Version	Date	Comments / Changes
1.0	December 2020	Initial Clinical Practice Guideline Released
2.0	April 2021	Revision

A systematically developed statement to assist practitioners and patients/residents/clients make decisions about appropriate intervention/treatment options for health care in specific clinical circumstances.

1. PURPOSE

1.1 To identify the roles and responsibilities of the healthcare team when providing end of life (EOL) care in the Royal Columbian Hospital (RCH) Neonatal Intensive Care Unit (NICU).

1.2 To provide consistency and standards for the healthcare team during the provision of EOL care in the NICU

2. BACKGROUND

EOL care is provided to neonates when their parents and the healthcare team believe that life extending care is no longer in the best interest of the infant.

EOL care in the NICU is a multidisciplinary approach used to minimize symptoms by providing comfort care to the neonate. Palliative care aims to meet the physical, psychological, social and spiritual expectations and needs of the neonate and their family while remaining sensitive to their personal, cultural and religious values.

Referral to Canuck Place for palliative care consultation is available when desired by the family and the healthcare team. Parental consent is needed for the referral to Canuck Place. Instructions on the referral process to Canuck Place can be found on: https://www.canuckplace.org/resources under Referral Process and Urgent Referrals. Referrals can be done via email to: intake@canuckplace.org by doctors, nurses, medical specialists, social workers, families or their support persons.

3. DEFINITIONS

The term “parents” will be used to refer to the legal guardian throughout this document. We acknowledge that some parents may not be the legal guardian of the neonate.

4. EXPECTED OUTCOMES

5. ASSESSMENT

Palliative care should be considered for an infant when it becomes apparent that treatment aimed at curing or prolonging life is leading to a significant reduction of an infant’s quality of life.

Conditions appropriate for palliative care can be categorised as

1. Life limiting: any condition clearly associative with a limited life span with no curative treatment available (eg. anencephaly)
2. Life-threatening: any conditions where treatment may be feasible but may not be successful (eg. extreme prematurity)
3. Progressive conditions: treatment is available for symptom control but no curative option exists currently.(eg. spinal muscular atrophy)
4. Burden of disease or treatment outweighs the benefits as perceived by the health care team including the family (eg. trisomy 13 or 18)

6. INTERVENTION

6.1 Family Discussion Checklists
- 6.1.1 Medical Checklist
- 6.1.2 Family Support Checklist

Medical Checklist

Central Nervous System	Provision of pharmacologic and nonpharmacologic for symptom management. 1. Pharmacologic a. See Neonatal Palliative Care Medications on backside of NICU Terminal Wean from Mechanical Ventilation PPO - Appendix B 2. Non-Pharmacologic a. Skin to Skin b. Swaddling/containment/holding c. Non-nutritive Sucking d. Minimal stimulation i. Lowering lights ii. Keeping extraneous sounds to a minimum e. Music or listening to familiar voices f. Oral care with breast milk if possible Discontinue Paralytic Agents
Cardiovascular System	Cardiorespiratory Monitoring and Oxygen Saturation Monitoring 1. Individualized discontinuation of continuous monitoring should be discussed Discontinue Cardiac Medications 2. See Medication section below
Respiratory System	Terminal Extubation 1. Provide the family with the expected sequence of events of the removal of the ventilator. a. The infant's physical response i. Symptom management ii. The infant may or may not die immediately b. Role of the family during this process i. If they choose to be present/hold their infant ii. Ceremony or meaningful rituals to be done at this time prior to extubation

