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Approaching the End-of-Life: Pediatric Palliative Care Information for Healthcare Providers

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.

In the event of difficulties managing particular patients, or concerns about recommendations herein, we strongly suggest consultation with a specialized pediatric palliative care team.

You are welcome to download and save a local copy of this document in the PDF formats provided. As the *Approaching the End-of-Life: Pediatric Palliative Care Information for Healthcare Providers* document is subject to ongoing revisions and updates, we recommend you regularly check the online version posted at **https://www.pogo.ca/pediatric-palliative-care** to ensure you have the most up-to-date content.

In the event of any inconsistency between the content of a local copy and the online version of the *Approaching the End-of-Life: Pediatric Palliative Care Information for Healthcare Providers*, the content of the online version shall be considered correct.

This document may not be used for any commercial purposes.

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Introduction

The impending death of a child[1] is a tragedy and requires thoughtful and precise care of the whole family. This document is designed to provide guidance to healthcare providers on approaching the expected death of a child. This includes revisiting existing therapies; anticipation, prevention, and treatment of common issues and symptoms; and, coaching families and caregivers through the expected changes and experiences that may occur as the body gradually shuts down. The dying process is often a predictable series of physical changes which are not medical emergencies and do not require invasive interventions. Advising families that these physical changes are an expected part of the dying process can play a critical role in helping families cope with what their child may be experiencing. Of course, access to adequate psychosocial and 24-hour medical support is of the utmost importance during this time.

The Provincial Pediatric Palliative Care Steering Committee convened a multidisciplinary working group comprised of pediatric palliative care experts (details and methods in Appendix A) 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 a guide only intended for healthcare providers. Healthcare providers are encouraged to connect families to available family-directed resources (such as https://caringtogether.life) and to seek additional support, clarification, and guidance from the regional pediatric palliative care specialist resources, as required. Expansion of virtual care has created opportunities for unprecedented access to specialist supports across the Ontario. Access should never be the barrier that prevents children and families from receiving the care they require.

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

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.

A companion document, *Symptom Management for Children Near/At End-of-Life*, is available and can be found here.

Re-examining Current Management

Therapeutic interventions should provide an ongoing net benefit to the child. As a child's situation changes, the benefits and risks of various interventions change and need to be re-evaluated. As death approaches, many long-standing or typically "standard" treatments may no longer offer net benefit to the child. When modification of treatment is appropriate, parental input and, where appropriate, involvement of the child should be considered.

Investigations

Specific investigations are considered "standard of care" in certain situations (e.g., checking blood gases while mechanically ventilated, checking electrolytes when receiving total parenteral nutrition, infectious workup for febrile neutropenia, or continuous cardiorespiratory monitoring for a patient on an escalating infusion of sedation such as midazolam). These standards apply in most scenarios in pediatrics wherein there are expressed or assumed goals of life-prolongation or cure. However, the results of such investigations are typically less helpful in meeting comfort-focused goals of care in the scenario of expected death (as none of these investigations reliably correlate with comfort). Each investigation should be considered for its likelihood to add suffering (e.g., a workup for febrile neutropenia may mean leaving the comforts of home, an intravenous [IV] poke may cause pain while drawing blood from an existing central line will not) and its likelihood of providing comfort to the child and/or family.

During end-of-life care, if an investigation may cause suffering for a child and will not help to guide comfort measures or improve accuracy of prognostication, it is not indicated regardless of the "standard." On the other hand, if an investigation will not cause suffering and may provide the child/family with useful information or assist in comfort care, it can be a useful tool in providing quality end-of-life care -- just because a child is dying does not mean all the tools at one's disposal to provide the best possible care are stopped. As an example, a common belief is that monitors add to a family's anxiety and distress as death approaches, and while it is true that many families may prefer those last moments to be uncomplicated by wires and monitors, a minority of families may find solace in the visual cues of the body's slowing. For these families, the monitors may be anxiety-alleviating with minimal impact on the child. Alarm settings should be set to off for the most part. Some families may want alarms to be on during the night so that they are awake and present at the time of their child's passing.

