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

## Introduction:

Parents often ask their healthcare providers what to expect as their child nears death. This can leave health care providers who do not routinely look after dying children feeling uncomfortable. This document will explain some of the changes and experiences that may occur as the body gradually shuts down and major organ dysfunction progressively ensues. The process is usually a predictable series of physical changes which are not medical emergencies that require invasive interventions. Letting parents know that these physical changes are an expected part of the dying process can go a long way in helping them cope with what they are seeing. Of course, adequate psychosocial and 24h medical support is of the utmost importance at this time.

The information included in this document is a guide only. Please be sure to seek additional support, clarification and guidance from your local palliative care support team if required.

## As Death Approaches

### 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. It can be particularly problematic in children with neurodegenerative diseases or brain stem lesions where swallowing is impaired. 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 as the noise can be particular distressing to bystanders and observers although 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 "Common Medications Used at End of Life")

### Incontinence

During the dying process, relaxation of the muscles of the gastrointestinal and genitourinary tracts may result in the incontinence of both stool and urine. It is important for 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 that their child's dignity be respected. Disposable draw sheets are also very useful for diarrhea.

As the child's enteral intake reduces, the frequency, and consistency of bowel motions will change as will the color and frequency of voids. For patients with colostomy, ileostomy or ileo-conduit the same changes in bowel or bladder function may occur. Appropriate anticipatory guidance should be provided to parents and other caregivers in order to reduce their anxiety.

### Poor Appetite & Weight Loss

There are many reasons for a loss of appetite and weight loss. Symptoms like pain, nausea, constipation or shortness of breath may reduce the desire to eat and drink. Chemical changes within the body also decrease appetite. Terminal oncology patients often lose weight and become increasingly weak due to worsening of the disease – not because of lack of food or fluid.

## Food & Fluids

As death approaches, the desire to eat and drink often diminishes. Although this can be particularly distressing to parents and other family members, it is important to iterate and normalize the loss of appetite that occurs as death approaches. As death nears, blood flow to the gastrointestinal tract may become impaired resulting in gut ischemia; consequently abdominal cramps, vomiting and changes in bowel function may ensue. These symptoms often result in loss of appetite and the automatic reduction of oral intake. In orally fed individuals, our approach to care is to offer fluids and food to the child in small amounts allowing the child to consume based on want and desire with a plan to feed for comfort. Parents need guidance to understand that feeding for nutrition and growth is no longer the goal. It is alright to allow the child to enjoy only their favourite foods and to not worry about ensuring that all food groups are represented in the diet. For children who have difficulty with 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.

In children who have been routinely fed via nasogastric, GT or GJ tubes the limitation or discontinuation of enteral nutrition can be particularly challenging for parents and healthcare providers alike. Many of these children have received nutrition by alternative means for a prolonged period of time due to long standing oral aversion, failure to thrive, aspiration/reflux or other medical issues including the inability to swallow. Others may have been more recently initiated on NG/NJ feeds as they have acutely decompensated. Regardless of the situation, the family or primary healthcare team may have strong feelings about feeding and nutrition making the topic of artificial nutrition and hydration particularly sensitive.

Through careful patient assessment, recognition of feeding intolerance, and anticipatory guidance and negotiation with family it may become appropriate to reduce or discontinue enteral feeds as death ensues. The administration and more importantly the withholding of artificial nutrition and hydration can be a highly contentious topic amongst parents and healthcare providers. As the body slowly shuts down, the child may develop worsening symptoms including abdominal pain/cramps, vomiting and diarrhea. As this occurs the concentration of feeds may be reduced and at some stage even replaced with pedialyte. Excessive fluid administration from forced enteral feeding can result in worsening dyspnea, and secretions; unrecognized feed intolerance can result in worsening vomiting/diarrhea/abdominal pain and increased risk of pulmonary aspiration, gastric perforation and uncontrolled pain and suffering. Subsequently, due to worsening symptoms it may become appropriate to stop all artificial nutrition and hydration, swabbing the lips and gums with water or Vaseline, and allowing oral intake as tolerated and desired. The use of ice chips or freezies may be very helpful here. Ongoing anticipatory guidance and support of the family is paramount. Palliative care subspecialist support should be sought asappropriate.