	iii. Ongoing care plan if the infant continues to breathe 2. See Respiratory Therapy Clinical Procedure - Neonatal Terminal Extubation - Appendix C
Fluid & Nutrition/ Gastrointestinal System	Discuss the family's wishes for nutrition and hydration 1. Intravenous (IV) Access a. If the IV catheter is insitu and comfortable for the infant, consider maintaining the IV as tolerated for medication administration. b. To minimize the amount of medical equipment on the infant, consider the removal of the intravenous catheter and use alternate routes (oral, sublingual, buccal, subcutaneous or rectal) for medication administration. 2. Nutrition and Hydration a. Medically provided fluids may be withheld or withdrawn when it is no longer consistent with the goals of care. b. Discuss enteral feeds as a comfort measure rather than nutrition. i. Discuss the risks and benefits of artificial nutrition and hydration. 1. The gastrointestinal slow downs during the dying process. 2. Loss of ketotic euphoria 3. Prolonging the dying process ii. Discuss the use of the nasogastric or orogastric tube for medication administration. c. Continue mouth care d. Discuss possible release of bowel movement during the end of life
Genitourinary	Discontinuation of urinary catheter Discuss the use of diuretics Maintain skin integrity Continue diaper changes
Diagnostics	Discontinue or minimize invasive tests and painful procedures when they are no longer consistent with the goals of care.
Medications	Consider discontinuing medications when they are no longer consistent with the goals of care, for example:

	1. Paralytics 2. Inotropes and Vasopressors 3. Pulmonary Hypertension Medications a. Inhaled Nitric Oxide b. Sildenafil 4. Antibiotics 5. Diuretics Pain and Sedation 1. Discuss the importance of appropriate pain control and sedation a. Appendix B
Autopsy and Organ Donation	Contact BC Organ Donation service to notify of expected death Discuss with Family and obtain consent if applicable

Family Support Checklist

Location	Private area if possible: 1. Family Room 2. Isolation Room 3. Possible areas on hospital campus a. Discuss possible visit prior to terminal extubation i. Garden area ii. Chapel iii. Other units 4. Canuck Place a. Potential to do EOL at home
Support Persons	Religious and cultural support people for ceremonies/rituals Discuss feasibility of delaying EOL until a specific support person (ie grandparent, godparent) arrives.
Ceremonies/Rituals	Discuss with family if there is anyone specific who can offer them religious or culture support. 1. If they would like support but do not have a designated contact then consult the Religious/Cultural support contact list. 2. Specific items in baby's room/bed/worn by the infant 3. Food, music, prayer-recordings and other items parents want to bring in.

Photography	Now I Lay Me Down to Sleep Photographers 1. Arrange for designated photographers to come 2. If photographer unable to come: a. For posing: https://www.nowilaymedowntosleep.org/medical/posing-guide/ b. For editing: https://www.nowilaymedowntosleep.org/medical/requesting-services/retouching/ Family Support System present if desired Registered Nurses to assist and support
Memory Box	Some examples of possible items for a memory box: Lock of infant's hair (if culturally appropriate), hand and foot prints, nametag, crib card, etc. 1. If available: a. Hand and foot prints clay kit b. Family friendly cardstock, envelopes and bags to hold contents that do not fit inside the memory box.
Bereavement Care and Follow-up the community	If the family desires, contact with Canuck Place prior to EOL Funerary Options 1. Up to date information about appropriate funerary options given by social work 2. Social Work to arrange for possible derral of cost of funeral Continuing Social Work Follow-Up 1. Referral to Reproductive Mental Health team in their community 2. Regular check-ins with social work and/or counsellors during EOL planning and procedure 3. EI/Work documentation for extended bereavement leave/short term disability etc. 4. Discuss the option of the unit sending a 1 year remembrance card to the family Follow-up with Neonatologist if applicable 1. Referral to be done prior to the infant passing if applicable a. To discuss questions or pending test results that may arise after the baby has passed away

	Lactation Suppression - Pamphlet in Neonatal Loss binder Family Care Provider follow-up in community Future family planning (i.e. genetic counselling) if applicable

7. DOCUMENTATION

Advance Care Planning (ACP) and Do Not Attempt Resuscitate Orders (DNAR) documents have not been developed for use at RCH NICU as of this revision. Therefore, a written plan must be documented in the Progress Notes and on the Doctors Orders by the physician. Family meetings can be documented by the bedside nurse on "Nursing Care Plan Communication Tool." If the care plan changes after a meeting, ensure the updated plan is documented and all care team members are aware.