Medications

A child's medication list should be re-examined regularly to determine the ongoing benefit of each medication. Provision of unnecessary medications can pose risks to the child and add to the caregiving burden. Consideration should be given to:

i. the expected effect of the medication (e.g., does this medication provide active benefit to the child within the timeframe of expected survival?),
ii. changes in physiology which might alter medication metabolism (e.g., is the child in renal or liver failure?), and
iii. new medications (e.g., is the desired effect of this medication now being achieved through another medication that has been started such as a midazolam infusion?).

If a medication no longer provides net benefit to the child, consideration should be given to the best way to stop the medication. Likely, unnecessary medications can be stopped or weaned as appropriate.

Enteral Nutrition and Hydration

As death approaches, the desire to eat and drink often diminishes. Although this can be distressing to families, it is important to explain and normalize the loss of appetite that occurs at this time; blood flow to the gastrointestinal tract may become impaired resulting in decreased gut motility, decreased hunger cues, reflux, nausea and/or vomiting, cramping, changes in bowel function, and emergencies such as bowel perforation. These children are not *dying because they are not eating*; they are *not eating because they are dying*. Oral intake beyond what the body can tolerate can worsen symptoms and quality of life; appetite is often a helpful indicator of what the body can tolerate.

For children who can communicate their needs clearly, it is appropriate to offer fluids and food in small amounts allowing the child to consume based on desire, including orally or through a feeding tube. Families should be counselled that the goal of feeding is no longer growth and development or even sustenance, but rather comfort and pleasure. Children should be allowed to enjoy their favourite foods without worry about caloric totals or ensuring all food groups are represented. For children with impaired swallowing, chewing and sucking on favourite foods to extract all the taste before spitting the food back out into a napkin may be a helpful option.

For children who cannot communicate their feelings clearly, decisions around enteral nutrition can be challenging for families and healthcare providers alike. Many children in this category may have received nutrition via tube for a prolonged period. The tube bypasses their ability to self-regulate intake based on hunger or discomfort and can add to distress at end-of-life. When death is expected in days to weeks, it may be appropriate to proactively decrease fluids and nutrition and monitor for signs of either hunger (before feeding) or intolerance (after feeding). Discussions should occur with neurology/dietetics for children on a ketogenic diet.

Through careful assessment, recognition of feeding intolerance, and anticipatory guidance and negotiation with family, there may come a time when it is appropriate to stop nutrition and hydration near end-of-life.[2] Mouth care is of critical importance at this stage, including swabbing the lips and gums with water or applying lip balm to prevent drying of the lips. The use of ice chips or freezies may also be helpful. Ongoing anticipatory guidance and support of the family is paramount. Palliative care subspecialist support should be sought as appropriate.

Parenteral Nutrition and Hydration

As options for enteral nutrition and hydration decline, many families may wonder about parenteral options (i.e., intravenous/subcutaneous fluids or total parenteral nutrition). It is important to understand that these interventions typically do not help to provide comfort near the end of a child's life. Additional fluids are typically not well absorbed or regulated during the dying process, particularly in the context of renal failure. Fluids end up in the "third space," resulting in edema, worsening dyspnea, and hypoxia. Additional calories and nutrients are typically not required at this stage or utilized effectively, particularly in liver failure. Therefore, in most scenarios, it is not recommended that parenteral nutrition/hydration be added to supplement a child's enteral intake during the dying process. If a child is already receiving parenteral nutrition/hydration, these may need to be weaned or discontinued, either proactively or in response to decreasing renal function or peripheral and/or pulmonary edema. In some scenarios, provision of parenteral nutrition and hydration is an important aspect of care for families. In this case, a low volume trial may be appropriate.

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[2] This document is focused on limiting or discontinuing artificially administered nutrition and hydration *during a child's dying process*. For information regarding withdrawal of artificial nutrition and hydration in other circumstances, the Canadian Pediatric Society position statement, Withholding and withdrawing artificial nutrition ethically acceptable, is a helpful resource for healthcare providers.

