ and I have asked them to come by and meet your family later today. We will be working together to be sure that you have whatever you need during this difficult time.
  ○ I would like to contact a team that can help us manage symptoms and better understand our treatment options and their effects on your family.
  ○ I think the best way to help meet your family’s needs is to have you meet a special team who is here to provide an additional layer of support to families facing serious illness.

• Where PPC services are not available:
  ○ I’m going to ask our social worker/nurse coordinator to talk with you and help us find some resources that may help meet some of your family’s needs.

Advanced Care Planning

• General: As a cure is no longer possible, it is important that the care provided to a child aligns with the family and child’s goals of care. This should be a fluid discussion that may shift or change as the child’s condition changes, although often the core principles a family hold stay the same – such as a desire for as many days at home as possible, or being able to be surrounded by loved ones. These discussions are best held in a non-urgent manner, before the child is critically unwell. Families do need guidance to help realize the breadth of care that can be provided – and to realize that there are no longer any ‘right’ answers. Where possible, these discussions should be documented on the POST form (available on the HHS Intranet, Order Set library, under: AND or CPR or Code Status or ICU).
  ○ This will be a very difficult time. The decisions are no longer black and white, or clearly right or wrong. Most families who go through this tell me that nothing feels right. But there are sometimes things that can feel really wrong for some families. For example, for some families, it feels really wrong to take any more disease-directed medicines, and they only want medicines for pain and symptoms. For other families, these medicines have become so normal that not taking them, especially if they might offer a few more days, feels more normal than not taking them. You and your family will have to guide us as to what the best
decisions are for your family. Of course we will tell you if we think something is likely to help
or not, but right now, it’s more about trying to keep you/your child comfortable, and meet
some of those other goals we talked about.
• Filling out the POST: In our hospital, there is a form we use so that these goals we’ve
discussed are in your child’s chart. That way, if for some reason you and I are not around, or
something happens quickly, the team knows how to react. This form can be changed at any
time if our goals change. We can also say on the form, that we need to react differently in
different situations: for example, if something surprising happens, like if your child is eating
and chokes on their lunch, that we should intervene, but maybe if (s)he is having breathing
trouble from the disease progressing, that we only focus on comfort.

• Resuscitation: Parents typically need some guidance to be able to say that heroic interventions
that may be possible are not in their child’s best interest, and will only serve to prolong
suffering. These interventions are not benign and should be framed in the light that they will:
1) not help to cure the child of their underlying disease, 2) cause discomfort and harm.
• As difficult as this is to say, in light of my understanding of your child’s medical condition, if
his/her heart should stop, I believe that would mean that (s)he has reached the natural end
of his/her life. As such I would recommend that (s)he receive comfort measures and not
measures to restart his/her heart. Does this make sense to you?³
• If they ask for clarification: It is possible do things such as put a breathing tube down your
child’s throat so that a machine could breathe for him/her. It is important to know that this
does not help to cure the underlying disease, which is still progressing. It is uncomfortable
for your child to have this breathing tube, so much so that (s)he would need to be sedated. I
don’t think doing this would be in your child’s best interest.
• If a family is insistent, you may need to ask: What are you hoping that CPR will accomplish?
How have you come to this decision? Will this intervention maintain or improve the child’s
quality of life?³ What burdens will this intervention impose on the child’s experience?³
Would this intervention be only suffering without any potential benefit?

• Fluids and Feeding: Removing these interventions are often the most difficult for families, as
they have always been the most natural roles that a parent holds during the illness process.
Parents need the reassurance that these are unnecessary, and in fact harmful for their child.
• It seems like these extra fluids/feeds are becoming a problem for your child’s body to deal
with. As the end of life approaches, the body’s organs naturally slow down and need less
water and energy. Often at these times, providing extra fluids/feeds just increases
discomfort as they get backed up in the body. I think we should put these on hold. If your
child wakes up and feels hungry or thirsty, we can always restart them, but for right now
they just seem to be causing discomfort. Is this okay with you?

