Perinatal Palliative Care

Caring for Baby and Family

Roger NEILSON Children's Hospice

For care providers.

For Children. For Families. For Life.

Roger NEILSON Children's Hospice

We offer specialized, compassionate care from diagnosis to end-of-life and grief support.

We enrich the quality of lives, no matter how short.

Perinatal Palliative Care

Roger Neilson Children's Hospice's Perinatal Palliative Care Program is a specialized and comprehensive program for parents and families who learn during pregnancy or soon after birth that their baby has a life-limiting condition.

Regardless of the situation, we offer specialized care and support to parents and families. Like so much of what we do at Roger Neilson Children's Hospice, our Perinatal Palliative Care Program focuses on families, memory-making and creating a legacy for every life, no matter how short.

Contact Information

Perinatal Palliative Care Coordinator: 613-523-6300 Ext: 4671
Monday to Friday, 8 am – 4 pm

Being with Families

Supporting families during the end of a baby's life

Supporting families during the end of a baby's life is one of the most challenging and delicate situations. Providing emotional support requires sensitivity, compassion, and an understanding of the unique grief they are experiencing.

Here are some ways to support them:

Be Present

Offering silent support and being present is often enough. Silence can be powerful, and simply being there without trying to fix anything can be comforting. Silence can allow the family to process information and facilitates opportunity for them to ask questions or share their emotions. Active listening allows the family to express their feelings, fears, and memories. Listening without interrupting or offering solutions can be very supportive. Create a safe space for the family with adequate privacy. It is okay to ask families what they need.

Caring for Baby and Family

Acknowledge their Pain

Validating their emotions and letting them know it's okay to feel angry, sad, or confused. Grief manifests in different ways, and all emotions are valid. Offering gently reassure that their emotions are normal in such a situation. Avoid clichés or phrases like "everything happens for a reason", these can be hurtful. Instead, acknowledge that what they're going through is incredibly hard.

Provide Practical Support

Ask families what they need from you. Offering help with simple tasks like offering meals, contacting social work, or making phone calls can alleviate stress. Help with memory making while normalizing this important practice. Assist with creating memories if they wish, such as taking photographs, making handprints, or collecting mementos. Memory making will be described in depth further on in this document.

Respect their Wishes

Follow their lead, some families may want to talk, while others may prefer silence or focus on other tasks. Respect their needs and follow their cues. Honor rituals by supporting any cultural or religious practices they wish to observe. Ask them if it is okay to use their baby's name.

Communicate Clearly and Gently

Use simple language with minimal medical jargon. Medical jargon can create confusion in an already confusing time. Be clear but gentle in your communication and be honest about what is happening. Often asking families how they want to receive information can be important. Some want extreme detail while others only want to know what is important for them to know.

Provide Anticipatory Guidance

Gently provide the family with information about what to expect at the end of life. This can be done before symptoms arise or as they are witnessed. Asking them how much they want to know can be helpful. If symptoms arise before they are discussed be sure to reassure the family that they are normal, and medications will be given to support these symptoms. Suffering is a significant fear for families and knowing that managing symptoms is a priority can alleviate stress. Continue support after baby has died. Follow up and check in on them after the baby has passed.

Take Care of Yourself

Acknowledge your own emotions. Supporting others in such intense situations can take an emotional toll. Ensure you have your own support system and practice self-care. If needed, seek support. Consider speaking with a counselor or peer support group for professionals.

Each family's needs will be different, so being adaptable and compassionate is key. Your role is to be a steady, compassionate presence during one of the most difficult times in their lives. Bearing witness and supporting families through this experience can be extremely rewarding for you as a provider.

Memory Making

Benefits of Memory-Making

The experience of perinatal loss, encompassing miscarriage, stillbirth, or neonatal death, is deeply traumatic for parents. However, creating memeories can serve as an essential part of the greiving and healing process.

Here are several Benefits of Memory-making after a perinatal loss:

Achnowledge the Loss

Creating memories allows parents and families to acknowledge the reality of the loss. It helps in recognizing the significance of their child's brief life and validates their grief.

Healing

The process of creating memories can be therapeutic. It provides a constructive outlet for grief and can help families process their emotions.

