

Neonatal Palliative Care Guide
Maternal Newborn Child & Youth SCN

Neonatal Palliative Care Guide for Neonatal Intensive Care Units



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Date

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Introduction

The following document provides information to **health care providers** with consensus-based guidance on best palliative care practices for infants with life-limiting conditions and to support their families served in the Neonatal Intensive Care Unit (NICU). All Alberta Health Services (AHS) employees, members of the medical and midwifery staffs, students, volunteers, and other persons acting on behalf of AHS (including contracted service providers as necessary) who are involved with palliative care delivery within the NICU should become familiar with the information in this guide.

It is important to emphasize that health care providers can choose to participate in or abstain from the provision of palliative care.

We hope that this resource will provide guidance and practice support to the NICU health care team and address their needs that might arise during provision of palliative care.

While this document helps support the practice of most clinical situations, clinical judgment may be exercised when a situation is determined to be outside the parameters provided in this document. If a deviation is determined to be appropriate or necessary, documentation of the rationale shall be included on the patient's **health record**.

We hope that this resource will provide guidance and practice support to the NICU health care team and address their needs that might arise during provision of palliative care.

Principles of Palliative Care

Palliative care encompasses more than medical care; it is a holistic approach focusing on the quality of life of infants with life-limiting conditions. Every infant and family member is treated with dignity and respect whatever their physical or intellectual ability, gestational age, or size.

Palliative care embraces physical, emotional, social, cultural, and spiritual foundations of care while also including the management of distressing symptoms, care at the end-of-life, and bereavement support. This holistic approach requires that the infant is treated within the context of their family. The values and beliefs of the family are explored and supported in a model of shared-decision making.

Palliative care is not limited to a specific timeframe and the emphasis in treatment may shift between curative and palliative intents. Palliative care needs to be sensitive and timely to the specific situation and needs of a particular infant, family, and health care team.

Palliative care plans may be reassessed at any time depending upon the needs of the infant, family, and/or health care team.

Criteria for Palliative Care







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 (see [Appendix A: Palliative Care Conversations](#) for additional information).

Conditions appropriate for palliative care may be categorized as follows:

- a) Life-limiting: any condition clearly associated with a limited life span with no curative treatment available (e.g., anencephaly).
- b) Life-threatening: Treatment may be feasible but may not be successful: (e.g., extreme prematurity irrespective of additional risk factors).
- c) Progressive conditions: Treatment is available for symptom control but no curative option exists currently (e.g., spinal muscular atrophy).
- d) Burden of disease or treatment outweighs the benefits as perceived by the health care team including the family (e.g., trisomy 13 or 18).

The relationship between palliative care and treatments aimed at cure or prolonging life is fluid, in such that the [Goals of Care](#) for a given infant may change during the course of his or her treatment. The decision to switch between curative/prolonging life and palliative care depends on the patient and their illness. This is shown in Figure 1 below.

Figure 1: Palliative Care Pathways

Relationship between palliative care and treatments aimed at cure or prolonging life	
	As the illness progresses the emphasis gradually shifts from curative to palliative treatment.
	Highly technical invasive treatments may be used both to prolong life and improve quality of life alongside palliative care, each becoming dominant at different stages of the disease.
	No cure is possible and care is palliative from the time of diagnosis.
	At first it is not apparent that this will be a terminal illness and palliative care starts suddenly once that realisation comes.
Key:	 curative  palliative

Health care providers should inform families about palliative care services and grief supports as soon as it is evident that an infant may benefit from palliative care services. The Aid in Symptoms and Serious Illness Support Team (ASSIST) is a specialized group of pediatric palliative care practitioners including nurses, doctors, and allied health care providers. Health care providers should consider referral to ASSIST for planning the next stages of care.

Team-based Approach to Palliative Care

Alternate decision makers (ADM) or **guardians** are the primary caregivers and should be involved as partners in the care of their hospitalized infant(s) in the NICU.

- a) The ADM or guardian(s) are surrogate decision-makers in what treatment choices are perceived to be in the best interests of their infant.
- b) The health care team should provide the ADM or guardian(s) with timely disclosure of their infant's condition in an environment appropriate to the situation (see [Appendices A](#) and [B: Goals of Care](#)).
- c) Treatment decisions may evolve over time, dependent on the infant's situation, the information itself, parent/ADM/guardian understanding, and other factors.