## What about Intravenous/Subcutaneous Fluids?

It is important to understand that intravenous (IV) or subcutaneous (SC) fluids do not help to provide comfort at the end of life. They do not contain nutrients and in end-stage illness, are not well absorbed. Additional fluids administered at this stage often result in edema, worsening dyspnea and hypoxia. As a result, we do not usually recommend IV/SC fluids. If a patient is already receiving IV fluids, these may need to be weaned or discontinued in response to the development of decreasing renal function or peripheral and/or pulmonary edema.

## Eye Changes

During the dying process, pupils may become fixed and dilated. The eyes may become sunken, or bulge and be glazed over. If the eyes are bulging (which may occur in neuroblastoma), a small damp bandage may be placed on the eye 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.

## Restlessness & Agitation

Generally speaking, a child will spend an increasing amount of time sleeping as death approaches. This can be due to progressive disease and changes in body metabolism, as well as progressive anemia or sedation from opioids required for pain relief. Some, however, remain alert and responsive until the moment of death while others may become confused, semiconscious or unconscious several 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. A calm peaceful environment and the presence of familiar people including parents, siblings, and other family members can assist in relieving the child's anxiety. The child's speech may become increasingly difficult to understand; although they may be unable to communicate, given hearing is the last sense to be lost, family should be encouraged to talk to their child, play their favorite music, read stories or to simply sit and touch their child to limit their sense of isolation. Medications such as midazolam, haloperidol, olanzapine can also be used to treat terminal agitation. (See "Common Medications Used at End of Life")

### Swelling

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

### Bleeding

Oncology patients may experience bleeding secondary to tumor 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 of care (blood products are usually not given in the hospice setting and cannot be given at home). For some patients massive hemorrhage may be the terminal event. When this is anticipated, dark bedding and towels should be on hand in the home or health care facility (even a few drops of blood look like a lot on a white pillowcase or towel). Preparation is the key to management, family and health care providers need to be aware of the potential for this occurrence so they can respond in as calm a manner as possible. An anxiolytic like midazolam should be made available (if the child is at home the medication should be in home with the dosage and method of administration worked out well in advance, if the child is in hospital or hospice the orders should be written 'on hold.' Children, parents and the child's siblings should be provided with anticipatory guidance as the site of blood can be particular anxiety provoking.

### Odors

Body odors may increase due to infection, breakdown of tumor and other changes within the body. There are a variety of ways that we may be able to help to reduce and control odors e.g. dressing products, air fresheners. Again anticipatory guidance is the key to reduce anxiety and to normalize the experience.

### Shortness of Breath & Secretions

Depending on the underlying disease and its progression, shortness of breath, dyspnea and secretions may become increasingly problematic as the disease continues to progress and the body weakens. 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 result in dyspnea and increased secretions. Consequently, patient comfort may be improved by limiting the intake of artificial nutrition and hydration (see Food and Fluids).

Although the child may appear to be 'working' hard to breathe he/she may tell you they are quite comfortable. Distress from breathlessness can be managed with:

- treating reversible causes of respiratory distress such as pneumonia
- 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
- an open window or an oscillating fan blowing at a gentle speed can serve to lessen the sensation of dyspnea
- resisting the urge to crowd around the child's bed
- allowing as much natural light as possible in to the room (dark areas feel more claustrophobic
- using distraction or guided imagery

- oxygen,(by mask, nasal cannula or just blow by) which can be given at home, in hospital or in a hospice;
- targeted medications to help open the airways, reduce anxiety, and control fever;
- the sense of dyspnea can also be reduced/relieved through the administration of opioids

(See "Common Medications Used at End of Life")

### Respiratory Support Systems including Non-Invasive Ventilation (NIV)

With advances in medical technology, it has become common place for medically complex children to be managed in the home with oxygen or NIV support (i.e. CPAP, BiPAP). Many of these children have been dependent on nocturnal NIV for months to years. As the underlying disease progresses, and death approaches, parents and healthcare providers alike may find themselves wondering what to do with the NIV support. Children with underlying neuromuscular/neurodegenerative disease who are dependent on NIV for respiratory failure may become increasingly dependent on the NIV as their disease progresses. There may be a period of gradual increase in support (i.e. increased pressure) or a more sudden, marked, inability to wean from 24/7 NIV support associated with admission to hospital. Ongoing 24/7 CPAP/BiPAP is not feasible in the community for a number of reasons. For example, as the child's tolerance of feeds decreases or oral intake becomes reduced the subcutaneous fat stores will shrink resulting in an increased tendency towards facial break down and pressure sores from the NIV mask. The presence of such sores often results in significant pain requiring increases in analgesic support including opioids.