Blood Transfusions

Disorders leading to issues with blood cell production, function, consumption, or destruction can lead to death through infection (low white blood cells), bleeding (low platelets), or anemia/heart failure (low red blood cells). Blood product transfusions can be used to attempt to mitigate two of these problems: low platelets and red blood cells (white blood cell infusions are possible in certain scenarios but are complicated and very rarely appropriate). Many children with these disorders have a long history of receiving blood transfusions; the decision to discontinue blood transfusions may therefore be a difficult one. Blood transfusions for pediatric patients are typically restricted to inpatient and outpatient settings of a hospital.

Some families may wish to forego transfusions for the opportunity to remain at home. In this case, clear goals of care should be delineated, and plans developed, in the event that issues such as those noted above arise (e.g., acetaminophen and comfort-focused medications; antibiotics as indicated for fever or infection; dark towels and sheets, possibly tranexamic acid, for bleeding; and a rapid sedation protocol for acute crises).

Other families may wish to remain in hospital or come to clinic for transfusion support. It is important to note that while transfusions may prolong life by avoiding death by anemia or bleeding, there is the risk (in an otherwise incurable condition) that prolonging life may prolong suffering or increase the risk of significant suffering. For example, a child who may otherwise have died of painless internal bleeding may instead have increased tumour burden, increased pain and ultimately die of a pneumonia with associated fever and dyspnea.

Respiratory Support Systems including Non-Invasive Ventilation (NIV)

With advances in medical technology, it is not uncommon for children with medically complex conditions to be managed in the home with oxygen or NIV support (e.g., continuous positive airway pressure [CPAP], bilevel positive airway pressure [BIPAP]). Many of these children may have been dependent on nocturnal NIV for months to years. As the underlying disease progresses and death approaches, families and healthcare providers alike may find themselves wondering what to do with the NIV support.

Children who are dependent on intermittent NIV for respiratory failure may become increasingly dependent on the NIV as their disease progresses. There may be a period of gradually increased needs (i.e., increased pressure) or a more sudden, marked increase and an inability to wean from continuous (24/7) NIV support. Typically, continuous NIV is not sustainable or feasible in the long term, particularly in community settings. Pressure from the mask can lead to skin breakdown and pressure wounds on the face, resulting in significant pain. Continuous pressure can also lead to limited oral intake or feed intolerance, which can lead to malnutrition and worsen a child's risk for wounds, infection, and poor wound healing.

As death approaches, reviewing a child and family's goals of care with respect to NIV support should be a part of the plan. When the likely cause of death is respiratory failure, NIV may have the capacity to prolong a child's life. However, it may do so at the cost of increased suffering during the dying process. The decision to discontinue NIV in this circumstance is difficult, but often necessary. Some families may struggle significantly with this and will require ongoing support and anticipatory guidance. Palliative care subspecialty support should be sought as appropriate.

Discontinuing NIV support is usually associated with an increase in carbon dioxide, a decrease in oxygen, and may be associated with dyspnea. Children may require an increase in dyspnea medications, such as opioids. These processes often lead to a state of decreased level of consciousness. Even if the chest continues to work hard to regulate oxygen and carbon dioxide to the best of its ability, with appropriate dyspnea treatments, these children generally feel and appear restful, relaxed and at peace. The removal of the mask/apparatus allows for meaningful interaction with family.

Tracheostomy and Ventilator Dependence

Tracheostomy is becoming increasingly common amongst children living in the community. There are various uses for tracheostomy including pulmonary hygiene, subglottic stenosis, severe obstructive sleep apnea, severe chronic lung disease, respiratory muscle weakness, and central apnea. Many of these children may not require oxygen or ventilatory support, however, some may require both. Many of these children have been frequently and chronically hospitalized and often their families struggle with the knowledge that their children will have a shortened life span. The lives of these children are contingent upon the ongoing functioning of the ventilator and its circuitry. Consequently, they are at risk of sudden death from technology/equipment malfunction, tracheostomy obstruction or malfunction, etc.