8. EDUCATION

9. EVALUATION

10. MONITORING

11. REFERENCES

BC Women's Hospital and Health Centre. (2017, April 13). *End of life care: Clinical practice guideline.* Neonatal Program Policy & Procedure Manual. http://policyandorders.cw.bc.ca/resource-gallery/Documents/BC%20Women's%20Hospital%20-%20Neonatal%20Program/NN.18.01%20End%20of%20Life%20Care%20Clinical%20Practice%20Guideline.pdf

Alberta Health Services. (2019). *Neonatal palliative care guide for neonatal intensive care units.* Neonatal Palliative Care Guide, Maternal Newborn Child & Youth SCN. https://www.albertahealthservices.ca/assets/about/scn/ahs-scn-mncy-neonatal-palliative-care-guide-nicu.pdf

Newman, V., Vesely, C., Collinson, C., & Winters, Y. (2015, September). *End of life symptom management.* UCSF Benioff Children's Hospital, Oakland. https://www.eastbaynewborn.com/docs/End%20of%20Life%20Symptom%20Management-NICU.pdf

SickKids Staff. (2009, October 28). *Palliative care for newborn babies.* AboutKidsHealth. https://www.aboutkidshealth.ca/article?contentid=474&language=english

12. APPENDICES

12.1 **Appendix A - End of Life Checklist**
12.2 **Appendix B - Pre-Printed Orders for NICU Terminal Weaning From Mechanical Ventilation**
12.3 **Appendix C - Respiratory Therapy Clinical Procedure - Neonatal Terminal Extubation**

Appendix A – EOL Checklist

Before withdrawal of life-sustaining treatment

- Role clarification before the family meeting between multidisciplinary attendees
- Family meeting with primary care provider, social worker, PCC etc
  - Review Family Discussion Points for areas to be covered during family meeting
  - Discuss outcome and timeline using a systematic approach
  - Develop care plan for withdrawal of care with parents (See "Care Plan")
  - Document family meeting discussion and post on Backing Form
  - MRP to complete PPO
  - Discuss funerary arrangements
- Connect family with applicable Canuck Place resources
- Discuss location of EOL and make appropriate arrangements
- Contact Now I Lay Me Down to Sleep photographer with estimated time and date
  - Discuss what processes they would like photographed

Discuss with parents any other personalisation details they'd like immediately before/during withdrawal of care (eg. certain music played, a walk, blankets/clothes etc)

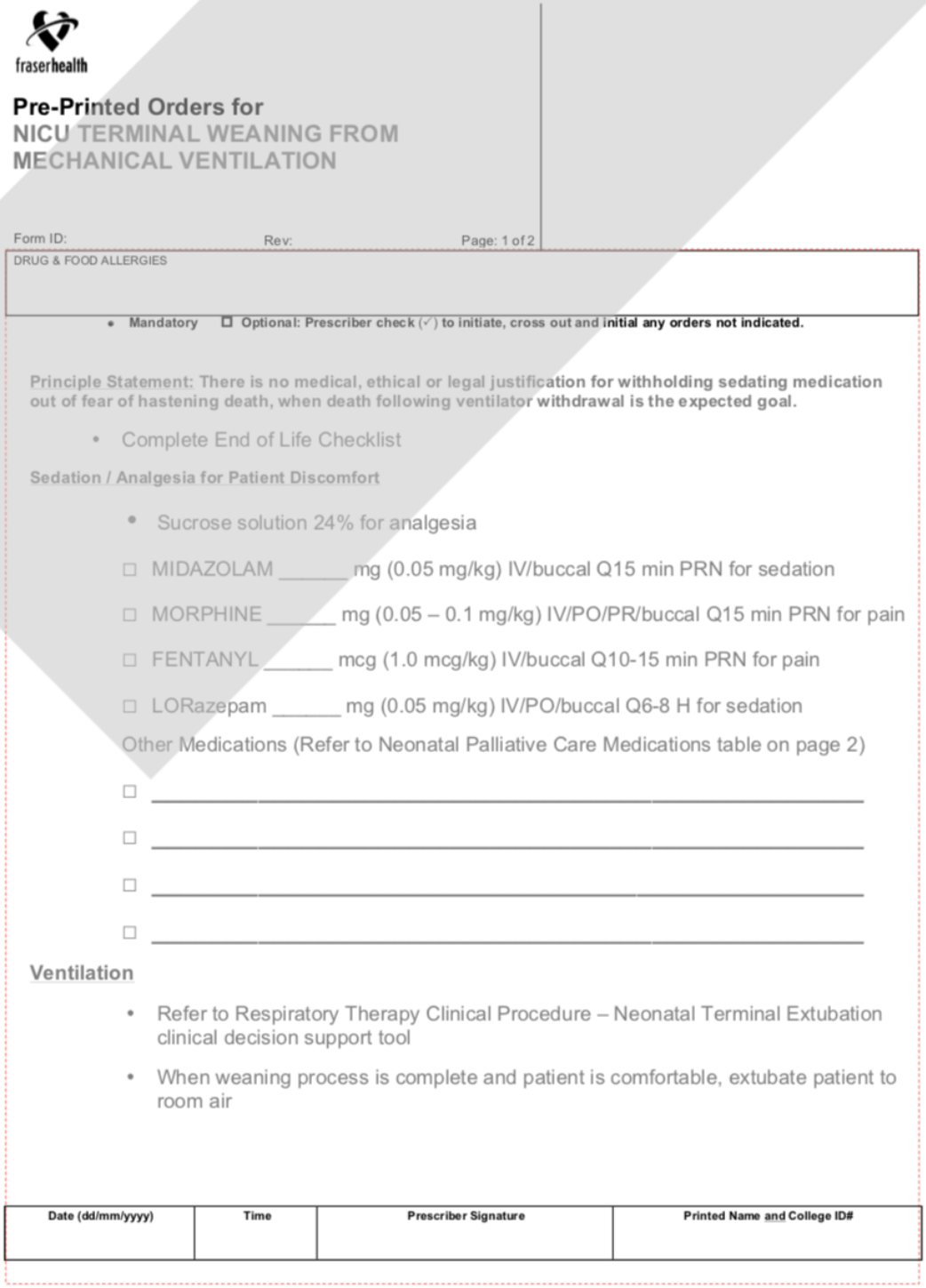
During withdrawal of life-sustaining treatment