As death approaches and the goals of care/treatment change, the discontinuation of NIV support should be discussed as part of the plan to maintain comfort without prolonging the dying process. Although discontinuation of the NIV support may hasten the child's death, it is important for families and primary healthcare providers alike to realize the goal at this stage is to provide comfort and to reduce burdensome symptoms. Oxygen and or opioids can be provided to reduce the sense of dyspnea and air hunger. For most children who have been on long term non-invasive ventilation the transition is fairly smooth. With stopping NIV support, carbon dioxide levels will rise and oxygen levels will fall, both result in a state of decreased level of consciousness. That patient generally appears restful, relaxed and at peace. If they are conscious, the removal of the interface device allows for meaningful interaction with their loved ones. Some families may struggle significantly with this and will require significant ongoing support and anticipatory guidance. Palliative care subspecialty support should be sought as appropriate.

### Tracheostomy and Ventilator Dependence

Tracheostomy is becoming increasingly common amongst children living in the community. Many children who have a life limiting condition and have a tracheostomy require it for pulmonary toilet, subglottic stenosis or severe obstructive sleep apnea. The majority of children with a tracheostomy may not require any oxygen or require minimal oxygen via tracheostomy mask for chronic lung disease/repeated pulmonary aspiration. Some children living in the community with chronic complex medical conditions, however, not only have a tracheostomy but are also ventilator dependent. Many of these children have been frequently and chronically hospitalized and often their families struggle with the knowledge that their child 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. They 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 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 that in hospital. Oxygen, and opioids, such as morphine, should be provided to manage dyspnea. Consultation with the palliative care service may be helpful to both the family and primary healthcare providers.

### Discomfort/Pain

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. In the final hours however, the level of pain may not change dramatically. As the child becomes more sleepy, moves around less and the body's chemistry changes, there may actually be less discomfort and escalation of analgesics may not be required. The child may moan when moved

from side to side or when he or she breathes out. 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 limit in dosages of pain medications that can be prescribed. There are a number of ways to administer pain medications – orally, sublingually, or via subcutaneous or intravenous infusion. The medications can be given initially as needed (PRN) only if patients are opioid naïve or require infrequent opioid dosing. However, many children at the end of life will require scheduled or continuous opioid dosing with breakthrough PRN dosing. 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.

### Temperature and Vital Signs

Fever is common because the body's temperature regulator is decreasing in its function. Tumor presence or infection may also cause a fever. In addition to antipyretics, cool cloths can be applied to enhance patient comfort. Ongoing monitoring of a child's vital signs including heart rate, blood pressure and oxygen saturation are not necessary at this time; it will only serve to disturb the child's rest and increase parental anxiety. Changes in vital signs do not 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 is quite uncomfortable. Respirations may become rapid, shallow and irregular and be associated with periods of apnea. The Cheyne-Stokes breathing pattern is fairly common and may occur in the last hours or days of life. This pattern of breathing can be distressing to witness and parents as well as siblings should be reassured that it is part of the dying process and is not distressing the child.

### Withdrawal & Disorientation

As a person nears death, he or she 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 aren't left feeling disheartened and rejected. The child may seem unresponsive, withdrawn, or in a comatose like state. The eyes may be partially open and not blinking; he/she is becoming less aware of his/her surroundings and is starting to "let go". He/she 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 he or she seems more awake and alert, or remain quietly at the bedside for company while encouraging friends and extended family to visit a few at time and for short periods.

At times, 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 him or her. Friends and family should be advised to speak clearly and truthfully to him/her, and explain what they are doing. In cases of terminal delirium resulting in patient or family distress, nonpharmacological means should initially be employed; in situations where this fails, medications including an escalating infusion of sedation (midazolam) may be appropriate. In such circumstances, consultation with a palliative care specialist is recommended. (See "Common Medications Used at End of Life")

### Vision-like Experiences

As the dying process proceeds, the person may speak to or 'see' 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 behavior and families should be counseled accordingly so they are less distressed by its occurrence.