Children dependent on tracheostomy and ventilatory support remain at risk of ongoing gradual deterioration including worsening of the underlying disease as well as worsening chronic lung disease, aspiration, pneumonia, or sepsis. Given their fragility, it is important to maintain an open line of communication between the family, healthcare providers, and when appropriate, the child, to frequently reassess goals of care and treatment, particularly after a recent hospital admission. The process by which invasive ventilator support would be discontinued in the community would be similar to NIV. Medications, such as opioids, should be provided to

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manage dyspnea. Consultation with the palliative care service may be helpful to the family, healthcare providers and the child, when appropriate.

Symptoms in the End-of-Life Phase

Many symptoms are possible during the weeks to days before a child’s death. It is often helpful to identify the symptoms the child is at risk of developing, counsel the family, and, when appropriate, the child, on these symptoms and create a symptom management plan for if/when these symptoms arise. For each symptom, it is useful to document a first-line, second-line, and possibly third-line treatment for the given symptom and ensure that those therapies are available to the child/family/caregivers, particularly in the home setting where they may not have 24/7 access to a pharmacy or healthcare providers.

Pain/Discomfort

Depending on the underlying disease process, pain or discomfort has the potential to worsen and change in its nature during the last few days to weeks of life. Often in the final hours, however, the level of pain does change dramatically. As a child becomes sleepier, moves around less and the body’s chemistry changes, there may be less discomfort, and escalation of analgesics may not be required. The child may moan when moved from side to side or when they breathe out. It is important to let the family know that moaning is not necessarily an indication of pain. However, persistent tensing or wrinkling of the forehead, or moving the hands to a specific part of the body, may be a sign of discomfort. Pain should be assessed frequently, and a proactive pain management plan should be in place to provide adequate relief in a timely fashion to reduce the child’s suffering. This may involve the use of a breakthrough dose of analgesic prior to diaper changes, repositioning, suctioning or any other care that is noted to consistently cause the child distress.

There is no specific limit in dosages of opioid that can be prescribed, as this class of medications does not have a ceiling effect (e.g., higher doses typically provide greater symptom relief). However, the aim should always be to use the lowest dose possible that adequately treats the symptom. When escalating doses result in no evidence of improved comfort, worsening side effects, or symptoms suggesting neurotoxicity, narcosis or hyperalgesia, discussion with a palliative care subspecialist is warranted. There are several ways to administer pain medications – orally, sublingually, intranasally, or via subcutaneous or intravenous infusion. The medications can be given as needed initially, particularly if the child is opioid naïve or has infrequent bouts of moderate to severe pain. However, some children will require scheduled or continuous opioid dosing with breakthrough pro re nata (PRN) dosing at the end of their lives. The scheduled or continuous dose of opioids should be reassessed frequently and adjusted based on a thorough pain assessment and record of PRN doses required. Palliative care subspecialty support should be sought as appropriate.

Neurologic Symptoms

Seizures

As with other symptoms, knowledge of the child's past medical history and understanding the underlying disease will assist in predicting which children may be at risk of seizures. For example, many children with complex medical conditions have an underlying seizure disorder while others may develop seizures secondary to infection or as a consequence of raised intracranial pressure or intracranial hemorrhage secondary to a brain tumour. Others may develop seizures secondary to metabolic disturbances, including hypoglycemia, hyponatremia, hypocalcemia, or hepatic encephalopathy.

Even brief seizures can be very distressing for families to witness. Families should be prepared in advance for such a possibility. It is important to remind families that while seizures may be very distressing to observe, the child experiencing the seizure is often unaware of the event and does not experience any discomfort. Children with a history of epilepsy should have a seizure response plan and continue their baseline antiepileptic medications to reduce the chance of breakthrough seizures. If the child becomes unable to receive and absorb their maintenance medications, alternative treatments may be necessary (e.g., midazolam infusion). Discussions should occur with neurology/dietetics for children who are on a ketogenic diet.

Children at risk for new onset seizures should also have a seizure response plan +/- a preventative antiepileptic plan, depending on the degree of risk and capacity to respond (e.g., one healthcare provider might have a lower threshold to start a preventative medication for a child who is at home in a remote community vs. a child who is in the Pediatric Intensive Care Unit [PICU] with an intravenous [IV] line in situ]).