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Personal Connection

Memory-making helps parents establish a personal connection with their baby. Even if the time spent with their child was short or even nonexistent outside the womb, tangible memories (such as footprints, photographs, or holding the baby) can foster a deep sense of connection.

Legacy Building

Through memories, the baby's presence and impact on the world are acknowledged. Parents often find comfort in knowing that their child's life, however brief, is remembered and celebrated.

Supporting Grieving

Sharing memories with family, friends, and even support groups can help parents feel supported and less isolated in their grief. It opens channels for expressing feelings and sharing their child's significance with others.

Coping with Anniversaries

Memories and memorials can provide solace during difficult times, such as anniversaries, holidays, or expected due dates. They serve to honor the baby's memory during these particularly challenging times.

Navigating the Grieving Process

Everyone grieves differently. Memory-making allows each family member to engage in the grieving process in a way that is meaningful to them. It can be a communal activity that brings families together in their time of loss.

Continuing Bonds

Memory-making is a way to maintain an ongoing relationship with the baby who has died. It acknowledges that the child will always be a part of the family's life and history.

Lactation

The initiation of milk production can be an emotionally and physically challenging experience for mothers. It is important to review the management of symptoms the mother may experience. This would include stopping lactation if not desired. Some mothers may choose to donate their breast milk to a milk bank, which can be a way to find meaning and help other infants in need. If there is interest in donation, please contact: www.ottawamilkbank.ca

Creating Meaning with Memory-Making

Families experiencing stillbirth or perinatal loss

Creating comprehensive memory-making experiences for families experiencing stillbirth or perinatal loss is a delicate and compassionate process. It involves offering various opportunities for the family to create lasting memories with their child. Supporting families in creating memories can be a fulfilling time for care providers. Often it will require the provider to normalize this practice by describing the benefits.

Here are some suggestions:

Encourage Moments of Connection
Encourage the family to hold their baby. Care providers can model this behavior if families are expressing discomfort. Taking a moment to explain the benefits of holding their baby is important and sharing that families who did not hold their baby expressed feelings of regret.

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Capture Photographs

The process of creating memories can be therapeutic. It provides a constructive outlet for grief and can help families process their emotions.

Capture Photographs

Offer professional photography services to capture meaningful moments with the baby. This may include images of the baby alone, with family members, and any items of significance. Encourage family members to take their own photographs if they feel comfortable doing so. In some areas of Ontario, there is a volunteer service called NILMDTS who can be contacted to come and take professional photos at the hospital. **www.nowilaymedowntosleep.org**

Hand and Footprints

Provide materials for creating hand and footprints of the baby. This can be done using ink, or other safe and non-toxic mediums. These can be laminated to preserve the prints as keepsakes. Imprints in clay can be done with purchased kits online. Castings can be done with imprint alginate (Geltrate) and plaster if your organization has the supplies. Memorial Baby Casting: Casting Deceased Babies with Compassion & Ca (thecraftecademy.co.uk)

Locks of Hair

Gently collect a small lock of the baby's hair for the family to keep. Provide a small, decorative container for safekeeping. If the sample is tiny tape the hair to a piece of paper before placing, it in the container.

Memory Boxes

Offer memory boxes or keepsake containers where the family can store mementos, such as hospital bracelets, clothing, and other items associated with their baby. A special note or certificate can be included to acknowledge the baby's presence.

Respect Cultural and Religious Preferences

Be sensitive to the family's cultural and religious preferences, incorporating rituals or practices that hold meaning.

How to Perform a Baptism if Desired

Allow the family time to choose and announce the baby's name. Provide a certificate of birth and loss with the baby's name, date of birth, and any other pertinent details. Baptisms can be performed by your hospital chaplain, community spiritual adviser, or layperson such as the bedside nurse. Small baptism kits can be created with a small seashell to use as a font and a small container of Holy Water. Simply place some Holy Water in the shell, wet your thumb, and while making the sign of the cross say, I name thee [full name] in the name of the Father, the Son, and the Holy Spirit.

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Supportive Resources

Share resources on grief support, counseling, and support groups. Ensure that the family knows about available services for coping with their loss.