A multidisciplinary approach to care should be promoted and include of health care providers who work within and outside of the NICU.

Health care providers shall discuss composition of the health care team with the ADM or guardian(s). Health care teams should foster supports for providers and families to facilitate continuity of care, emotional support, and decision-making.

Day-to-day management of infant care shall continue to be the responsibility of the most responsible health care provider (MRHP). Two-way communication is essential between the primary physician(s) and the on-service physician – unless planning for transfer to an alternate most responsible physician.

All multidisciplinary care team members involved in an infant's care should be supported to articulate what they perceive is in the interest of the infant. These discussions need to be sensitive to the family/ADM's/guardian's situation.

The health care team needs to be consistent in their communication with and messaging to family members. It is their professional responsibility to respect and support families/ADMs/guardians in their decisions once made.

Parents/ADMs/guardians should be encouraged to take ownership over the end-of-life care of their infant, and their wishes should be supported as much as possible within available resources.

Parents/ADMs/guardians should be supported to include other family members and supports during the end-of-life period.

Health care providers should be sensitive to the ADMs or guardian(s)' wishes and support end-of-life care within the limits of the facility.

Conflict Resolution

Conflict may arise between the ADM(s), guardian(s) and providers, various members of the health care team, and/or between family members.

When there is disagreement on a treatment plan, the health care team should meet as often as needed and consider seeking additional opinions and investigations.

The MRHP in collaboration with the health care team shall review the risks and benefits of the recommended treatment plan(s) with the guardian(s), and family (when applicable) in order to address any concerns and to try to resolve conflict and build consensus so that agreement for the treatment can be obtained.

The health care team shall support clear communication to facilitate consensus building with the ADM, guardian(s), and family, as applicable. All possible attempts shall be made to ensure that care plans are discussed, agreed upon, and delivered through collaboration and communication with the ADM, guardian(s), and family (when applicable), using the principles of family-centered care.

The health care team should direct the ADMs, guardian(s), and/or family members to Clinical Ethics, Spiritual Care Services, or the ASSIST teams when additional support is required for conflict resolution.

The health care team may involve AHS Legal Services, and/or Child Protectives Services where appropriate.

When it is established that a conflict has escalated to dispute resolution, the health care provider shall refer to the AHS Dispute Resolution and Prevention in the Critical Care Setting Policy (#PRR-03-01).

Advanced Care Planning and Goals of Care Designation

This section outlines the recommended approach for how to organize and proceed with conversations relating to Goals of Care for NICU patients and their families. **Advanced Care Planning** and Goals of Care conversations describe the multiple conversations held over hours or days that provide direction about the general focus of care and some specific actions within the focus of care (see [Appendices A and B](#) and the AHS Advance Care Planning and Goals of Care Designation (GCD) [Policy \[#HCS-38\]](#) and [toolkit](#) for additional information).

The MRHP is responsible for ensuring that Goals of Care conversations and Designations have been discussed, established, and documented. The Goals of Care conversation shall be documented on the patient's health record to allow continuity of care. Documentation of the Goals of Care conversation includes more than a GCD. Documentation should be completed using the AHS *Pediatric Goals of Care Tracking Record Form* (#103767) and *Pediatric Goals of Care Designation Order Form* (#103768).

Goals of Care conversations focus on “what care can be provided for the infant” to have a better outcome in various domains like clinical, comfort, and pain. The conversations should not be about “what can be removed or withdrawn from the infant's care.” Goals of Care conversations are not meant to generate a “Do not resuscitate order list.”

Goals of Care conversations while being pragmatic and factual should respect a family's desire to maintain hope for a positive outcome; recognizing what constitutes a positive

outcome may vary depending on a family's religious, cultural, and personal beliefs, and where they are in their NICU journey.

Goals of Care conversations should be held in a transparent, sensitive manner, respecting the privacy and emotional needs of the family.

Goals of Care conversations:

- Do not need to immediately lead to a GCD.
- Are not intended to generate a “Do not resuscitate order list.”
- May include end-of-life care planning.
- Should be held in a quiet, private space sensitive to the evolving situation and ADMs or guardian(s)' needs and requests.
- Focus on the best interests of the infant while recognizing that “best interests” occur in the context of family-centered care.
- Shall be held in a timely manner once health care team members and/or the ADM, or guardian(s) the family/ADM identify the need for such conversations.
- Should generally include multi-disciplinary team members.