Psychologic/Behavioural Symptoms

Restlessness & Agitation

In general, a child will spend an increasing amount of time sleeping as death approaches. This can be due to progressive disease, changes in organ function, as well as medication effect. Some children do remain alert and responsive until the moment of death, while others may become confused, semi-conscious or unconscious in the hours or days before death. Restlessness and agitation are not uncommon during the terminal phase and may be secondary to hypoxia, nausea, increasing pain, fear, or anxiety. Agitation may be the only way the child has of communicating distress. Reversible causes for agitation should be sought and appropriately treated (e.g., vision changes, itch, nausea). A calm and peaceful environment, and the presence of familiar people including parents, siblings, other family members, and others who are important to the child and family, may be able to assist in relieving the child's anxiety. The child's speech may become increasingly difficult to understand. Even if a child is unable to engage or communicate, family should be encouraged to talk to their child, play their favourite music, read stories, or to simply sit and touch their child to limit their sense of isolation. Medications such as midazolam, haloperidol, olanzapine, or methotrimeprazine can also be used to treat terminal agitation. (See *Symptom Management for Children Near/At End-of-Life* Document)

Delirium

Children of all ages who are near the end-of-life often have several risk factors for delirium (e.g., polypharmacy, high symptom burden, changes in consciousness level, unfamiliar environment, and sleep disturbance). Hyperactive delirium can be difficult to distinguish from restlessness and agitation. Should a child's predominant features include confusion, prolonged periods of wakefulness or worsening with increased sedative medications, delirium should be considered in the differential. Most delirium can be managed conservatively (e.g., familiar faces, environment, reassurance, frequent orientation to space and time), however, some may require pharmacologic intervention (See *Symptom Management for Children Near/At End-of-Life* Document).

Respiratory Symptoms

Respiratory Distress/Dyspnea

Depending on the underlying disease and its progression, respiratory failure, shortness of breath/dyspnea, and secretions may become increasingly problematic. Respirations may become rapid due to fever, infection, or changes in kidney function resulting in acidosis and the need to blow off carbon dioxide. Excessive fluid administration and accumulation can contribute to dyspnea and increased secretions. Consequently, the child's comfort may be improved by limiting the intake of artificial nutrition and hydration (See *Enteral Nutrition and Hydration* section or *Parenteral Nutrition and Hydration* section).

Respiratory insufficiency may be addressed through:

- treating reversible causes of respiratory distress such as pneumonia and pulmonary edema; and/or
- placing the child in an upright position with support or leaning the child forward with arms resting on a table; children will often reposition themselves into a position of comfort, but this will become increasingly problematic as they become more obtunded.

Even when a child appears to be working hard to breathe, they can be quite comfortable if dyspnea is adequately managed. Dyspnea can be managed through:

- an open window or an oscillating fan blowing at a gentle speed;
- resisting the urge to crowd around the child's bed;
- allowing as much natural light as possible into the room (dark areas feel more claustrophobic);
- using distraction or guided imagery;
- oxygen/medical air (by mask, nasal cannula or just blow by) titrated to comfort rather than to maintain a specific saturation level;
- targeted medications to help open the airways, reduce anxiety and/or control fever; or
- medications that treat dyspnea directly (See *Symptom Management for Children Near/At End-of-Life* Document).

Gastrointestinal (GI)/Genitourinary (GU) Symptoms

Nausea/Vomiting

Nausea and vomiting may be a result of many factors and an understanding of the specific etiology should be pursued (e.g., medications/chemotherapy, malignant bowel obstruction, opioid-induced ileus, increased intracranial pressure, withdrawal, reflux). Nausea and vomiting may be an indication that the body is no longer able to adequately process enteral nutrition, and cessation of feeding may improve the symptoms. There are many medications with anti-nauseant effects through a variety of mechanisms of action. Treatment should be tailored to the putative etiology. (See *Symptom Management for Children Near/At End-of-Life* Document)

Bilious vomiting or vomiting of post-pyloric feeds is a sign of bowel obstruction. If this is occurring, feeds and any prokinetic or laxative medications should be held; other enteral medications should be evaluated one-by-one for importance, parenteral alternatives, and location of absorption. If there is a nasogastric tube (NG) or gastronomy tube (G-tube) in place, it can be set to straight drain or intermittent suction. Bowel obstruction may lead to bowel ischemia, pain, GI bleeding, perforation, sepsis, or death.

