



Montreal Children's Hospital
McGill University Health Center

Palliative Care in the NICU

NURSING GUIDELINES

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NEONATAL INTENSIVE CARE UNIT, MUHC
IN COLLABORATION WITH THE PEDIATRIC ADVANCED CARE



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INTRODUCTION

WORLD HEALTH ORGANIZATION Definition of Palliative Care for Children:

- Palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family.
- It begins when life-limiting illness is diagnosed, and continues regardless of **whether or not** a child receives treatment directed at the disease.
- Health providers must evaluate and alleviate a child's physical, psychological, and social distress.
- Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited.

NEONATAL PALLIATIVE CARE

The Nation Association of Neonatal Nurses' definition of end of life care for newborns:

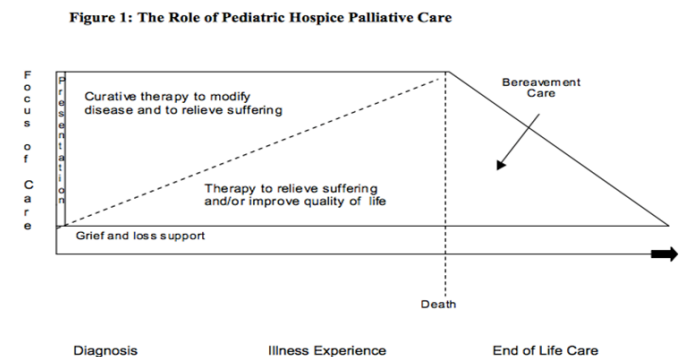
- Infants born with life-limiting conditions or who develop life-limiting conditions during their neonatal hospitalization may receive palliative care.
- Palliative care focuses on improving a patient's quality of life and may be offered concurrently with curative care to treat symptoms, minimize suffering, and offer improved quality of life.
- Through the ongoing assessment of care goals, parents, nurses, and other providers determine the appropriateness of continuing intensive therapies and weigh the benefits of shifting the goals of care toward the provision of comfort for the infant and family.

GOAL

The **goal** of this model is to achieve the best quality of life possible for babies with life-limiting conditions, within which curative and comfort care coexist. Initially, cure-oriented and disease-modifying care may have more weight, but if it becomes no longer helpful or appropriate for the patient's wellbeing, a palliative approach can be increasingly emphasized.

Care will be provided with dignity, love and respect and may help the parents abandon guilt, and find comfort through the creation of loving memories of their time with their child.

Palliative care exists on a continuum with curative care. Palliative care does not always equal end-of-life care.



PALLIATIVE CARE SYMBOL: A SILENT SYMBOL

The Quality Standards for End-of-Life Care [1] recommends:



- The symbol was developed by the Neonatal Palliative Care Workgroup
- It is inspired by the first baby who died in palliative care in the new MUHC NICU. The pajama and mittens he was wearing at the time of death were covered in fish.

Purpose of the symbol

- Identify the families that are beneficiary of a palliative care approach
- Support the family's desire for intimacy, privacy, connection and physical contact with their child.
- Upon seeing the symbol, we expect :
 - Staff to recognize the sensitivity and fragility of the situation surrounding this particular family.
 - Staff to uphold an atmosphere of peace and quiet, avoid mobile phone use and prepare themselves to meet people who are grieving.
 - Staff to provide special support to the team members, caring for this family.

Displaying the symbol

- **The symbol should be considered when you have a signed DNR or Levels of care/cardiopulmonary resuscitation**
- It should be displayed on the baby's door (using the Velcro stickers) or on the screen in front of the room's window
- It should be displayed on the unit map by the unit coordinator

Another interesting symbol used to represent neonatal loss and bereavement



The purple butterfly logo is used when the baby was part of a multiple pregnancy in which not all babies survived, it is used to honor the deceased twin or multiple.

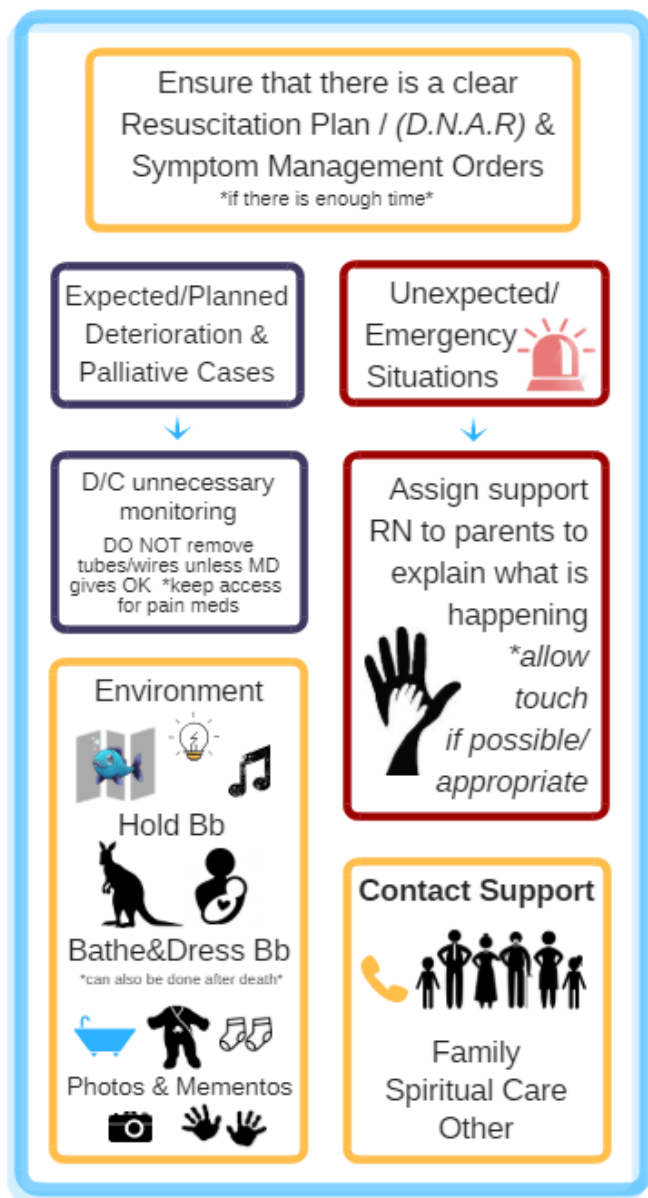
It is a symbol to remind staff and visitors to be mindful of the situation

Please, if you feel comfortable, talk about the loss with the parents, it is very important for their grieving process.

[1] The Quality Standards for End-of-Life Care (2010) recommend: 'A universal symbol, which is recognized by all staff and by the public as indicating that a death has occurred, is clearly visible in the ward/department'.