Conversations should be informed by balanced, unbiased, and complete information. Individual team member's biases should not compromise disclosure or ADM or guardian(s) decision-making.

Any member of the health care team, the ADM or guardian(s) may initiate and undertake Goals of Care conversations. Health care teams shall provide training and support to health care providers involved in having Goals of Care conversations.

Families/ADMs should be encouraged to reflect on their religious, cultural, and personal beliefs in Goals of Care conversations. Upon request of an ADM or guardian(s), the health care team should allow the inclusion of additional supportive persons (e.g. family members, friends, or community) as needed by the ADM or guardian during the Goals of Care conversations.

The GCD should be considered as dynamic and flexible in nature, potentially changing from comfort care through non-resuscitative medical care to resuscitative care as the clinical condition of the infant changes.

Health care providers should be aware that each ADM, or guardian(s) may have different beliefs even with similar cultural and religious backgrounds that exist within and between families.

Goals of Care conversations should address and forge an understanding of the broad themes encompassed in a goals of care designation:

- Resuscitative care - an approach where a patient is expected to benefit from any appropriate tests and/or interventions including resuscitative measures.
- Medical care - an approach of care where a patient is expected to benefit from any appropriate tests and/or interventions excluding resuscitative measures. Non escalation of existing care, location of care as desired by the family in keeping with parental/ADM's values and wishes that are in the best interests of the infant should be discussed and facilitated.
- Comfort care - an approach where the aim of tests and procedures are to control symptoms, maintain function and reduce pain.

Considerations for Health Care Teams in End-of-Life Care

ADMs and/or guardian(s) should be encouraged to take ownership over the end-of-life care of their infant, and their wishes should be supported as much as possible.

ADMs and/or guardian(s) should be supported to include other family members and supports during the end-of-life period.

Health care providers should be sensitive to the ADMs' and/or guardian(s)' wishes and support end-of-life care within the limits of the facility.

Location of End-of-Life Care

Families should be supported in their choice of location for provision of end-of-life care recognizing that resources will differ depending on where they are within the province.

The MRHP should offer end of life care options in hospital or in the infant's home, when possible and after discussion with families.

If a decision is made to pursue end-of-life care within the hospital, different care environments should be explored with the family for their appropriateness (e.g. NICU, post-partum rooms, pediatric units, rooming in rooms, outdoor spaces or gardens, indoor spaces, or other available areas).

Hospice care may be an option for families depending upon the location of the family. (e.g., The Rotary Flames House is an available resource in the Calgary-zone for families.)

The ASSIST Team is also available to support the provision of end-of-life care in urban and rural centers across the province with the assistance of homecare where available and other local resources.

Physiological Monitoring

During end-of-life care, discussions with families should include the consideration of discontinuing:

- Non-invasive cardiorespiratory monitoring, recognizing some families may prefer to keep monitors on.
- Invasive clinical activities such as routine blood work.
- Monitoring wires, saline lock intravenous (IV), or ports that are no longer needed, where possible.

Monitor the infant for signs of distress, and monitor the dying process by such activities as intermittent auscultation of the heart.

Warmth and Contact

The health care team should:

- Offer skin-to-skin contact or clothed contact, according to the ADM, or guardian(s) preferences.
- Provide warm blankets or cuddle cot to keep the infant warm and comfortable.
- Provide warmth and contact for the infant if the ADM, or guardian(s) is unable to hold their infant during this process.

Symptom Management

It is common to feel fearful that the infant may experience pain and suffering as death approaches. The health care team should acknowledge the ADM, guardian(s) and/or family's fear and reassure them that the team will be present to continue caring for their infant and do everything possible to make sure the infant is comfortable at all times.

The use of neuromuscular blockades should be avoided. They should be discontinued prior to, or when life sustaining medical therapies are discontinued.

Opioids may be used, as necessary, for treatment of potential pain occurring at the end-of-life. Sedative medications are a useful adjunct if an infant remains distressed despite reasonable doses of opioids. (See [Addendum 1](#) for additional information on pharmacological measures.)