Diarrhea/Constipation

Problems with bowel movements stem from a variety of factors. As end-of-life approaches, consideration should be given to the net benefits of enteral feeding. As death approaches, intake generally lessens and bowel movement frequency decreases. Constipation should be defined by difficulty/discomfort related to infrequent bowel movements and not defined solely by their frequency/consistency. Constipation associated with significant discomfort can be managed with osmotic +/- stimulant laxatives, depending on the severity and etiology. (See *Symptom Management for Children Near/At End-of-Life* Document)

Diarrhea may have a variety of causes, including terminal feeding intolerance. Overflow diarrhea related to constipation should be ruled out early. Non-infectious diarrhea may be managed with loperamide. Management of infectious diarrhea should be discussed within the context of the goals of care. Diarrhea resulting from GI bleeding may require consideration of hematologic treatments (e.g., tranexamic acid, blood products). In addition to the discomfort/annoyance, diarrhea can cause secondary problems through interference with medication absorption. In the context of diarrhea, it is important to pay careful attention to medications and their effects, and to monitor for signs of decreased absorption (e.g., whole pills found in stool, breakthrough symptoms and decreased levels).

Incontinence & Urinary Retention

During the dying process, relaxation of the muscles of the GI and GU tracts may result in the incontinence of both stool and urine. It is important for children and parents to be forewarned, and to establish a mutually agreed upon management plan, in advance. Parents may be reluctant to catheterize a child and may choose to use diapers, pull-ups, incontinence pads, or disposable draw sheets. It is extremely important to families, and the child, that the child’s dignity be respected. Disposable draw sheets are also very useful for incontinence of stool.

Hematologic Symptoms

Bleeding

Children with oncological conditions who are at the end-of-life may experience bleeding secondary to tumour growth/erosion into blood vessels, or from coagulopathy/thrombocytopenia. Bleeding may be controlled with specialized dressings, medications, or transfusion of blood components, depending on the state of the disease and the location in which the care is being provided (blood products are generally not given in the hospice setting or at home). For some children, massive hemorrhage may be the terminal event. When this is anticipated, dark bedding and towels should be on hand in the home or healthcare facility, since even a few drops of blood look like a lot on a white pillowcase or towel.

Preparation is the key to management and the child, family, and healthcare providers need to be aware of the potential for bleeding so they can respond in as calm a manner as possible. An anxiolytic/sedative (e.g., midazolam) should be made available. If the child is at home, the medication should be in the home with the dosage and method of administration worked out well in advance; if the child is in the hospital or hospice, the orders should be written and "on hold". This should include a rapid sedation plan for acute crises such as severe airway/pulmonary hemorrhage. Children, parents, and siblings should be provided with anticipatory guidance as the site of the blood can be particularly anxiety provoking and distressing.

Miscellaneous Symptoms

Fever

Near end-of-life, fever may be a sign of infection or may be related to underlying changes in physiology (See *Temperature and Vital signs* section). Investigation and treatment for infection should be considered in the context of the goals of care.

Swelling/Edema

Swelling in the hands and feet is common because of a loss of protein and oozing of fluids into the tissue, as well as a lack of general movement and muscle activity. Elevating and supporting the limbs and lymphatic massage may help with some re-absorption of the fluid.

Muscle Spasms/Cramps

Secondary to immobility, pain, electrolyte imbalance, medications, or neuropathy, a child may experience muscle spasms/cramps. Prevention and treatment with non-pharmacologic therapies includes careful repositioning, gentle passive range of motion exercises, and massage, as tolerated. Benzodiazepines, such as lorazepam, diazepam, or clonazepam, can be used for acute or recurrent muscle spasms. Appropriate analgesia will reduce the associated pain. Children with long-term spasticity concerns are often on regular baclofen and/or diazepam and may require modification of their treatment regimen.