• Anticipatory guidance & addressing symptoms: Where reasonable/feasible, it is often helpful
for parents to know about distressing symptoms that are likely to arise. It is important to know
that while it may be distressing to see, that their child is not suffering. For example, if child
begins to have Cheyne-Stokes breathing:
• This is a sign that your child’s time is very short. As the end of life approaches, the body
stops having a normal drive to breathe. When this happens the carbon dioxide in your
child’s blood rises, which makes them feel very comfortable – like morphine without the
side effects - but also causes a reflex to happen which makes your child take big breaths,
like this with pauses. This kind of breathing can be distressing to watch, but you need to
know that it isn’t making your child uncomfortable at all.

Replying to a child’s question/concern
Parents need to know very early that while you will respect their family’s approach to a difficult
prognosis, that you also cannot lie to a child if you are asked a direct question. It can be much
more distressing to a child to feel unwell, and not know why – which is why all families are
encouraged to be open with a child about their prognosis. Child Life specialists have expertise in
discussing complex issues with children and should be a part of the care team at end of life.
• General questions: Try to take the lead from the child. Generally it helps if you can figure out
why they are asking, and what they are wondering about. Some useful answers could be:
• What a great question - what do you think?³
• Why do you ask that? What are you worried about?³
• It would help me to better answer your question if you could tell me why you are asking.³
• Pain: Pain can be difficult to assess in children. You can use numbered pain scales for older children, and faces scales in younger children. It can be helpful to ask about how bad the different forms of pain are. For children who try to protect others by not disclosing pain, sometimes using family members or imagination can be helpful.
  - How would you rate the burning pain in your feet? And the constant pain in your back?¹
  - How much does your heart hurt?²
  - Giraffie Pete, can you tell me if Sarah has an owie in her feet right now?¹
• About death: Do not impose your own views. Most often children are looking for support for their thoughts, which are typically influenced by their family’s beliefs.
  - “What will happen when I die?” What do you think happens after a person dies?² (once they tell you, you can say: I can’t know for sure, but that sounds really nice).
  - “When will I die?” You are still very much alive. We will tell you when things are getting closer. You should also feel free to tell us if you feel you are getting closer.¹

Death
At the time of a child’s death, a simple touch or a hug, and saying “I’m sorry” go a long way.¹ Many families spend some time reminiscing about their child, and appreciate when members of the health care team have a personal memory of their child to share, such as: I will never forget his/her laugh that time when __. Crying with/in front of a family is often seen as a genuine sign that you cared for their child; but never to the extent that the bereaved family feels the need to console members of the health care team.

CONTRIBUTORS:
• Edited by: Dr. Stacey Marjerrison, MD, MSc, FRCPC – Pediatric Hematologist/oncologist, McMaster
• Major content contributions:
  - Paula MacDonald, Bsc Phm – Pediatric Hematology/oncology Pharmacist, McMaster
  - Dr. Mihir Bhatt, MD, FRCP – Pediatric Hematology/oncology Fellow, McMaster
  - Dr. Adam Rapoport, MD, MHSc, FRCP – Pediatric Palliative Care Physician, SickKids Hospital
  - Patti Bambury, RN, RScN – Pediatric Resource Nurse, Grand River Hospital

REFERENCE LIST:
1. EPEC-Peds Course Material: http://www.epec.net/epec_pediatrics.php?curid=6

SYMPTOM MANAGEMENT KEY REFERENCES:
• Hain, R. and Jassal, S. Paediatric Palliative Medicine, Oxford Specialist Handbooks in Paediatrics. 2010.
• Waterloo Wellington Symptom Response Kit Clinical Guidelines and Order Form. Revised 2014.
• POGO/PCMCH Provincial Pediatric Palliative Care Steering Committee. Symptom Management Guidelines.
Symptom Management

Symptom Management in palliative care requires an acute care team that is aligned to the status of the patient, as well as the goals of care for the patient and family. The first step to best symptom management comes from appropriate identification of the etiology of the symptom. Then, it is important to have an armamentarium of management strategies in the hope of aligning the choice of intervention with the goals of care.