END OF LIFE: INCLUDING UNEXPECTED/RAPID DEATHS

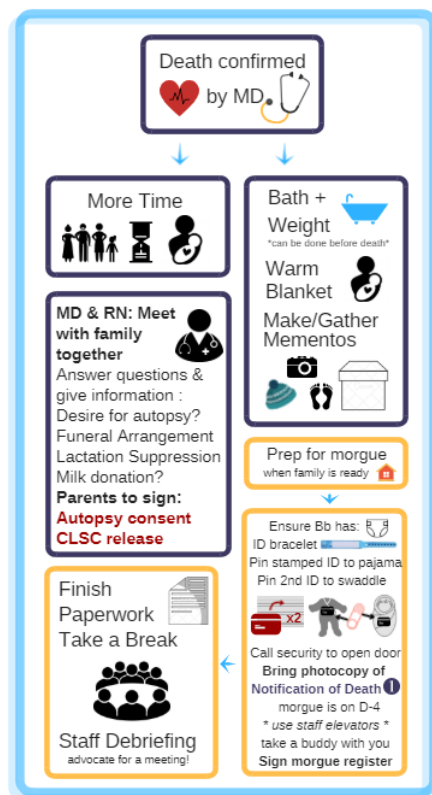
When a an infant's death is imminently expected:



- If a decision to withdraw life-sustaining therapies/treatments (e.g. to extubate) is made and time permits, ensure that there are clear resuscitation guidelines and sedation orders.
- WITH MDs PERMISSION, remove such items as the foley catheter, cardiac monitor, electrodes, saturation probe, repleg or nasogastric tubes. It allows the parents to have a last image of their infant without too much medical equipment HOWEVER some equipment must be left if there is to be a coroner case, always verify with MD!
- Keep a medication (IV etc) access in case the infant requires sedation or pain relief.
- Ensure that the environment is calm and intimate
 - Dim lights
 - Soft music
 - Display Fish Symbol
- Whenever possible, dress the infant in a hat, mittens, and booties before death. Clothing kits, in different colors and sizes, are available in the storage room in the first hallway (B06.2645).
- Offer the parents time alone to hold their baby and extend this offer to grandparents, friends, or other relatives that the parents may wish to have present. If possible, allow parents to touch baby before death occurs, even in emergent situations.
- Take photographs of the infant while alive if possible. When possible, use the parents' camera or phone. (A camera and printer is also available in the nurse educator's office.)
 - If you use the unit's camera, the first picture should be of the addressograph for identification purposes. (Please refer to section on guidelines for taking photographs for ideas and tips to make these photos special). If appropriate, the family can also be offered the services of the Portraits d'Étincelles Foundation. Please contact palliative care nurse or Catherine Rioux-Crochetiere (spiritual care) for information.

END OF LIFE: INCLUDING UNEXPECTED/RAPID DEATHS

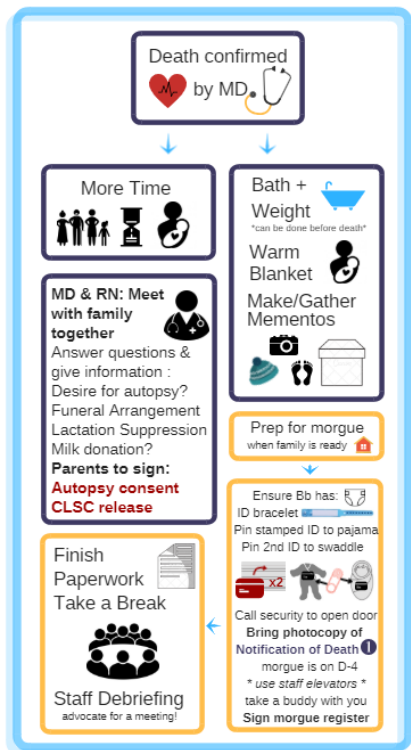
After an infant's death has occurred:



- When death is suspected, have a doctor come and confirm the death.
 - Give the family as much time as they need/want with their child to hold him, take pictures, meet family members etc.
 - For parents who at first refuse to hold their baby, sometimes simply explaining to them that in your experience other parents have later found this helpful will be enough to change their minds. Likewise, if you hold the dead infant and appear comfortable in this role, the parents will be encouraged that this is a "normal" thing to do. While the parents are holding their baby, take the time to change the infant's bed and make it look clean and fresh. Do not remove the baby's bed from the room until the parents have left.
 - Offer to bathe and weigh the baby with their help. The weight of the baby can then be added to the baby's identification card and vaccination booklet/"carnet de santé" that are given to the parents - families often appreciate these fine details.
 - Dress the infant in a cute pajama. The parents may prefer to dress the infant in a sleeper they have brought, or alternatively, you will find cute pajamas and sweaters in the clothing kits which are available in the cupboard near the back offices.
 - Wrap the infant snugly in a preheated blanket.
 - Go get memory box if not already done. They are in the storage room in the first hallway (B06.2645). After asking for the parents' permission, collect as many mementos as possible for them.
 - While the parents are holding their baby, take the time to change the infant's bed and make it look clean and fresh. Do not remove the baby's bed from the room until the parents have left.
 - Make sure the nurse is present with the parents when the doctor asks for permission for autopsy. It is important to offer support and make sure the parents know that their decision does not have to be made immediately.
 - Take the time to speak to the family about funeral arrangements and encourage them to personalize this experience as much as possible.
- Offer the document: Making arrangements for your child's funeral to the parents. Encourage them to contact the funeral home of their choice when they feel ready. There is no emergency for them to contact a funeral home.
 - Tell parents that it is normal to have a variety of reactions within the next few weeks. An information package on grief will be sent to their home by mail in the next few days. Please make sure that we have the right address on the hospital card and in Oasis.
 - Books and pamphlets for siblings are available in the storage room in the first hallway (B06.2645). Other books on grief are available if the family wishes additional literature at a later date. (From the PACT team)
 - Provide information on lactation suppression if appropriate.
 - Basic advice includes telling the mother to avoid nipple stimulation, apply ice or cool compresses, take Tylenol PRN, and that she can expect engorgement for 3 - 4 days. (Involve the lactation consultant for extra support)

END OF LIFE: INCLUDING UNEXPECTED/RAPID DEATHS

After an infant's death has occurred: Accompanying the baby to the morgue



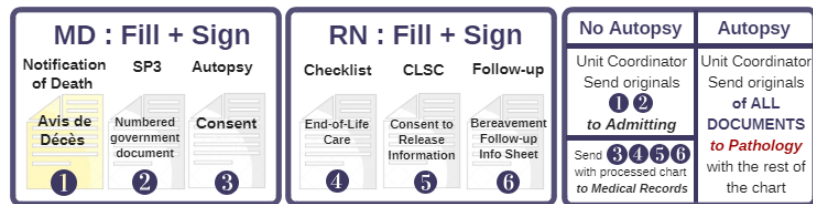
- It is not usually appropriate for the parents to accompany the nurse to the morgue. Simply inform the parents that they can stay with their baby in the room for as long as they like, and when they are ready, you will continue to care for their baby (and transport Bb to the morgue). If the parents insist, they may accompany you to the morgue, but should not enter past the door, it can be traumatizing to watch baby being placed in the fridge.
- When parents are ready to let go of the baby's body, complete two index cards (one index card should be taped to the infant's pajamas and the other one will have to be placed in the pink box) with the following information:
- baby's addressograph + birth and death weights + birth date and death date
- Verify that the baby is wearing an identification bracelet
- Call security (78282), they will meet the nurse at the morgue to open the door.
- Carry the baby in your arms to the morgue with the baby's face covered by a small piece of the blanket (if you prefer), USE the staff elevators only. The morgue can be accessed through the 4th floor.
- Ask another staff member to accompany you.