Wounds

Wounds may be related to pressure or underlying disease complications. Prevention is the best therapy. Early and ongoing assessment of skin integrity, positioning, and surfaces are critical. Consultation with wound management specialists can be of enormous benefit in order to determine the best possible regime of topical treatments and dressings. Topical antibiotics (e.g., metronidazole) can be of benefit for fungating wounds.

Odors

Body odors may increase due to infection, breakdown of a tumour, and other changes within the body. There are a variety of ways in which odors can be reduced and controlled (e.g., dressing products, air fresheners). As with other symptoms, anticipatory guidance with the child and family is the key to reducing anxiety and to normalizing the experience to the extent possible.

As Death Approaches (Final Hours)

There are some changes that occur proximal to death and, in some cases, herald that death is near. Below are symptoms that may be a natural part of the dying process, most of which require no treatment.

Withdrawal & Disorientation

As a child approaches death, they may withdraw and relate to only a few people or even one significant person. It is important for all family members to be aware of this, so they are not left feeling disheartened and rejected. The child may seem unresponsive, withdrawn, or in a comatose-like state. Their eyes may be partially open and not blinking; they may become less aware of their surroundings and start to “let go.” The child may be too weak to respond or may not be able to speak but will still be able to hear and understand what is being said. Voice and touch are reassuring. Families should plan visits and conversations for times when the child seems more awake and alert or remain quietly at the bedside for company while encouraging friends and extended family to visit a few at a time and for short periods.

As death approaches, the child may develop a terminal delirium and seem to be confused about time, place, and the identity of the people surrounding them. Friends and family should be advised to speak clearly and truthfully to the child and explain that they are dying, using words familiar to the child in this regard. In cases of terminal delirium resulting in child or family distress, non-pharmacological means should initially be employed; in situations where this fails, medications, including an escalating infusion of sedation, may be appropriate. In such circumstances, consultation with a palliative care specialist is recommended. (See *Symptom Management for Children Near/At End-of-Life* Document)

Vision-like Experiences

As the dying process proceeds, the child may start speaking to or “seeing” people who have already died, or they may see things not known or visible to others. They might also make statements about “packing their bags” or “going home.” This is not unusual behaviour and families should be counselled accordingly so they are less distressed by its occurrence.

Noisy/Rattling Breathing

Rattling respirations result from either excessive secretions or difficulty in clearing pharyngeal secretions. This generally occurs in the terminal phase of a child’s illness and is associated with a decreased conscious state. Repositioning the child on their side with their head tilted down will assist postural drainage; however, children still capable of moving will often find the position that works best for them, no matter how uncomfortable it may seem to those around them. Providing the family with reassurance and explanation is essential. Although the noise can be distressing to bystanders and observers, the child is usually unaware and untroubled by the noise and the secretions. Medications such as glycopyrrolate, scopolamine, or atropine ophthalmic drops can be used if the secretions are particularly problematic. (See *Symptom Management for Children Near/At End-of-Life* Document).

Eye Changes

During the dying process, a child's pupils may become fixed and dilated. Their eyes may become sunken, or bulge and be glazed over. If the eyes are bulging, a small damp bandage may be placed on their eyes to provide some comfort. If the eyes do not completely close, ocular lubricants should be applied. Excessive or crusted ocular secretions can be removed with a warm damp cloth.

Temperature and Vital Signs

Fever is common because the body's temperature regulator is decreasing in its function. Tumour presence or infection may also cause a fever. In addition to antipyretics, cool cloths can be applied to enhance the child's comfort. Ongoing monitoring of a child's vital signs including heart rate, blood pressure, and oxygen saturation are not necessary at this time; and may disturb the child's rest and potentially increase parental anxiety. At this point, changes in vital signs do not necessarily help predict when the end-of-life will occur.