- Who will be present?
  - Which members of the multidisciplinary team
    - Role clarification for team members who will be present
  - Which family and support people will be present
    - Who will hold or do S2S with the baby during extubation?
- Prep location immediately before EOL
  - Where will the baby be extubated?
  - Photographer (present before, during, and/or after extubation)
- Removal of unnecessary equipment (use vaseline, adhesive remover, or baby oil as necessary)
  - PIV/Central lines
  - Cardiorespiratory monitors (incl tCO_2)
  - Pulse oximeter
  - Remove neobar and tape before S2S
  - Provide EOL medication as per PPO - includes routes
  - Decrease ventilation settings according to respiratory CPG

After death

- Print and complete documents from Neonatal Loss Manual
- Create memento box
- Use kraft paper bags to pack extra belongings that do not fit in memento box
- Bathe and dress the infant with the family
- Arrange area for photographer, use list of suggested poses if no photographer is available (https://www.nowilaymedowntosleep.org/medical/posing-guide/)
- Have staff sign sympathy card

Appendix B - End of Life Pre-Printed Orders (front)



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Pre-Printed Orders for
NICU TERMINAL WEANING FROM MECHANICAL VENTILATION

Form ID: Rev: Page: 1 of 2

DRUG & FOOD ALLERGIES

• Mandatory ☐ Optional: Prescriber check (✓) to initiate, cross out and initial any orders not indicated.

Principle Statement: There is no medical, ethical or legal justification for withholding sedating medication out of fear of hastening death, when death following ventilator withdrawal is the expected goal.

- Complete End of Life Checklist

Sedation / Analgesia for Patient Discomfort

- Sucrose solution 24% for analgesia
- ☐ MIDAZOLAM _____ mg (0.05 mg/kg) IV/buccal Q15 min PRN for sedation
- ☐ MORPHINE _____ mg (0.05 – 0.1 mg/kg) IV/PO/PR/buccal Q15 min PRN for pain
- ☐ FENTANYL _____ mcg (1.0 mcg/kg) IV/buccal Q10-15 min PRN for pain
- ☐ LORazepam _____ mg (0.05 mg/kg) IV/PO/buccal Q6-8 H for sedation

Other Medications (Refer to Neonatal Palliative Care Medications table on page 2)

- ☐ _____
- ☐ _____
- ☐ _____
- ☐ _____

Ventilation

- Refer to Respiratory Therapy Clinical Procedure – Neonatal Terminal Extubation clinical decision support tool
- When weaning process is complete and patient is comfortable, extubate patient to room air

Date (dd/mm/yyyy)	Time	Prescriber Signature	Printed Name and College ID#

Appendix B - End of Life Pre-Printed Orders (back)

Neonatal Palliative Care Medications (RCH) Reference Chart

Typical Starting Doses – Oral, Rectal, Buccal, Intravenous**
Intravenous route can be used in palliative management, but not preferred route at final stage.
Individualization for each patient required as not all medications and doses may apply.