Be creative and explore other memory-making options with the family while caring for them:

- **Artwork** - if possible, create an opportunity for the family to participate in artwork together. This symbolic act can be a powerful and therapeutic way to express emotions.

- **Music and Recorded Messages** – offer the family the option to record messages or choose music that holds significance for them. This can be included in a memory keepsake, providing comfort in the future.

- **Recording heartbeat and fetal monitor strip** – in the case where there is a known life-limiting condition offer the family a recording of the baby's heartbeat and a strip of fetal monitoring.

- **Ceremonial Acts** – facilitate ceremonial acts, such as lighting candles or releasing balloons, to symbolize the baby's presence and the love the family holds for them.

- **Keepsake Jewelry** – provide options for the family to create or choose keepsake jewelry, such as lockets or charms, that can contain a small remembrance of their baby. If mom is producing breastmilk there are options to create breastmilk jewelry. Inexpensive kits can be purchased online.

- **Memory Book** – suggest a memory book where the family can write down thoughts, memories, and messages to their baby. Include photos and other memorabilia.

Throughout this process, communication is key. Always be open to the family's wishes and provide support and guidance. Creating a comprehensive memory-making experience can contribute to the healing process and help families cherish the brief time they had with their child.

Professional guidance, such as from bereavement counselors or support groups specializing in perinatal loss, can provide additional support and ideas for creating lasting and meaningful memories. These professionals can also offer strategies for navigating the complex emotions that accompany the creation of these memories

Caring for Baby at end of life

Pain

Effective pain management in perinatal palliative care requires a compassionate, individualized approach that balances pharmacological and non-pharmacological strategies, and emphasizes family involvement. The goal is to provide the highest quality of life possible for the neonate while supporting the family through this challenging time. Often non-pharmacological comfort measures are adequate to keep neonates comfortable. It is important to assess pain by using a validated pain scale for neonates.

Common Medications used for Pain at End of Life

- Sucrose (PO)
- Morphine (PO, BUC, SC)
- Fentanyl (SC, IN)
- Midazolam (PO, SL, SC & IN)

Non-Pharmacological Intervention for Pain and Discomfort:

- Parental presence
- Cuddling
- Skin-to-skin
- Using voice to calm
- Provide warmth, warm bathing
- Swaddling
- Message, therapeutic touch
- Positioning
- Therapeutic sounds

Assessing Pain in the Neonate | Pain Scales

N-PASS – Neonatal Pain, Agitation, & Sedation Scale

Assessment Criteria	Sedation		Normal	Pain / Agitation	
	-2	-1	0	1	3
Crying Irritability	• No cry with painful stimuli	• Moans or cries minimally with painful stimuli	• Appropriate crying • Not irritable	• Irritable or crying at intervals • Consolable	• High-pitched or silent-continuous cry • Inconsolable
Behavior State	• No arousal to any stimuli • No spontaneous movement	• Arouses minimally to stimuli • Little spontaneous movement	• Appropriate for gestational age	• Restless, squirming • Awakens frequently	• Arching, kicking • Constantly awake or Arouses minimally / no movement (not sedated)
Facial Expression	• Mouth is lax • No expression	• Minimal expression with stimuli	• Relaxed • Appropriate	• Any pain expression intermittent	• Any pain expression continual
Extremities Tone	• No grasp reflex • Flaccid tone	• Weak grasp reflex • ↓ muscle tone	• Relaxed hands and feet • Normal tone	• Intermittent clenched toes, fists or finger splay • Body is not tense	• Continual clenched toes, fists, or finger splay • Body is tense
Vital Signs HR, RR, BP, SaO_2	• No variability with stimuli • Hypoventilation or apnea	• < 10% variability from baseline with stimuli	• Within baseline or normal for gestational age	• ↑ 10-20% from baseline • SaO_2 76-85% with stimulation – quick ↑	• ↑ > 20% from baseline • $SaO_2 \leq 75\%$ with stimulation – slow ↑ • Out of sync with vent

Premature Pain Assessment

+ 3 if < 28 weeks gestation / corrected age
+ 2 if 28-31 weeks gestation / corrected age
+ 1 if 32-35 weeks gestation / corrected age