At the morgue

- The morgue is located in Block D, 4th floor (Room D04.1220).
- Leave one index card on baby, attached to the pajama
- Put the other one in pink box (Pediatric side).
- Sign the register along with the security person.
- Place the baby in one of the first two doors on the left that say "pediatrics".

Documentation/Paperwork

Your charting should include a brief description of the events surrounding the baby's death. Document in the nurse's notes the post-mortem care and your interventions with the family, along with the parents' reactions. The baby's post-mortem/most recent weight should also be included on the graphics sheet.



Complete the following nursing papers for the bereavement follow-up nurse:

Bereavement follow-up information sheet

Authorization to release information contained in the medical record (for the CLSC)

Have the doctor complete the following:

Déclaration de décès (formule SP3) + Avis de décès (yellow form) + Autopsy consent or denial form

COMFORT CARE PLAN

A nursing tool designed to improve the quality and consistency of care that palliative babies and their parent receive in the NICU



NICU COMFORT CARE PLAN



Privileged Visitors:
Social Support System:
Siblings

Social Worker: _____
Psychologist: _____
Translator: _____
Spiritual Care: _____

Visit/Call Log: YES / NO _____ DYP involved: YES / NO _____

Languages: _____

NEXT MEETING

Last Meeting: _____
Goals: _____
Date: _____ Location: _____
Participants: _____

EMOTIONAL COPING

MOTHER	FATHER
Feelings Expressed: _____ _____	Feelings Expressed: _____ _____
Date: _____	Date: _____

PRESENT CONCERNS

Date: _____

SPIRITUAL BELIEFS

Religions: _____
Meaningful Rituals and Practices: _____

PARENT'S REQUEST FOR END OF LIFE

PARENT EMPOWERMENT

Empower parents to participate in care as much as possible.
List acquired skills and topics for further teaching.

Skills (ex: bath, feed, pump, touch, temp, PO/NG meds, eye care, GT care)

Teaching topics: _____

Lactation consultation re-milk suppression/donation


COMMUNICATION TIPS

Ask simple, open ended questions, be patient, wait for responses, allow for silence, sit together for longer conversations. Involve family in care. Validate their role as parents.


- ◊ What is your priority for baby today?
- ◊ What is worrying you the most? Are you able to sleep?
- ◊ Are there any thoughts that give you comfort?
- ◊ Have you been able to talk to anyone (friends/family/etc) about what is going on with baby?

Avoid platitudes: "I understand how you feel" "time heals" "be strong" "baby will be in a better place"

NOTES



NICU COMFORT CARE PLAN



Name _____

Mother: _____
Father: _____
Other: _____

Primary RNs: _____
Primary MD: _____
Consultants: _____

RESUS MEASURES

DATE: _____

PARAMETERS

RESPIRATORY VENTILATORY PARAMETERS

iNO: _____
Baseline FIO₂: _____
SpO₂ targets: _____
Chest Physio: Q _____
Suctioning: Q _____

CHEST TUBES

		Rt	Lt
Sutured @			
Inserted			
Removed			

TRACHEOSTOMY

Trach Size: _____
Next Trach Δ: _____

RT NOTES

CARDIOVASCULAR

Vitals Q: _____ BP Q: _____
Pulses Q: _____

VASCULAR ACCESS

PICC / CVL: _____ lumen
Fr: _____ Ext. portion: _____
Inserted: _____
Removed: _____
Drsg Δ due: _____
Insuflon: _____

UVL UAL

Sutured @ _____
Inserted _____
Removed _____

ELIMINATION

Strict In/Out: Yes / No _____
Foley Inserted: _____
Ostomy notes: _____

NEURO / PAIN

Pain/Sedation Scale Q: _____
Type: _____
Goals: _____
Neuro Vitals Q: _____

GASTRO-INTESTINAL

WT: _____ Lt Q: _____
HCO: _____ Abdo Girth Q: _____
Milk Type: _____
Route: _____
Frequency: _____
Duration: _____
- NG - NJ - OG - OJ -
Inserted: _____
Secured @: _____
GT - GJ Size: _____
Inserted: _____
Balloon check: _____
Q: _____ ml: _____

FLUIDS

TFI: _____ Weight: _____

SYMPTOM MANAGEMENT

Bath Q1-2D Last: _____ Next: _____	Δ Position Q2-6h (max) Q: _____
Mouth care Q: _____ Chlorhex: Yes / No _____	Favorites: _____ Avoid: _____

MED: _____ Non-pharmacological measures: _____
MED: _____
MED: _____

SYMPTOMS	INTERVENTIONS (pharmacological & non-pharmacological)

RESPI / CARDIO / GI / NEURO / OTHER

Updated by: _____
Date: _____

CHILD AND FAMILY CARE PRINCIPLES

Based on the Canadian Hospice Palliative Care Association and the Canadian Network of Palliative Care for Children [2]

Primary nursing care [3]: (Reserved for palliative care patients, when feasible)

- The *Primary Care Nursing Team* is responsible for establishing an **individualized therapeutic relationship and nursing plan of care** with the patient/family/significant other for their primary patients from date of assignment through discharge.
 - Important for continuity of care and building a trusting relationship with the family
- The *Primary Nursing Care Team* should strive to create/maintain an environment that is safe and comforting, that provides ample opportunity for communication, intimacy and privacy, supports family relationships, and supports the family/caregiver therapeutic relationship.
- Continuity in relationships is perceived as key in ensuring that clinicians know and care about the child and parents, which in turn contributes to parents' confidence that their child is receiving the best possible care. In the absence of continuous, caring relationships with staff, parents reported frustration, hyper-vigilance, and mistrust about the quality of care that their child received. [4]
 - Primary Care Nurses should have at least 3 years of experiences to take a primary care patient in palliative care.
 - Exceptions can be made if the nurse was already very involved in the baby's care before palliative care was initiated.
 - The Primary Care Nurse shall be given priority and will be assigned first to this patient each scheduled shift **if possible** (To the discretion of the team leader)
 - Each nurse may only have one primary care patient at a time.
 - There can be up to 4 total associate primary nurses for each patient; made up of two members from the night shift and 2 members from the day shift, ideally.
- The name of the primary RN and the associate primaries should be written on the care plan
- ***There can only be one primary doctor and they may assign themselves to the care of the baby with the consent of the parents. The MD's name and contact info should be written on the care plan as well (if applicable).***

The form is a light blue rectangular box. At the top, there is a long horizontal line labeled 'Name'. Below this, there are three rows: 'Mother:', 'Father:', and 'Other:'. To the right of these rows are three blue telephone handset icons. To the right of the 'Name' field, there are three rows: 'Primary RNs:', 'Primary MD:', and 'Consultants:'. To the right of the 'Primary MD:' row is a single blue telephone handset icon.