## Seizures

As with other symptoms, knowledge of the patient's past medical history and having an understanding of the underlying disease will assist you in predicting which children may be at risk of seizures. Even brief seizures can be very distressing for parents to witness; thus families should be prepared in advance for such a possibility. 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 progressive hydrocephalus and raised intracranial pressure or intracranial hemorrhage secondary to a brain tumor. Others may develop seizures secondary to metabolic disturbances including hypoglycemia, hyponatremia, hypocalcemia or hepatic encephalopathy.

Children with a history of epilepsy should be continued on their baseline antiepileptic medications to reduce the chance of breakthrough seizures. However, if the child is unable to tolerate their medications or absorb them, seizure control may be lost and alternative treatments including a midazolam infusion may be necessary. Children with new onset seizure activity will require appropriate emergency seizure treatment as well as ongoing maintenance treatment which may be given orally or via SC or IV infusion if they are unable to tolerate enteral medications.

Secondary to immobility, pain or neuropathic spasms/cramps a child may experience muscle spasms. Appropriate analgesia will reduce the associated muscle spasms. Low dose diazepam can also be utilized in addition to careful repositioning and gentle passive range of motion exercises as tolerated. Children with long term muscle spasm concerns are often on regular baclofen and/or diazepam and may require modification of their treatment regimen.

## What to Do When a Child Dies?

No amount of preparation can entirely prepare a family for the emotionally painful experience that ensues when a child dies. For many parents, the death of their own child may be the first death they have witnessed. The experience and reaction that ensues is very individual. 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 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 minimal legal requirements that need to be observed following the death of the child in the home i.e. assessment by a health professional confirming death has occurred and completion of the required documentation. They should be provided with the necessary information as to who to call after the child has died. There may be a need for prompt action for some families where cultural or religious rituals require specific time frames to be adhered to, if autopsies are required, or in the rare case if the death is a Coroner's case (i.e. under the care of CAS). If the death was expected, an EDITH should already be in place which avoids the need for the Coroner to be involved. As well, it may be helpful for the family to have a letter for the ambulance, a resuscitation plan, or document stipulating "Allow Natural Death" which explains the illness and expected treatments. In general, parents should be made aware there is no urgency for the above; they should be able to do what is truly important – be with their child and say their goodbyes. Having said that, the practicalities and the time frame in which they need to be completed should be explained. For example, most families will require counseling in regards to funeral arrangements etc.

Families, if not already aware, should be informed of the various financial services and resources available to them, including compassionate leave benefits. 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 aspects of the dying process. This may include sharing family moments, and activities prior to death, caring or tending to the dying child, to helping plan and participate in the funeral proceedings. Although parents may be apprehensive about sharing information

with the dying child's siblings, inclusion of the child(ren) will prevent or reduce their sense of fear, anxiety and isolation. Consequently they are less likely to struggle during the bereavement period and be better adjusted. It is important for parents to know that like individuals, all children grieve differently and certainly their level of development and understanding will impact on their outward behavior/demeanor/actions. Having knowledge of the locally available bereavement support services to which the family will have access is important. For school age children, parents should be encouraged to inform the teacher and school such that additional supports can be put in place for the sibling and their classmates as well as the classmates of the decreased child. Although there are a number of tasks that ought to be completed, parents may wish to delegate their completion to friends or family.

Please refer to the "Common Medications Used at the End-of-Life" Fact Sheet for additional information about medications commonly used in paediatric palliative care at this stage .

References

Cancer Care Program of North York General Hospital Approaching End of Life: **Information for Patients and Families; Some Thoughts. . .**

Children's Health Queensland Hospital and Health Service, Paediatric Palliative Care, 2014