In discussion with experts in palliative care provider may be essential to determine which strategies listed below could be helpful for your patients.

Abdominal Distress

Familial social interactions and items can help with orientation. Minimize noise and unnecessary stimulation.

- Loperamide: 0.02-0.05mg/kg SL/IV, max 48h
- Hyoscine: 0.05mg/kg IV
  - Acute: 0.025-0.05mg/kg PO, may repeat 0.025mg/kg in 4 hr if needed
  - Maintenance: 0.01-0.05mg/kg PO TID
- Metoclopramide (Naxzine): 0.05-0.1mg/kg PO/GD/GDU 4-6 h or prn (max of 25mg/dose)
- Olanzapine (oral or intramuscular): 2.5-5mg q4h
- Reserpine:
  - Age 5-12 (1.0-2.5mg): dose 0.25mg PO q12h, increase by 0.25mg every 12h to 0.75mg max
  - Age 13+ (0.5mg): starting dose 0.25mg q12h, increase by 0.25mg every 12h to 1.5mg max

Blinding – mucosal

Have dark towels on hand.

If blinding does not respond to medication/treatment, and is excessive, consider palliative sedation to decrease associated anxiety.

- Transcutaneous acid
- PO: 30-25mg (max 1.5g) 1-3TID
- IV: 50mg/kg over 2hrs continuous infusion or 10mg/kg bolus q4h (max 1000mg q4h)
  - topical: place gauze soaked in lidocaine and ice solution
- Fibre (Gastro)
- Topical application: 1,000mg/g on gauze
- Correction of laboratory abnormalities with transfusion:
  - Plasma: 10mL/kg if bleeding and IC
  - FFP: 10mL/kg – contains all factors & complement
  - Cryoprecipitate: 2u/kg ≤18mo, max – contains fibrinogen, FVIII, FXII, FXIII
  - Vitamin K: 2.5-5mg (2ml of 50mg) IV/PO

Constipation

Manage proactively when administering opioids.

- Polyethylene glycol 3350: 0.5g/m2 (adult 17g)
- Sena
- Loperam
- Docusate
- Methylcellulose: 0.5-1mg SC (max dose 12.8 mg) for refractory opioid induced constipation – given every other day as needed (NOTE: not for constipation at HS)

Diarrhea

Consider: new illness, diet, medications, treatment. Identify:

- Consider holding opioids for induced constipation.
- Consider hydration
- Loperamide: 0.1-0.2 mg/kg (max 2mg/dose) 3-4 time daily could be used cautiously for non-infectious causes

Dyspnea/ Respiratory

Try deep breathing and distraction. Oxygen beneficial for relief of hypoxia. A fan blowing on the face is effective for decreasing the sensation of breathlessness.

Suctioning can cause irritation and increased distress.

Seizures at end of life may resolve within a few days of treatment.

Histamine releasing properties: usually resolve within a few days of treatment.

Symptom Management

- Benzodiazepines may be used as adjunct.
- Opioids are used for the relief of dyspnea.
- Respond to low dose lorazepam
- Infusion
- Ketamine (under direction of PPC specialist)
- Acetaminophen: 1g/kg/day (adult 17g)
- Transdermal hydrobromide

Nausea & Vomiting

Determination of etiology should guide treatment and medication modalities.

Strategies to help approach anorexia and aversion to foods might include: small meals, sign of full, restLib r, increased intake and aversion lying flat after eating. Control nausea in the home, good oral hygiene. Visualization, distraction and relaxation have also proven effective.