[2] http://www.chpca.net/media/7841/Pediatric_Norms_of_Practice_March_31_2006_English.pdf

[3] Weidner, N. J., Cameron, M., Lee, R. C., McBride, J., Mathias, E. J., & Byczkowski, T. L. (2011). End-of-life care for the dying child: What matters most to parents. *Journal of palliative care*, 27(4), 279.

[4] Heller, K. S., Solomon, M. Z., & Initiative for Pediatric Palliative Care (IPPC) Investigator Team. (2005). Continuity of care and caring: what matters to parents of children with life-threatening conditions. *Journal of pediatric nursing*, 20(5), 335-346

RESUSCITATIVE MEASURES / LEVEL OF CARE

Definition:

- Medical order written by a doctor to instruct health care providers on how to intervene if ever the babies decompensate. It will also guide them on what is appropriate to do and what is not. Important for continuity of care and building a trusting relationship with the family
- Resuscitative measures are determined in relation to the goals of care, which are decided by the medical team in collaboration with the family.

RESUS MEASURES	

DATE:	_____

Purpose:

- Prevent non-beneficial interventions
- Offer the child/family therapies that are appropriate to the child's/family's goals of care and have the potential to relieve the child's suffering and/or improve quality of life without disproportionate risk or burden.

Legalities: **** Important** any limitation to resuscitative measures needs to be legally prescribed**

- Levels of care and cardiopulmonary resuscitation **OR** Signed Physician Orders
 - If there have been changes to the goals of care, whichever of these orders that is signed the most recently is valid. CHECK THE DATES!
 - These orders need to be signed by the medical team with the parents after/during a goals of care meeting
 - (All PACT orders need to be cosigned by our medical team)

NEXT MEETING	Goals: _____

	Date: _____ Location: _____
	Participants: _____

Possible options for when it comes to resuscitative measures and level of care (see document DT-9262)

- Goal A : Prolong life with all necessary care
- Goal B: Prolong life with some limitations to care
- Goal C: Ensure comfort as a priority over prolonging life
- Goal D: Ensure comfort without prolonging life

The Level of care and cardiopulmonary resuscitation sheet should be placed on the front page of the patient's chart. However, orders specifying treatment limitation also need to be considered as well.

The medical team should always fill out a new DNR sheet if changes are made, so please ask the medical team to clarify orders if you are unsure. It is important to make sure we provide safe appropriate care.

PARAMETERS AND HEALTH HISTORY

Health History and Therapeutic Interventions

- It is important for every healthcare worker who will take care of the child and his family to know the child's history of therapeutic interventions and their effectiveness, resolved and unresolved issues, and adverse events. Make sure you fill that box with all the important diagnosis, surgeries or major interventions that happened throughout the baby's stay. Important for continuity of care and building a trusting relationship with the family

Parameters

- Elements of care that are prescribed by the medical team or decided by the nursing team. It will guide your colleagues on what is allowed to do and what is not.
- The parameters box contains all the systems that you will see on your regular care plan. That will allow the transition of any baby to any level of palliative care.

D	x	S	x	DATE	

Routine care, exams and procedures:

- Palliative care prioritizes *comfort and quality of life***
- Try to avoid superfluous routine interventions/exams
- PRO TIP:** before any intervention, no matter how routine, always ask yourself:

What am I (or the medical team) going to do with the information?

Is it relevant to the goals of care? How invasive is the intervention?

- Examples: Auscultation: None invasive, but do you have a justification? (If you are concerned about secretions? constipation? It may be useful, it may not be..)
- Temperature: Axilla, rectal, touch? (what is most appropriate, least disruptive)
- BP/NeuroVitals/Reflexes/weight/abdo girth/length etc. (what is relevant?)
- Medical exams and test: Is the medical team requesting the intervention because it is *NECESSARY* or is it out of routine, curiosity, or to reassure themselves? (ex. bloodwork, Xrays, diagnostic tests, physical exams)
- THINK CRITICALLY, remember the goals of care and gently advocate for the baby.**

PARAMETERS	RESPIRATORY	CARDIOVASCULAR	NEURO / PAIN
	VENTILATORY PARAMETERS _____ _____ _____ _____ iNO: _____ Baseline FIO ₂ : _____ SpO ₂ targets: _____ Chest Physio: Q _____ Suctioning: Q _____ CHEST TUBES Rt Lt _____ Sutured @ <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Inserted <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Removed <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> TRACHEOSTOMY Trach Size: _____ Next Trach Δ: _____ RT NOTES _____ _____	Vitals Q: ___ BP Q: ___ Pulses Q: _____ VASCULAR ACCESS PICC / CVL: ___ lumen Fr: ___ Ext. portion: ___ Inserted: _____ Removed: _____ Drsg Δ due: _____ Insufton: _____ _____ UVL UAL Sutured @ <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Inserted <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Removed <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> ELIMINATION Strict In/Out: Yes / No Foley Inserted: _____ Ostomy notes: _____ _____ _____	Pain/Sedation Scale Q: ___ Type: _____ Goals: _____ Neuro Vitals Q: _____ GASTRO-INTESTINAL Wt Q: ___ Lt Q: ___ HCO: ___ Abdo Girth Q: ___ Milk Type: _____ Route: _____ Frequency: _____ Duration: _____ - NG - NJ - OG - OJ - Inserted: _____ Secured @: _____ GT - GJ Size: _____ Inserted: _____ Balloon check: Q: _____ ml: _____

FLUIDS AND HYDRATION

Issues regarding feeding at end of life:

- *In western culture, feeding is viewed as symbolic of life and non-feeding at the end of life is often considered unacceptable. This sentiment is magnified for infants. Reframing non-feeding into comprehensive care can be achieved by anticipatory guidance, which can make the experience of infant death meaningful for parents. [5]*
- Non-feeding is a DELICATE issue: Parents frequently feel (or are told by family members or friends) that we are asking them to “starve or kill their child by starvation” by withdrawing artificial nutrition.
- The health care workers may also feel distressed by the decision to withdraw enteral or parenteral nutrition as it becomes less beneficial for the baby.

Reframing non-feeding into an acceptable end-of-life practice includes reviewing with parents and healthcare workers, the benefits and complication of this type of end-of-life care. Ongoing emotional support needs to be provided as the family may begin to have doubts and moral questions that resurface frequently in regards to their decision.