DRUG	USE	DOSE	FREQUENCY	COMMENTS
Acetaminophen	Analgesia Pyrexia	10 – 15 mg/kg PO/PR	Q4h PRN Usual max daily dose for PMA: 24-30 wks – 30mg/kg/d 31-36 wks – 50mg/kg/d ≥37 wks – 60mg/kg/d	Pyrexia can occur as body function shuts down.
Atropine	Antisecretory	0.02 mg/kg PO	Q4h PRN	Alternative Glycopyrolate
Chloral hydrate	Sedation	10 – 30 mg/kg PO/PR	Q6h PRN	
Fentanyl	Pain Respiratory distress	1 mcg/kg buccal/IV	Q10-15 min PRN	Give first dose prior to extubation. Buccal conc'n: 50 mcg/mL
Glycopyrrolate	Antisecretory	2 - 4 mcg/kg sc/IV 20 - 40 mcg/kg PO	Q6-8 H Q8–12 H	IV/sc conc'n: 200mcg/mL or diluted 2mcg/mL (for vol <0.2mL) PO conc'n: 100 mcg/mL
Lorazepam	Sedation	0.05 mg/kg PO/buccal/IV	Q6-8 H	Longer sedation time compared to Midazolam
Midazolam	Respiratory distress Sedation	0.05 – 0.1 mg/kg buccal/IV	Q15 min PRN	Buccal conc'n: 5 mg/mL inj IV conc'n: 0.2mg/mL
	Seizure	0.2 – 0.3 mg/kg buccal/IV	Max 10 mg	
Morphine	Pain	0.05 – 0.1 mg/kg PO/PR/buccal/IV	Q15 min PRN	
	Respiratory distress	0.03 mg/kg PO/PR	Q15 min PRN	
Phenobarbital	Seizures	Loading dose: 10 – 20 mg/kg PO/IV Max Load=40mg/kg		
		Maintenance dose: 3 - 5 mg/kg PO/IV	daily	
Famotidine	GERD	0.5-1mg/kg PO 0.25-0.5mg/kg IV	daily	PO conc'n: 8mg/ml
Ranitidine	GERD	2 mg/kg PO 0.5-0.8mg/kg IV	Q12 H	
Sucrose solution 24%	Analgesia for painful procedure	Refer to Mosby's skills		

Updated March, 2021

Appendix C - Respiratory Therapy Clinical Procedure - Neonatal Terminal Extubation

Respiratory Therapy Clinical Procedure – Neonatal Terminal Extubation

Place baby S2S with the parent if this aligns with family's wishes.

Turn off all ventilator alarms or reduce to minimum level and discontinue monitors if this aligns with parents wishes.

Wean ventilator settings based on the mode of ventilation (within approximately 5 minutes):

HFJV:

- Decrease PIP to 20
- Decrease RR to 240
- Decrease Ti to .020
- Decrease FiO2 to 0.21
- Decrease PEEP on conventional ventilator to 5 cmH20

HFO:

- Decrease Amplitude 20
- Decrease MAP to 5 cmH20
- Decrease FiO2 to 0.21
- If baby appears air hungry, consider switching the mode to AC and wean as per below

ACPC **(Ensure VG is turned off for weaning)**:

- PIP 10 cmH20
- Decrease PEEP to 5 cmH20
- Decrease RR to 5bpm
- Decrease FiO2 to 0.21

Monitor patient for distress. If the baby appears to be in discomfort, consider adjusting pain management medications.

Suction orally and via ETT.

Extubate to room air as per Pre Printed Orders. Consider using baby oil to assist with removing neobar.