Circulatory and Respiratory Changes

As the heart slows and the heartbeat becomes irregular, the circulation of blood to the extremities decreases. This results in the child's hands, feet and face becoming cold, pale, and cyanotic. They may also sweat profusely and feel damp to touch. Parents may wish to change the child's clothes or cover them with warm blankets. It should be noted that adults at the end-of-life report that they do not feel cold even when they are noted to have cool extremities and that the "piling on" of blankets can be quite uncomfortable. Respirations may become rapid, shallow, and irregular, and be associated with periods of apnea. The Cheyne-Stokes[3] breathing pattern may occur in the last hours or days of life. This pattern of breathing can be distressing

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[3] Rudrappa, M., Modi, P., & Bollu, P. C. (2022). Cheyne stokes respirations. In StatPearls [Internet]. StatPearls Publishing. Available from: https://www.ncbi.nlm.nih.gov/books/NBK448165/

to witness and parents, siblings, and others who may be present should therefore be provided reassurance that it is part of the dying process and is not distressing to the child.

What to Do When a Child Dies?

No amount of preparation can prepare a family for the emotionally painful experience that ensues when a child dies. For many parents, the death of their child may be the first death they have witnessed. The experience and reaction that ensues is very individual, even within the same family. Parents will require gentle and sensitive preparation for what needs to be done when their child dies, and they should receive this information preferably from a member of the team with whom they have travelled this journey. Some parents will ask questions as they prepare for their child's death, while others cannot bring themselves to discuss the topic prior to their child's death. With parental permission, the dying child and siblings should be included in the information sharing process in order to reduce their sense of isolation and to encourage them to share their thoughts, fears, and wishes.

Parents should be made aware of the minimum legal requirements that need to be observed following the death of the child in the home (i.e., assessment by a healthcare provider confirming death has occurred and completion of the required documentation). Advance care planning is important to do because it sets the stage for the child's death. There should be a clear process regarding who the family will call after the child has died. There should be a written plan documenting the family's care wishes, including a Do-Not-Resuscitate Confirmation (DNR-C) form. If the death was expected, a DNR-C form relieves emergency responders from the mandate to provide cardiopulmonary resuscitation if called to the scene and generally avoids the need for the coroner to be involved. In cases where child protection services are involved, discussion with these programs should occur in advance as well as at the time of death.

Organ and tissue donation is life-changing and life-saving for many recipients. For some families, organ and tissue donation becomes an important part of their child's legacy. Discussion with the family, and where appropriate the child, regarding organ and tissue donation should, ideally, be considered in advance, and in the context of local guidelines.

For some families where cultural or religious rituals require specific timeframes to be adhered to, there may be a need for prompt action (e.g., if autopsies are required, or in the rare event that the death is a coroner's case). In most situations, however, there is no urgency for the above; families should be able to focus on what is truly important – being with their child and saying their goodbyes. Having said that, the practicalities, and the timeframe in which they need to be completed, should be explained.

Families, if not already aware, should be informed of the various financial services and resources that may be available to them, including compassionate leave benefits.[4] The child's parents may require letters of information/support or for forms to be completed by their primary healthcare providers to assist with obtaining access to the various programs available to them.

Sibling Support

Siblings of the dying child should, with parental permission, be included in all or some of the aspects of the dying process if they would like to be included. This may include sharing family moments and activities prior to death, caring or tending to the dying child, and helping to plan and participate in the funeral proceedings. Although parents may be apprehensive about sharing information with the dying child's siblings, including siblings can prevent or reduce their sense of fear, anxiety, and isolation and may, in turn, help alleviate some of the challenges following the death of their sibling. It is important for parents to know that all children grieve differently, and certainly their level of development and understanding will impact their outward behaviour/demeanour/actions. Having knowledge of the locally available bereavement support services to which the family will have access is important. For school-age children, parents (or a delegate) should be encouraged to inform the teacher and school so that additional supports can be put in place for the sibling and their classmates, as well as the classmates of the deceased child.

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[4] EI Caregiving Benefit – What these Benefits Offer. Available from https://www.canada.ca/en/services/benefits/ei/caregiving.html

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Appendix A: 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; re-formatting 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

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opportunity to provide final comments in August 2023 prior to finalizing both documents 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 & 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

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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