How to use the N-Pass scale

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Assessment of Sedation

- Sedation is scored in addition to pain for each behavioral and physiological criteria to assess the infant's response to stimuli
- Sedation does not need to be assessed/scored with every pain assessment/score
- Sedation is scored from 0 → -2 for each behavioral and physiological criteria, then summed and noted as a negative score (0 → -10)
- A score of 0 is given if the infant's response to stimuli is normal for their gestational age
- Desired levels of sedation vary according to the situation
  - "Deep sedation" → score of -10 to -5 as goal
  - "Light sedation" → score of -5 to –2 as goal
- Deep sedation is not recommended unless an infant is receiving ventilatory support, related to the high potential for apnea and hypoventilation
- A negative score without the administration of opioids/ sedatives may indicate:
- The premature infant's response to prolonged or persistent pain/stress
- Neurologic depression, sepsis, or other pathology

Assessment of Pain/Agitation

- Pain assessment is the fifth vital sign – assessment for pain should be included in every vital sign assessment
- Pain is scored from 0 → +2 for each behavioral and physiological criteria, then summed
- Points are added to the premature infant's pain score based on their gestational age to compensate for their limited ability to behaviorally or physiologically communicate pain
- Total pain score is documented as a positive number (0 → +10)
- Treatment/interventions are indicated for scores > 3
- Interventions for known pain/painful stimuli are indicated before the score reaches 3
- The goal of pain treatment/intervention is a score ≤ 3
- More frequent pain assessment indications:
  - Indwelling tubes or lines which may cause pain, especially with movement (e.g. chest tubes) → at least every 2-4 hours
  - Receiving analgesics and/or sedatives → at least every 2-4 hours
  - 30-60 minutes after an analgesic is given for pain behaviors to assess response to medication
- Post-operative → at least every 2 hours for 24-48 hours, then every 4 hours until off medications

Pavulon/Paralysis

- It is impossible to behaviorally evaluate a paralyzed infant for pain
- Increases in heart rate and blood pressure may be the only indicator of a need for more analgesia
- Analgesics should be administered continuously by drip or around-the-clock dosing
  - Higher, more frequent doses may be required if the infant is post-op, has a chest tube, or other pathology (such as NEC) that would normally cause pain
  - Opioid doses should be increased by 10% every 3-5 days as tolerance will occur without symptoms of inadequate pain relief

Caring for Baby and Family

Scoring Criteria

Crying / Irritability

-2 → No response to painful stimuli, e.g.:
- No cry with needle sticks
- No reaction to ETT or nares suctioning
- No response to care giving

-1 → Moans, sighs, or cries (audible or silent) minimally to painful stimuli, e.g. needle sticks, ETT or nares suctioning, care giving

0 → Not irritable – appropriate crying
- Cries briefly with normal stimuli
- Easily consoled
- Normal for gestational age

+1 → Infant is irritable/crying at intervals – but can be consoled
- If intubated – intermittent silent cry

+2 → Any of the following:
- Cry is high-pitched
- Infant cries inconsolably
- If intubated – silent continuous cry

Behavior / State

-2 → Does not arouse or react to any stimuli:
- Eyes continually shut or open
- No spontaneous movement

-1 → Little spontaneous movement, arouses briefly and/or minimally to any stimuli:
- Opens eyes briefly
- Reacts to suctioning
- Withdraws to pain

0 → Behavior and state are gestational age appropriate

+1 → Any of the following:
- Restless, squirming
- Awakens frequently/easily with minimal or no stimuli

+2 → Any of the following:
- Kicking
- Arching
- Constantly awake
- No movement or minimal arousal with stimulation (inappropriate for gestational age or clinical situation, i.e. post-operative)

Facial Expression

-2 → Any of the following:
- Mouth is lax
- Drooling
- No facial expression at rest or with stimuli

-1 → Minimal facial expression with stimuli

0 →Face is relaxed at rest but not lax – normal expression with stimuli

+1 → Any pain face expression observed intermittently

+2 → Any pain face expression is continual

Extremities / Tone

-2 → Any of the following:
- No palmar or planter grasp can be elicited
- Flaccid tone