Paediatric Palliative Care: Approaching the End-of-Life
Common Medications Used at the End-of-Life

| Drug and Indication | Route, dose and frequency | Ceiling Dose |
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| Acetaminophen<br>*Analgesic for mild pain* | PO/NG/NJ/GT 10-15 mg/kg/dose q4h-q6h PRN | max 1g/dose or 4g/day<br>Should be avoided in patients with severe liver dysfunction/failure |
| 1% Atropine Drops<br>*Reduce secretions* | SL/buccal<br>1-4 drops q4-q12h PRN (start low)<br>(~ 0.5 mg/drop) | Nil<br>Monitor closely for side effects (especially bowel and bladder) |
| Dexamethasone<br>*Cerebral edema and spinal cord compression* | PO/NG/NJ/GT/IV/SC 0.25-0.5 mg/kg/dose q6-12h<br>Seek specialist advice (bolus dose 1-2 mg/kg may be initially provided while arranging urgent imaging as appropriate) | 20 mg/dose<br>*Per lexicomp maximum 16 mg/day |
| *Anti-inflammatory (nerve pain, compression, pain, bowel obstruction)* | PO/NG/NJ/GT/IV/SC 0.1-0.25 mg/kg/dose q6-12h | 8 mg/dose<br>*Per lexicomp maximum 16 mg/day |
| *Nausea* | PO/NG/NJ/GT/IV 0.1-0.25 mg/kg/dose q6-daily | 8 mg/dose<br>*Per lexicomp maximum 16 mg/day |
| Dimenhydrinate 'Gravol'<br>*Nausea/vomiting* | PO/NG/NJ/GT/IV/IM/PR 1 mg/kg/dose q4-6h | Max 50 mg/dose; 300 mg/day |
| Diphenhydramine 'Benadryl'<br>*Pruritus* | PO/NG/NJ/GT/IM/IV 1 mg/kg/dose q6h PRN | Max 50 mg/dose; 300 mg/day |
| Fentanyl<br>*Analgesic for moderate-severe pain* | IN/transdermal/ IV/SC<br>Infants<br>Opiate naïve- usually 1-2 mcg/kg/dose;<br>Young infants/chronic opiate exposure up to 4 mcg/kg/dose<br>continuous infusion 1-5 mcg/kg/hour (may require higher doses titrate to effect)<br>children<br>1-2 mcg/kg/dose<br>continuous infusion 1-5 mcg/kg/hour (may require higher doses titrate to effect)<br>adolescents<br>0.5-1 mcg/kg/dose<br>continuous infusion 0.5-3 mcg/kg/hour (may require higher doses titrate to effect) | 50 mcg/ml ampoules should be used when administering fentanyl intranasally[1] |
| Glycopyrrolate | PO/NG/NJ/GT 40 -100 mcg/kg/dose q6-8h | 200 mcg/dose |

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| *Reduce secretions* | IV/SC 4-10 mcg/kg/dose q3-4h<br>Can be administered as a continuous infusion | |
| Granisetron<br>*Nausea/vomiting* | PO/NG/NJ/GT/IV 20 mcg/kg/dose q 12h | |
| Haloperidol<br>*Agitation/delirium*<br>*Nausea/vomiting* | PO/NG/NJ/GT/SC/IV<br>< 12 yrs: 0.01-0.1 mg/kg/dose q8-q12h<br>> 12 yrs: 500 mcg-2.5 mg q8-q12h<br>Can be administered as a continuous infusion | 7.5 mg/day |
| Hydromorphone 'Dilaudid'<br>*Analgesic for moderate-severe pain* | Infants > 6 months; > 10 kg<br>PO/NG/NJ/GT 0.03-0.06 mg/kg/dose q4h PRN<br>IV 0.01 mg/kg/dose q3-6h PRN<br><br>Children (< 50 kg)<br>PO/NG/NJ/GT 0.03-0.08 mg/kg/dose q3-4h PRN<br>IV 0.015 mg/kg/dose q3-6h PRN<br>Infusion 0.003-0.005 mg/kg/hour<br><br>Adolescents/Children > 50 kg<br>PO/NG/NJ/GT 1-2 mg/dose q3-4h PRN (opiate naïve); with chronic exposure up to 8 mg/dose<br>IV 0.2-0.6 mg/dose q2-4h PRN (opiate naïve) | Infusion 0.2 mg/hour<br>NB: both immediate release and sustained release formulations are available |
| Ibuprofen 'Motrin'<br>*Oral analgesic for mild to moderate pain* | PO/NG/NJ/GT 10 mg/kg/dose q6-8h PRN | Contraindicated in children with bleeding disorders or increased risk of bleeding (platelet dysfunction/thrombocytopenia) |
| Ketamine<br>*Analgesic* | Neonates<br>0.2-2 mg/kg/dose (titrated to effect)<br>Children<br>PO/NG/NJ/GT 6-10 mg/kg 30 minutes prior to procedure<br>IM 3-7 mg/kg<br>IV 0.5-2 mg/kg<br>Continuous infusion 5-20 mcg/kg/minute | No maximum dose |
| Laxatives | PEG<br>Lactulose<br>Senna | Should be administered concurrently with opiates to avoid/reduce opioid induced constipation |
| Lorazepam 'Ativan'<br>*Anticipatory nausea/vomiting* | PO/NG/NJ/GT/SL 0.02-0.05 mg/kg/dose q8-q24h<br>IV/SC 0.02-0.05 mg/kg/dose q6h PRN | 2.5 mg/dose |
| *Dyspnea* | For anxiety – 0.05-1 mg/kg/dose q6h PRN | 4 mg/dose |
| *Seizures* | SL/buccal 0.05-0.1 mg/kg/dose<br>IV/SC 0.1 mg/kg dose | 4/mg/dose |
| Metoclopramide 'Maxeran'<br>*Nausea/vomiting* | PO/NG/NJ/GT/IV 0.1-0.2 mg/kg q6h PRN | |
| Methotrimeprazine 'Nozinan'<br>*Nausea and vomiting*<br>*Seizures* | PO/NG/NJ/GT/IV/SC<br>< 12 yrs: 0.1-1 mg/kg/dose q12-q24h<br>>12 yrs: 6.25-25 mg q12-24h<br><br>IV/SC infusion 0.1-0.4 mg/kg/day | <br>25 mg/day<br>50 mg/day |