FLUIDS	
TFI: _____	Weight: _____
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____

POSSIBLE COMPLICATIONS of Artificial Nutrition at end-of-life [5]	
Parenteral nutrition (15% risk)	Enteral nutrition (76% risk)
Infection	Increased secretions
Thrombosis	Choking episodes (the natural decline makes the body lose its ability to swallow)
Bleeding	Risk of pulmonary edema
Electrolytes imbalance	Nausea/Vomiting/Constipation
Loss of intravenous access	Discomfort from placement of the feeding tube if oro or naso-gastric

Healthcare workers will need to adjust the child's fluid and nutritional intake to accommodate changes in the child's ability to swallow and retain fluids in the intravascular space as well as changes in renal and hepatic function and other quality of life issues. [5]

The Feeling of hunger

The sensation of hunger or deprivation will most likely concern the parents. Research and adult testimony has shown that the sensation of hunger and thirst lessens after the first 1 or 2 days of fasting in response to the increased production of ketones. As muscle mass breaks down and the body naturally releases endogenous endorphins that act as a natural analgesic. [5]

[5] Vesely, C., & Beach, B. (2013). One facility's experience in reframing nonfeeding into a comprehensive palliative care model. *Journal of Obstetric, Gynecologic, & Neonatal Nursing*, 42(3), 383-389.

SYMPTOM MANAGEMENT

Symptom Management in Palliative Care :

- To guide complex medical management and decision making in the NICU, healthcare workers may rely on symptoms as indicators of the child suffering or quality of life. [6] However, the numerous symptoms that may present in end-of-life may be difficult to assess and manage.
 - Assessing specific patient needs related to pain and other symptoms, and managing them is a priority in neonatal palliative care.
 - Assessment should be ongoing and based on age appropriate and valid assessment tools (SUN SCALE)
 - The plan of care addresses those needs and includes an effective pain and symptom management plan.
 - With medication ordered regularly
 - With medication ordered PRN
 - With pharmacological and non-pharmacological measures to treat pain and other symptoms
- The palliative care team uses physical and occupational therapy resources to optimize the child's function and mobility, even when the child is expected to die in the future. It will provide comfort and optimizing the child's sensory experiences of touch, sight, hearing, taste and smell are considered non-pharmacological pain management measures.
- Positive sensory experiences can be achieved with bath, mouth care, feeding, musical therapy, reading, hypnosis, kangaroo care, rocking chair, vibrating chair.
- If you do not have the knowledge to ensure a child is as pain and symptom free as possible or if you feel like the child symptoms may be difficult to manage, ask the medical team to refer the child/family to specialized pediatric palliative pain and comfort management services. Refer to the Pediatric Advanced Care Team or Acute Pain Services if appropriate
- Prepare the family for the symptoms and physiological changes associated with the last hours of living and death. This knowledge, when delivered with sensitivity, can improve coping and reduce parent anxiety around the time of baby's death. (Refer to annex D)

SYMPTOM MANAGEMENT		
HYGIENE	Bath Q1-2D Last: _____ Next: _____ Mouth care Q: _____ Chlorhex: Yes / No	PHYSIO Δ Position Q2-6h (max) Q: _____ Favorites: _____ Avoid: _____
ROUTINE	_____	
DRUGS	_____	
PAIN	MED: _____ Non-pharmacological measures: _____ MED: _____ MED: _____	
PAIN / COMFORT / ANXIETY / OTHER	SYMPTOMS	INTERVENTIONS (pharmacological & non-pharmacological)
	_____	_____

[6] Shultz, E. L., Switala, M., Winning, A. M., Keim, M. C., Baughcum, A. E., Gerhardt, C. A., & Fortney, C. A. (2017). Multiples perspectives of symptoms and suffering at end of life in the NICU. *Advances in Neonatal Care*, 17(3), 175-183.

PSYCHOSOCIAL CONSIDERATIONS

- Formal caregivers ask the family about family relationships, available support systems, and resources, and share what they learn with other members of the team.
- The family's social network (friends, family etc) is as valuable as our healthcare team when it comes to providing psychosocial support to families.

Privileged Visitors:	Social Worker:
Social Support System:	Psychologist:
Siblings:	Translator:
	Spiritual Care:

Visit/Call Log: YES / NO _____ DYP involved: YES / NO _____ Languages: _____

Dedicated psychosocial notes

IMPORTANT for tracking psycho-social issues longitudinally, progress notes on flow-sheets are regularly thinned and the info gets buried and difficult to track, please use extra nursing notes for this purpose. Psychosocial notes are especially useful in Palliative care to improve therapeutic relationships and continuity of care.

Emotional Coping

- Healthcare workers need to ask the family about their specific thoughts, feelings, hopes, wishes, fears and memories, and develop an awareness of the family's psychological expectations and needs, their personalities, emotional status, coping strategies, cultural beliefs, past experiences, and any pre-existing psychological conditions.
- Acknowledge and address feelings of anxiety, depression, anger, anticipatory grief, helplessness, and hopelessness and take into account the family's cultural beliefs.
- The plan of care must address psychosocial needs and provide emotional support and therapies that promote the family's coping skills and positive adjustment, supports their achievement of personal goals, and optimizes their quality of life.
- Remember that men and women cope with grief differently and the parents should be assessed individually. Recommend to the parents that they be patient and compassionate with each other as they will likely not progress at the same rate and may not be at the same stage at the same time.
- **UPDATING THE CAREPLAN DOES NOT REPLACE PSYCHO SOCIAL NOTES:** always chart relevant conversations in psycho-social notes. Purpose of the care plan notes is simply to provide the next nurse with a general pulse (impression) of how the parents are coping,

EMOTIONAL COPING	
MOTHER	FATHER
Feelings Expressed:	Feelings Expressed:
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____
Date: _____	Date: _____
PRESENT CONCERNS	

Date: _____	

COMMUNICATION TIPS
Ask simple, open ended questions, Be patient, wait for responses, allow for silence, sit together for longer conversations. Involve family in care. Validate their role as parents.
◇ What is your priority for baby today?
◇ What is worrying you the most?
◇ Are there any thoughts that give you comfort?
◇ Have you been able to talk to anyone (friends/family/ etc) about what is going on with baby?
Avoid platitudes: "I understand how you feel" "time heals" "be strong" "baby will be in a better place"