-1 → Any of the following:
- Weak palmar or planter grasp can be elicited
- Decreased tone

0 → Relaxed hands and feet – normal palmar or sole grasp elicited – appropriate tone for gestational age

+1 → Intermittent (<30 seconds duration) observation of toes and/or hands as clenched or fingers splayed
- Body is not tense

+2 → Any of the following:
- Frequent (≥30 seconds duration) observation of toes and/or hands as clenched, or fingers splayed
- Body is tense/stiff

Vital Signs: HR, BP, RR, & O2 Saturations

-2 → Any of the following:

- No variability in vital signs with stimuli
- Hypoventilation
- Apnea
- Ventilated infant – no spontaneous respiratory effort

-1 → Vital signs show little variability with stimuli – less than 10% from baseline

0 → Vital signs and/or oxygen saturations are within normal limits with normal variability – or normal for gestational age

+1 → Any of the following:

- HR, RR, and/or BP are 10-20% above baseline
- With care/stimuli infant desaturates minimally to moderately (SaO_2 76-85%) and recovers quickly (within 2 minutes)

+2 → Any of the following:

- HR, RR, and/or BP are > 20% above baseline
- With care/stimuli infant desaturates severely (SaO_2 < 75%) and recovers slowly (> 2 minutes)
- Infant is out of synchrony with the ventilator – fighting the ventilator

Dyspnea

Many breathing changes can occur as death approaches and organs begin to shut down. These changes are not often a distressing experience for the patient. Dyspnea is different from these breathing changes; it is the sensation of difficulty breathing or shortness of breath as described by the patient. In the case of an infant, it is important to be assessed for signs of distress. Dyspnea can include many causes such as fluid overload or underlying lung pathology.

Medications:

- Morphine (PO, BUC, SC)
- Fentanyl (SC, IN)
- Midazolam (PO, SL, SC & IN)

Non-Pharmacological Interventions for Dyspnea:

- Calm environment
- Parental presence
- Allowing air to flow over the face will stimulate the trigeminal nerve, this reduces the sensation of breathlessness. it is important to keep the baby warm while using a blow-by or a fan.

Seizures

Seizures occur in the presence of abnormal and excessive electrical discharge of cortical neurons and is often a manifestation of an underlying issue (Gardner, S.L., Carter, B.C., Enzman-Hines, M., Niermeyer, s. 2021. 952.) neonate seizures are caused by changes in the brain. a variety of factors may contribute to these changes, including hemodynamic changes at end-of-life, how the brain developed in utero, or hypoxic injury sustained during pregnancy, labor, or delivery. seizure activity in the neonates can present in many different ways depending on the type of seizure.

Medications

- Midazolam (PO, SL, SC & IN)

Non-Pharmacological Interventions for Seizures

- Understand the risk for seizures and provide anticipatory guidance
- Parental presence
- Stay with the family

Agitation and neuro-irritability

Agitation and neuro-irritability has been described as an unpleasant state of arousal, restlessness and signs of discomfort that persist with the provision of pain management (Cortezzo, D.E., Meyer, M. 2020).

Medications

- Midazolam (PO, SL, SC & IN)

Non-Pharmacological Interventions for Seizures

- Provide anticipatory guidance to the family.
- Comfort measures, skin to skin.
- Parental presence

Secretions

Excessive secretions are not a common symptom for the neonate at the end of life. it can be seen when there are underlying issues with decreased tone, alertness, and activity nearing the end of life (Cortezzo, D. E., Meyer, M. 2020).

Medications

- Atropine eye drops (PO)

Non-Pharmacological Interventions for Secretions

- Anticipatory guidance
- Good oral care/mouth care
- Positioning for comfort and drainage
- Gentle suctioning only when absolutely necessary as suctioning can increase the production of secretions

Table 1 represents a reformatting of the table published in the following article: Stephanie Veldhuijzen van Zanten, Emanuela Ferretti, Gillian MacLean, Thierry Daboval, Lena Lauzon, Elmily Reuvers and Christina Vadeboncoeur (2022). Medications to manage infant pain, distress and end-of-life symptoms in the immediate postpartum period, Expert Opinion on Pharmacotherapy, 23:1, 43-48.