Consider: side effects: thickened, difficult to clear secretions, dry mouth and pruritis

- If opioid naïve, Morphine at low dose (30-50mg/m2/dose) IV/SC q12h (max 150mg/dose)
- If on another opioid, or already on morphine, give breakthrough doses to effect.
- Methylnaltrexone
- Methotrimeprazine
- Methyldopa: 1g/kg/day (adult 17g)
- Naloxone: can provide as 20% of total morphine dose (max 5mg) PO or in infusion (0.4mg in 100mL 0.9%)

Pain

A full pain assessment is imperative to effective pain management. Consider whether there is a neuropathic component.

- Acetaminophen: 10-15mg/kg q4h (if continuous) or refer to standardized weight-based dosing nomogram
- Ibuprofen: 10mg/kg/dose q6h caution if bleeding/GI issues (refer to standardized weight-based dosing nomogram)
- Morphine:
  - PO: 2-0.5 mg/kgqd q4-6h
  - IV: 0.025-0.05 mg/kgqd
  - Infusion: 10-20mg/m2/onc or pharynx
- Ketamine (under direction of PPC specialist)
- Dexamethasone: PO 0.1-0.25 mg/kg q4h (max 8 mg/dose)
- Loperamide (improperly for motility/anxiety related): 0.025 mg/kg q12h IV/SC q4h (max 2 mg/dose)
- Nalbuphine: 0.2mg PO/SC (max adult dose 5mg/day)

Pruritus

Can be a side effect of opioids due to their histamine releasing properties. usually resolves within a few days of treatment initiation or increased dosage.

- Polyethylene glycol: 30g q4h
- Hydroxyzine: 0.5mg/kg PO TID (max 40mg/day)
- Histamine: can provide as 20% of total morphine dose (max 5mg PO or in infusion (0.08mg/kg/hr in 100mL normal saline) to decrease pruritis or constipation associated with opioids.

Seizure Control

If child is too weak to do own seizures, consider position on side for potential drainage. Give frequent mouth care.

Sedating can cause irritation and increased secretions, and is often avoided if possible.

- Phenobarbital (if intractable)
- Benzodiazepines:
  - PO: 0.01 mg/kg/dose IV/PO
  - IV: 0.02-0.05 mg/kg/dose q4-6h
  - Infusion: 0.02-0.05 mg/kg/hr (or 2-6 micrograms/kg/hr) titrate to response (refer to continuous infusion preprepared order set)
- Midazolam:
  - PO: 0.1-0.2mg/kg q4h
  - IV: 0.01-0.04 mg/kg/hr (or 0.2-6 micrograms/kg/hr)
  - Infusion: ADD: 0.03-0.05 mg/kg/hr (or 2-6 micrograms/kg/hr) titrate to response (refer to continuous infusion preprepared order set)
- Remifentanil:
  - Transdermal patch: typically does not require for children not supplied by patches
  - Transdermal: 0.5 micrograms/kg/hr/ q4h (max 2mg/dose)
  - Methadone: (under the direction of a PPC specialist)

Adjuncts:

- Radiotherapy (in consultation with a radiation oncologist)
- Desmopressin: 0.1-2 micrograms/kg/hr (max 8mg)
- Gabapentin: for neuropathic pain
  - 5-10mg/kg/dose, to 24h and increase by 1mg/kg every 4-6 days (or 3-7 days for severe pain) until effective or 10mg/kg/day or sedated.
  - TCA’s: for neuropathic pain
  - Amitriptyline: 0.5-1mg/kg PO q12-24h (max increase by 0.2mg/kg every day until effective or 1mg/day or sedated or do not exceed 150mg/day)
  - Ketamine: (under direction of PPC specialist)
  - Topical lidocaine or capsaicin
  - Bisphosphonates (e.g. Benzo)

Ureteral Retention

Having a warm bath and encouraging the child to pass urine in the water is often the most effective treatment for opioid induced retention.

Catheterization may be necessary to relieve the discomfort of a full bladder.

It is recommended with the use of drugs at end of life that may cause urinary retention to have catheterization supplies in the event the child is unable to void.

Management strategy: narcotics (does not influence the infant’s milk).