PSYCHOSOCIAL CONSIDERATIONS

Spiritual and Cultural Considerations

- Healthcare workers must use appropriate language with families, including clear language related to dying and death, to minimize misconceptions and facilitate discussions to help prepare children and families for end of life.
- Communication is central to providing good palliative care. There is an important distinction between casual fluency in a language and complete comprehension. ex: understanding required for routine care vs goals of care meeting.
- Cultural diversity may impact interactions, communications, and decision-making and healthcare workers need to have access to cultural profiles that help them understand child and family preferences.
 - Ex: In some cultures, truth-telling is a means of empowering the patient, while other cultures perceive truth-telling as robbing the individual of hope. [7]
- The best and only way to identify the family's unique beliefs, values, and practices is to ask them directly. The goal of that discussion will be an attempt to respectfully harmonize the beliefs and values of the health-care system with the family's meaningful practices, without causing stress for the child.
 - Refer to your spiritual care worker for support with this subject. Refer to annex C for conversation starters about this subject.
- Consultation is available to family and caregivers when there is a conflict based on cultural values and beliefs. They may assist you in addressing the family's existential questions and spiritual issues. Resources: Spiritual Care Worker, Ethics, PAC Team

Languages: _____

SPIRITUAL BELIEFS

Religions: _____

Meaningful Rituals and Practices: _____

Parent's wishes for end of life

- Wishes for end-of-life must be charted and communicated throughout the nursing and medical team. Use this section to make sure the parents wishes are clear to everyone.
- Ex. Specific religious/non-religious ceremonies, a list of members of the support system that the family wishes to be present, the handling of the body etc.

PARENT'S REQUEST FOR END OF LIFE

[7] Candib, L., Quill, T.E., & Stein, H.F. (2002). Truth telling and advance planning at the end of life: Problems with autonomy in a multi-cultural world. Families, Systems, and Health, 20, 213-236.

PSYCHOSOCIAL CONSIDERATIONS

Parent Empowerment

- Encourage parental engagement at every opportunity to fulfill their caregiving role as parents for whatever time they have with their baby.
 - Involve them in the care, teach them how the pumps work, provide them with as many opportunities as possible to behave as the primary caregivers of their baby.
- Empowering the family will create a positive atmosphere around the child. It will reduce stress and create occasions for the nurse to connect with the parents and family members. It will provide parents with the tools and knowledge to better support their child on their palliative care journey, and will foster a more collaborative relationship between the parent and the NICU team.

Memory Making—Legacy Building

- Why is it important?
 - A common parental fear is that the child will be forgotten and his life will not have had meaning, memory making gives the family tangible souvenirs of their baby's life.
 - It may help the family to emotionally and psychologically prepare for the baby's death.
 - It may reduce stress and anxiety, improves social interactions and gives the family something positive to do with their child, which helps them create meaningful memories of their child's life.
- Memory making is NOT just for end-of-life!
 - As soon as a limitation of resuscitation measures are put in place, memory making activities can be started.
 - Endeavour to distribute the activities throughout the day/weeks, considering baby's life expectancy.

Refer to annex B for example of mementos

P A R E N T E M P O W E R E M E N T
Empower parents to participate in care as much as possible. List acquired skills and topics for further teaching.
Skills (ex: bath, feed, pump, touch, temp, PO/NG meds, eye care, GT care)

Teaching topics: _____

Lactation consultation re-milk suppression/donation <input type="checkbox"/>



FOLLOW-UP FOR FAMILIES AFTER A DEATH

- Following the death of a child, family members are offered bereavement care including: an information package, telephone follow-up, a memorial service, birth and death anniversary cards, support groups and support/counseling from bereavement care professionals. A bereavement care plan is developed based on an assessment of the family's strengths and needs and discussions with the family.
- The PACT nurse OR the spiritual care worker OR the social worker will follow-up with the family regularly.
 - They will mainly use the Bereavement Follow-Up Information Sheet to do so

SELF-CARE FOR NICU STAFF

- Have compassion for yourself: There is no such thing as “perfect” care or a “perfect” death - strive for “good”
 - Be present for your coworkers: offer, ask and accept help
 - Advocate for a debriefing after a death
 - Know your resource people: Palliative Care Ambassadors, NICU management, Medical Team, PAC team, Spiritual Care, Ethics
- **Compassion fatigue** [8]
 - Compassion fatigue has been described as the “cost of caring” for others in emotional pain. [9]
 - Although nurses obtain professional satisfaction from their work, their repeated exposure to the aftermath of critical illness puts them at high risk for compassion fatigue, a phenomenon with signs and symptoms similar to those of posttraumatic stress disorder.

How will it present itself? [10]	What can you do to protect yourself?
Hopelessness; a decrease in experiences of pleasure	Develop and maintain a strong social support both at home and at work
Constant stress and anxiety	Increase self-awareness through mindfulness meditation
Sleeplessness or nightmares	Use narrative work such as debriefing and journaling to process emotions
Pervasive negative attitude	Seek appropriate medical/counseling support if necessary
Decrease in productivity and inability to focus	
Development of new feelings of incompetency and self-doubt	

[8] Sacco, T. L., Ciurzynski, S. M., Harvey, M. E., & Ingersoll, G. L. (2015). Compassion satisfaction and compassion fatigue among critical care nurses. *Critical care nurse*, 35(4), 32-42.

[9] Figley, C. R. (2013). *Compassion fatigue: Coping with secondary traumatic stress disorder in those who treat the traumatized*. Routledge.

[10] "Compassion Fatigue - Because You Care" (PDF). St. Petersburg Bar Association Magazine. Archived from the original(PDF) on November 20, 2008. Retrieved February 2007.

PALLIATIVE CARE AMBASSADOR PROGRAM

In order to promote quality palliative care in the neonatal population, the MCH NICU team has created an ambassador program to raise awareness and capacity among our team. To become an ambassador, please express your interest to a current member of the NICU nursing palliative care committee to receive additional information.

Role of ambassadors

- Introduce yourself to nurses who are caring for an active or potential palliative case—be proactive!
- Offer to assist them in filling out the Comfort Care Plan
- Advocate for an appropriate primary nurse for palliative babies
- Provide support to new nurses taking care of families receiving palliative care
- Help to educate your coworkers and the families in the NICU about the nature of neonatal palliative care
- Help dispel myths and change the cultural attitude with regards to this essential type of care
- Memory Making—Legacy Building

Responsibilities of ambassadors

- Be familiar with the NICU Palliative Care Program and Guidelines
- Have knowledge of resources for memory making activities
- Have knowledge and experience with the process and paperwork surrounding a neonatal death
- Have strong communication skills and self-awareness
- Know appropriate uses of our fish symbol