Table 1. Medications given via noninvasive routes for initial symptom management at end-of-life for infants in the delivery room or on postpartum wards.

PURPOSE/USE	COMPONENT	DOSAGE BY WEIGHT AND ROUTE		COMMENTS FOR ADMINISTRATION
General comfort	**SUCROSE 24%**	**BW ≤ 1000 g**	☐ **Dose:** 0.1 mL PO q30 min PRN	To be administered by unidose vials (in drops) on the anterior tip of the tongue (with soother if needed)
		BW > 1000 g	☐ **Dose:** up to 0.5 mL PO q30 min PRN	
Comfort / Pain / Dyspnea or Breathlessness ↓ Choose one medication for comfort or pain	**MORPHINE** **Use oral solution** [1 mg/mL]	**BW ≤ to 500 g** ☐ **Dose:** 0.05 mg (= 0.05 mL) BUC* q2h PRN		Increase by 0.05 mg/dose if previous dose was ineffective. Titrate to effect with no maximum dose for opioids.
		BW > 500 g and <2000 g ☐ **Dose:** 0.1 mg (= 0.1 mL) BUC* q2h PRN		Increase by 0.1 mg/dose if previous dose was ineffective. Titrate to effect with no maximum dose for opioids.
		BW ≥ 2000 g and <4000g ☐ **Dose:** 0.2 mg (= 0.2 mL) BUC* q2h PRN		Increase by 0.1 mg/dose if previous dose was ineffective. Titrate to effect with no maximum dose for opioids.
		BW ≥ 4000g ☐ **Dose:** 0.3 mg (= 0.3 mL) BUC* q2h PRN		Increase by 0.15 mg/dose if previous dose was ineffective. Titrate to effect with no maximum dose for opioids. • Injectable formulation given by buccal route may be preferred as it will represent less volume
	MORPHINE **Use injectable** form [2 mg/mL]	**BW ≤ to 500 g** ☐ **Dose:** 0.05 mg (= 0.025 mL) BUC* q2h PRN		Increase by 0.05 mg/dose if previous dose was ineffective. Titrate to effect with no maximum dose for opioids.
		BW > 500 g and <2000 g ☐ **Dose:** 0.1 mg (= 0.05 mL) BUC* q2h PRN		Increase by 0.1 mg/dose if previous dose was ineffective. Titrate to effect with no maximum dose for opioids.
		BW ≥ 2000 g and <4000g ☐ **Dose:** 0.2 mg (= 0.1 mL) BUC* q2h PRN		Increase by 0.1 mg/dose if previous dose was ineffective. Titrate to effect with no maximum dose for opioids.
		BW ≥ 4000g ☐ **Dose:** 0.3 mg (= 0.15 mL) BUC* q2h PRN		Increase by 0.15 mg/dose if previous dose was ineffective. Titrate to effect with no maximum dose for opioids.

Legend: BUC buccal (given at the level of the buccal pouch between the lower gums and inner lining of the cheeks); BUC* = Administration via nasogastric/orogastric tube should be considered if unable to provide through buccal route; BW birth weight; IN intranasal; MAD® Mucosal Atomization Device; PO per os; PRN as needed; SL sublingual. Used with permission of The Ottawa Hospital, Ontario, Canada.

Table 1. Medications given via noninvasive routes for initial symptom management at end-of-life for infants in the delivery room or on postpartum wards.