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| *Terminal restlessness* | IV/SC<br>0.3-3mg/kg/day as continuous infusion | |
| Midazolam<br>*Agitation*<br>*Seizures*<br>*Dyspnea* | SL/PO/NG/GT/NJ/ IN<br>< 20 kg: 0.2-0.5 mg/kg/dose<br>> 20 kg: 5 – 10 mg/dose;<br>dose can be repeated<br>IV/SC 0.1-0.2 mg/kg/dose q4h (dose can be titrated)<br>Can be administered as continuous infusion 1-5 mcg/kg/min or to effect | 10-15 mg/dose higher in refractory cases (20 mg/dose)<br><br>5mg/ml concentration should be used for intranasal administration[1] |
| Morphine<br>Liquid/tablet/injectable<br>*Analgesic for moderate-severe pain* | PO/PR/NG/NJ/GT<br>Neonate-3 mo: 0.05-0.1 mg/kg/dose q4-6h<br>3-6 mo: 0.1 mg/kg/dose q4-6h<br>> 6 mo: 0.2-0.5 mg/kg/dose q4-6h<br><br>IV/SC<br>Neonate-3 mo: 0.025mg/kg/dose q6h<br>3-6 mo: 0.05 mg/kg/dose q6h<br>> 6 mo 0.1-0.2 mg/kg/dose q4-6h | Increase dose as required – no max dose |
| *Dyspnea* | 30-50% of the dose used for pain<br>PO/NG/NJ/GT 0.05-1 mg/kg/dose q4-6h<br>SC/IV 0.025-0.5 mg/kg/dose q4-6h | |
| Ondansetron<br>*Nausea/vomiting* | PO/NG/NJ/GT /SL/IV/SC<br>0.15 mg/kg/dose q8h | 8 mg/dose |
| Phenobarbital<br>*Sedation* | PO/NG/NJ/GT 2 mg/kg/dose TID<br><br>SC/IV<br>2 mg/kg/dose TID | Up to 40 mg/dose |
| Hyoscine hydrobromide<br>'Scopolamine'<br>*Reduce secretions* | IV/SC<br>Children<br>5-10 mcg/kg/ q4-8h PRN<br>Adolescents/adults<br>300 to 600 mcg q6-8h PRN<br><br>Transdermal patch<br>Available in 1.5 mg patches; can apply up to 3 patches at a time<br>1-3 patches q72h | 600 mcg/dose |

[1] Given the intranasal route can be particularly irritating and disturbing alternative routes of delivery should be sought

Please refer to the "Approaching End-of-Life: Information for Healthcare Providers" Fact Sheet for additional information about some of the changes and experiences that may occur in paediatric palliative care patients at the end-of-life stage.