ANNEX A: MCH RESSOURCES AND SUPPORT FOR PALLIATIVE

<p>Pediatric Advanced Care Team—PACT</p> <p><u>Availability:</u></p> <p>- Monday to Friday from 8:30 to 16:30</p> <p>EXT: 22253 (nurse)</p> <p>P: 514-406-2082 (Physician)</p> <p>- After hours from 16:30 to 23:00 or holidays or week-ends</p> <p>Call us through locating and ask for the on-call person. Our service is 24/7.</p>	<p>Team of physicians and nurses that work together in collaboration with the social workers and spiritual care workers to assist the neonatology team when caring for infants with life-limiting health issues.</p> <p><i>They may assist in:</i></p> <ul style="list-style-type: none"> Decision making at critical junctures in the neonate’s clinical course (including when ethics is also involved) Supporting family members, with integrating older siblings into NICU care & provide support to NICU team members particularly in situations where opinions differ between healthcare professionals. Planning for transitions in location of care (e.g. to the medical wards, to the home, or to the hospice (Le Phare) Managing difficult symptoms control Planning the transition to medication regimes that can then be continued in less intensive care like settings. <p><i>When and for whom should we consider contacting the PACT team (NICU specific)?</i></p> <p>Ask the neonatologist this question:</p> <p style="text-align: center;">"Would you be surprised if this infant died in the next year?"</p> <p style="text-align: center;">If the answer is no then a PACT consult may be helpful.</p> <p><i>Who can place a consult for them?</i></p> <p>The medical team can place a consult for the PACT team</p> <p>Although, nurses can participate in the decision to involve the PAC team, by voicing their concerns about the baby’s situation regarding pain/quality of life</p>
<p>Social workers</p> <p><u>Availability:</u></p> <p>- Monday to Friday from 8:30 to 16:30</p> <p>EXT: 24455</p> <p>- After hours from 16:30 to 23:00 or holiday or week-ends</p> <p>EXT: 53333</p>	<p>There are three fulltime social workers on the NICU who work in collaboration with Spiritual Care, Psychology, Child Life, the treating NICU team and the Pediatric Advanced Care Team. NICU social workers</p> <p><i>They may assist in:</i></p> <ul style="list-style-type: none"> Crisis intervention Supportive counseling Anticipatory and bereavement counseling to family members Instrumental assistance (e.g. information regarding funeral arrangements, referral to community resources for ongoing bereavement follow up). <p><i>Who can place a consult for them?</i></p> <p>Any MCH health professional can consult Pediatric Social Services.</p>

ANNEX A: MCH RESSOURCES AND SUPPORT FOR PALLIATIVE

<p>Spiritual care</p> <p><u>Availability:</u></p> <p>Call us through locating and ask for the on call person. Our service is 24/7.</p>	<p>The spiritual care professional visit families to offered emotional, spiritual and religious support. Their interventions always respects and welcomes differences and diversity and they are there for religious and non-religious families who are experiencing difficult situations.</p> <p><i>They may assist in:</i></p> <ul style="list-style-type: none"> Help the family call upon and identify their spirituals and religious strengths and resources. Help the families to examine their perception of illness, death, EOL issues and suffering. At the request of the family, they may engage in rituals of specific faiths. <li style="padding-left: 40px;">Ex: prayer, baptism, blessing or other rituals base on the family faith belief system. Help and provide support in times of grieving and bereavement and lead the family to appropriate resources. Help and support the medical and nursing team during difficult cases and end-of-life situations. <p><i>When should we consider contacting the spiritual care team?</i></p> <ul style="list-style-type: none"> Every time a patient is consider in critical condition or might die in the short or longterm period. Involve us early in the admission time so we can build a relationship with the family. When parent receive difficult news or information. When parent could benefit from emotional and spiritual support and active listening. Please let us assess the family needs ourselves by calling us before introducing our service to the family. <p><i>Who can place a consult for them?</i></p> <p>Everyone (doctor, nurse, RT, ...) can call for a consult or to ask to visit a family.</p>
<p>Ethics committee</p> <p>Availability:</p> <p>Monday to Friday from 8:30 to 16:30</p> <p>EXT: 23200</p>	<p>The Montreal Children's Hospital's Clinical Ethics Service provides support to patients, families and healthcare teams who face challenging situations or difficult choices.</p> <p>Some of these situations may involve negotiating a care plan for a patient or determining what course of action is in the best interest of the patient. Other situations may involve a patient's competency to make decisions, end-of-life care and refusal of treatment. Whatever the concern, we assist patients, families, and health professionals in identifying, examining and resolving a wide range of ethical challenges that can arise in health care.</p> <p>We ensure that our patients' and families' values and interests are taken into consideration and we promote ethical decision-making in the context of health care. The Clinical Ethics Service also provides ongoing ethics education to staff, residents and physicians and attempts to integrate ethics into all aspects of our daily practice.</p> <p><i>Who can place a consult for them?</i></p> <p>Everyone (doctor, nurse, RT, ...) can call for a consult or to ask to visit a family.</p>
<p>Psychologist</p> <p>Availability: by appointment</p> <p>Monday to Friday from 8:30 to 16:30</p> <p>EXT: 22154</p>	<p>Supportive counseling in complex circumstances</p> <p><i>Who can place a consult for them?</i></p> <p>Everyone (doctor, nurse, RT, ...) can call for a consult or to ask to visit a family.</p>

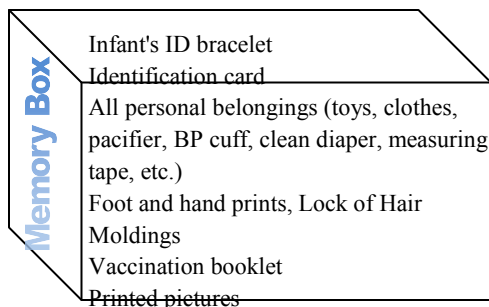
ANNEX A: MCH RESSOURCES AND SUPPORT FOR PALLIATIVE

<p>Childlife</p> <p>Availability: Monday to Friday from 8:30 to 16:30 EXT: 22529</p>	<p>Child Life Specialists are trained professionals with backgrounds in child development, education and related fields. In addition to play, they use a variety of educational and creative techniques to help improve the quality of life for children and their families who are dealing with a healthcare experience.</p> <p>Infant Massage Upon referral, a Child Life specialist certified in infant massage instruction can meet with a parent and their baby to teach infant massage. This approach promotes the use of positive touch and encourages the bonds between parent and child.</p> <p>Equipment Childlife has a variety of equipemnt appropriate for our babies, such as vibrating chairs, swings, mobiles etc.</p> <p><i>Who can place a consult for them?</i> Everyone (doctor, nurse, RT, ...) can call for a consult or to ask to visit a family.</p>
<p>Musical Therapy</p> <p>Availability: Monday to Friday from 8:30 to 16:30 PAGER: 514-406-2849</p>	<p>These professionals use music to maintain or improve the quality of life for children, adolescents, and their families. Music therapy helps promote adaptation to illness and hospitalization, provides a more normal environment for children, youth and families, and provides multi-sensory stimulation.</p> <p><i>Who can place a consult for them?</i> Everyone (doctor, nurse, RT, ...) can call for a consult or to ask to visit a family.</p>

ANNEX B: MEMENTOS

Photographs:

- Take a variety of different poses and a close-up photo of the face.
- Take a photo of the infant on a pretty blanket. (Lavender, purple, and royal blue colors are recommended; try to avoid pale colors).
 - Positioning a roll under the baby's neck may help to keep the baby in proper alignment.
- Take a photo of the baby in each of the parents' arms.
- Take a family photo (both parents with the baby and/or with siblings).
- Take a photo of the baby naked (even if abnormalities exist).
- Take a photo which includes a person's hand, or someone holding the baby in their arms.
- If the baby is one of twins or triplets, take a photo of both babies together.
- Include the baby's toys (large or small) in the photo; they help to personalize the photo and show the baby's relative size.
- Ask the parents if they would like "Portrait d'étincelle" or "NILMDTS" photographs to be involve for end of life pictures
 - Restrictions may apply, refer to PACT nurse or Spiritual Care worker



Memory Box

- Offer the mittens, booties, hat and/or blanket and clothing worn by the baby.
- If you know that the baby is about to die, a good trick is to put these clothing items on the baby before death. These may be the only clothes that the baby will have ever worn.
- Ask the parents if they would like a lock of their baby's hair.
 - ***Be careful, not all religions allow this!***
 - If the hair is cut around the region of the neck, the missing hair often does not show.
- Offer to do a footprint and handprint using the heel print paper kept in B06.2645 (kept near the "Books for Babies").
- Complete the infant's "Vaccination booklet" Place it in the memory box for the parents to keep.
- Contact Child Life to assess what else can be offered to the family including a molding of the baby's hand and a milestone bracelet for the baby.

If the parents refuse the above items, please identify them and leave them for the palliative care nurse. Tell the parents that these items will be kept and that they should feel free to contact us if



ANNEX C: RELIGIOUS, SPIRITUAL AND CULTURAL PRACTICES

Religious, Spiritual and Cultural Practices

- Grief is universal and crosses all cultures and religions. Spiritual, religious and cultural beliefs can play a significant role in the lives of families whose babies are seriously ill or dying. Showing consideration for those beliefs helps families cope with the illness and death of a loved one. Failing to carry out expected cultural or religious rituals can lead to unresolved feeling of loss for family members.
- Spiritual, religious and cultural values and beliefs will affect the family decision making process and how they understand suffering, hope and death. To be sensitive to the individual's practices and customs will help you create a safe place for the family to express their needs and emotions. Religion and spirituality are never black and white. There are various ways of being religious or spiritual.
- The best way to engage with religious and spiritual questions is to talk directly with the family and ask them what they believe in and what is important for them.
 - Use open-ended questions when you address the family.
 - Use a language that avoids stereotyping. Until you know the family's religious/spiritual tradition and practices use language that is interfaith, not grounded in one religious or spiritual tradition.
 - Ex: Faith community rather than church, Religious leader rather than priest, Higher power rather than God
 - Ask about sources of strength and hope, important customs, practices and beliefs.
 - Avoid judgment of religious/spiritual practices or beliefs that differ from yours
 - Respect the family limits on engaging in discussion about their faith.
 - Recognize limits of expertise, time and role. Involve and refer the spiritual care team. We can explore deeper with the family their inner sources of hopes and meaning. Contact the spiritual care professional if you have further questions or concerns. The spiritual care professional can also offer emotional support to nursing staff.

Questions to assess religious and spiritual needs

Some of the following questions might be helpful to identify the beliefs and practices that are important to the family, and to adapt your care of their baby to those things. You may want to use one or two of these questions to help understand the family's belief system, support them in parenting their child, and ensure you respect their religious, cultural and spiritual values. You don't need to complete a full assessment!

Some questions you might use with families:

- Can you help me understand your belief system and faith, so I can help you as best I could in the care of your child?
- Are there any rituals that are important for you to perform now or later on? How can I help you carry on your religious practices?
- Do you have religious/spiritual beliefs/values that might influence your medical decisions or the way you experience the illness of your child?
- Are there any specific practices or restrictions I should know about in providing you and your child care?
- Are there religious or spiritual practices that you wish to plan for the time of death, or following death?

ANNEX D: END OF LIFE SYMPTOM MANAGEMENT

Symptom management		Pharmacological	Non-Pharmacological interventions
Cardio - respiratory	Distress - Gaspings** - Stridor - Retractions	Morphine Midazolam iNO	Respiratory support: Cpap/ HiFlow / LowFlow Positioning prone if tolerated Elevating the bed head
	Secretions	Glycopyrrolate/ Robinul	Soft suction
Gastrointestinal	Nausea Vomiting Reflux	Dompéridone Lansoprazole Ranitidine	Gentle manipulation during feeds Elevating the bed head, Positioning on left side Reduce stimulation during feeds
	Constipation	Glycerin supp.	Prune juice Warm compresses or Warm Magic-bag on stomach
	Diarrhea		Ile's paste to protect skin on buttock Reduce fluid intake/stop feeding
	Feeding intolerance		Positioning on left side Slower rate of milk infusion / Continuous feeding Reduce milk intake, Ad lib feeds / Feed for comfort only Reduce stimulation during feeds
	Halitosis (bad breath)		Mouth care q. Check with Pink Toothette + Sterile water
Neurological	Seizures	Midazolam Phénobarbital, etc.	
	Fatigue /Diminution of consciousness		Respect sleep patterns Divide activities/interventions throughout the day Invite parents to interact with their baby when he's awake
	Restlessness / Agitation	Midazolam Lorazepam	Introduce / Respect sleep routine, Kangaroo care Musical therapy, Book reading
	Muscle spasm / Contractures / stiffness		Physio/Ergo Soft exercises, Splints, Gentle manipulation
	Decreased reflexes (Airway protective reflexes)		Risk of aspiration or choking, Feed as tolerated
General	Rash		Cold compresses, Moisturizing cream, Soft massages
	Sweating		Light pajamas, Fresh linen changed every shift and PRN
	Skin breakdown		Appropriate skin treatment

ANNEX D: END OF LIFE SYMPTOM MANAGEMENT

ROUTE	PROS	CONS
UVL	Reliable access, rapid absorption, less invasive	No full bath, less easy to manipulate baby, requires close monitoring, baby cannot be dressed..
PICC	Reliable access, rapid absorption, less invasive, possible to bathe and dress	Requires monitoring, restricts manipulation of baby, risk of infection
PIV	Rapid absorption	Unreliable, requires close monitoring, very invasive installation
SUB-CUT BUTTERFLY	Less invasive than PIV insertion, rapid absorption, reliable	Site rotation q3-5 days + PRN, risk of induration, bruising and cellulitis
OG/NG/PR	Minimally invasive, reliable	Aspiration, absorption? Slow acting
PO	Least invasive	Aspiration, absorption? Slow acting, unreliable dosing
NASAL/SL	Reliable, minimally invasive, rapid absorption	Not applicable for all meds

REFERENCES

1. The Quality Standards for End-of-Life Care (2010) recommend: ‘A universal symbol, which is recognized by all staff and by the public as indicating that a death has occurred, is clearly visible in the ward/department’.
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