PURPOSE/USE	COMPONENT	DOSAGE BY WEIGHT AND ROUTE	COMMENTS FOR ADMINISTRATION
Comfort, Pain, Dyspnea or Breathlessness ↓ Choose one medication for comfort or pain	**FENTANYL** **Use injectable form** [50 mcg/mL] with MAD® on a 1mL tuberculin syringe **for IN administration, draw up extra medication equal to the dead space volume of the MAD (verify for specific MAD device)	**BW ≤ 1000 g** ☐ **Dose:** 1 mcg (= 0.1 mL) IN q5 minutes PRN	Withdraw 2 mL (100 mcg) of Fentanyl, then add 8mL of normal saline Final Concentration: 10 mcg/mL Administer 1 mcg = 0.1 mL IN**
		BW > 1000 g and < 3000 g ☐ **Dose:** 2.5 mcg (= 0.25 mL) IN q5 minutes PRN	Withdraw 2 mL (100 mcg) of Fentanyl, then add 8 mL of normal saline Final Concentration: 10 mcg/mL Administer 2.5 mcg = 0.25 mL IN**
		BW ≥ 3000 g ☐ **Dose:** 5 mcg (= 0.5 mL) IN q5 minutes PRN	Withdraw 2 mL (100 mcg) of Fentanyl, then add 8 mL of normal saline Final concentration: 10 mcg/mL Administer 5 mcg = 0.5 mL IN**
Reduce Secretions	**ATROPINE 1% (eye drops)**	☐ **Dose:** 1-2 drops SL q4-6h PRN	Use 1% ophthalmic drops for sublingual administration
Sedation / Seizures	**MIDAZOLAM** **Use injectable form** [1 mg/mL]	**BW ≤ 1000 g** ☐ **Dose:** 0.1 mg BUC or SL = 0.1 mL q5 minutes PRN	Titrate to effect by administrating the same dose q5 minutes PRN
		BW > 1000 g and < 3000 g ☐ **Dose:** 0.25 mg BUC or SL = 0.25 mL q5 minutes PRN	Titrate to effect by administrating the same dose q5 minutes PRN
		BW ≥ to 3000 g ☐ **Dose:** 0.5 mg BUC or SL = 0.5 mL q5 minutes PRN	Titrate to effect by administrating the same dose q5 minutes PRN
		RELEVANT NOTE: If unable to provide Midazolam through BUC or SL route or if treating a seizure use MAD® with 1mL tuberculin syringe for IN** administration as indicated below (see legend for reference) **for IN administration, draw up extra medication equal to the dead space volume of the MAD (verify for specific MAD) **FOR SEIZURES**	
		BW ≤ 1000 g ☐ **Dose:** 0.15 mg = 0.15 mL IN q5 minutes PRN	
		BW > 1000 g and < 3000 g ☐ **Dose:** 0.3 mg = 0.3 mL IN q5 minutes PRN	
		BW ≥ 3000 g ☐ **Dose:** 0.6 mg = 0.6 mL IN (administer 0.3 mL per nostril) q5 minutes PRN	

Legend: BUC buccal (given at the level of the buccal pouch between the lower gums and inner lining of the cheeks); BUC* = Administration via nasogastric/orogastric tube should be considered if unable to provide through buccal route; BW birth weight; IN intranasal; MAD® Mucosal Atomization Device; PO per os; PRN as needed; SL sublingual. Used with permission of The Ottawa Hospital, Ontario, Canada.

Our heartfelt gratitude

Roger NEILSON Children's Hospice

We extend our heartfelt gratitude to the families who generously shared their experiences and insights, helping to shape this guide with authenticity and compassion.

Their invaluable contributions have ensured that the perspectives of those who have lived through perinatal loss are at the heart of this document.

Special Thanks

Special thanks also go to the dedicated Perinatal Palliative Care team at Roger Neilson Children's Hospice for their unwavering commitment to supporting families and care providers. Their expertise and dedication made this resource possible, and it stands as a testament to their tireless efforts in fostering understanding and empathy.

For Children. For Families. For Life.

Roger Neilson Children's Hospice is a unique home-like environment designed for the most challenging journey that families can experience. A journey that most families cannot imagine having to take.

Our uniquely trained, highly skilled and compassionate team cares for children, youth and families. We are there from the early stages of a life-limiting illness to end-of-life care and grief support. When a life ends, our compassion and support continue.

Our daily purpose, which gets us all up and going each day and every shift, is our commitment to enhancing the quality of young lives. To ease a difficult journey for children, youth and their families. To create memorable moments, lasting memories and enduring legacies. We are here for children and their families.

We are here to enrich the quality of every life, no matter how short.

Care at Roger Neilson Children's Hospice includes:

- Pediatric Hospice Palliative Care
- Grief Support and Services
- Perinatal Palliative Care Hospice Program

Roger NEILSON Children's Hospice

Discover more by visiting

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