- Non-painful routes of administration are recommended, if oral medications are not tolerated or an established parenteral route is not available.
- Subcutaneous or intranasal administration may be considered for infants unable to tolerate oral medications or those without parenteral access.

As the work of breathing increases, the infant might experience a greater need for opioids or sedatives when support is withdrawn. The health care team shall communicate to the ADM, or guardian(s) that administering opioids is intended to relieve symptoms, and not to hasten death.

Breathing may appear distressing for a dying infant, whether as a consequence of cyanotic heart disease, intrinsic lung disease, or removal of ventilator support.

Many conditions that infants die from are not painful, but any equivocal symptom should be treated as a potential sign of distress and treated as such.

Discontinuing Life Sustaining Medical Treatments

It is important to prepare the family for what they may see following discontinuation of life-sustaining treatments (see [Appendix C: Discontinuing Mechanical Ventilation](#) for suggestions and additional information). Consideration should be given to discontinuing:

- Any medications that do not contribute to the comfort of the infant.
- Narcotics bolus and/or infusions.
- Benzodiazepines bolus and/or infusions.
- Anti-seizure medications.
- Other medications contributing to the solace of the infant.

Medical treatments that are deemed appropriate to continue should be discussed with the ADM, or guardian(s) regarding their foreseeable benefit for comfort compared to prolonging the dying process. Consideration should be given to continuing:

- Oral or endotracheal suctioning.
- Enteral or parenteral nutrition.
- Antibiotics.

Routine bedside care (e.g. diaper changes, bathing, mouth care, etc.) should be continued through the dying process unless signs of discomfort are apparent during their provision.

Autopsy and Organ/Tissue Donation

Autopsy discussion should be specific to the particular family situation. Refer to Autopsy and organ donation documents as it applies to your site/zone.

Bereavement

The health care team shall allow the ADM, or guardian(s) to spend time with their infant in an appropriate environment after death has occurred.

Offer the ADM or guardian(s) and family the opportunity to participate in before and after death care such as:

- Bathing or dressing the infant.
- The creation of mementos.
- Using specialized cooling blankets and cots to help preserve the infant's body after death where available. These can be used to extend the period of time the infant can stay with the ADM or guardian(s) for as long as the ADMs or guardian(s) request; and/or preserve the body for autopsy.

If available, each family should meet with a social worker who can provide support, help with communication strategies should they have living children, navigate extended family concerns, identify resources for funeral/memorial planning and refer to ongoing bereavement counselling.

If the death occurs before the infant has been named, health care providers should explore preferences for naming with the ADM or guardian(s).

Wherever possible, ADMs or guardian(s) should not have to leave the hospital with empty arms. Some mementos that may accompany ADMs or guardian(s) when leaving hospital include a stuffed toy, a blanket used by the infant, and/or a memory box.

Photography

Photography should be offered to all ADMs or guardians during the end-of-life and/or bereavement periods. It should be recognized that for some families, photography will not be appropriate.

There are many forms of photography that could be potentially available:

- ADMs'/guardians' personal photography.
- Community volunteer groups (e.g. Now I Lay Me Down to Sleep).
- Hospital photographer.
- Photographs done by the inpatient unit with a hospital-owned camera.

The use of staff cell phones is not supported and should not be offered as an option. If the ADM or guardian(s) consent for pictures to be taken but are not ready to view them, provide the option of offering the pictures in a sealed envelope or memory card.

Creation of Memory Boxes

ADMs or guardian(s) should be offered the opportunity to create mementos of their infant's life. A conversation around the importance of these keepsakes in the grief journey can be helpful.

A memory box can be created with tangible items that have meaning and have been part of the infant's life, including hospitalization.

ADMs or guardian(s) have the right to choose whether they want a memory box. Their wishes should be respected if a memory box is declined. If ADMs or guardian(s) are uncertain then in some circumstances the memory box could be created with their permission and then give them the option to pick it up later if they want it.

Often the creation of the memory box may not be complete prior to the ADMs or guardian(s) leaving the hospital. If this occurs, the memory box should still be completed and arrangements can be made to pick-up at a later date.

Some examples of possible items for a memory box:

- Lock of infant's hair
- Hand and foot imprints (ink, embossed or both)
- Nametag
- Crib card
- Identification band-may need to have additional set of bands made
- Measuring tape with infant's information
- Brush and comb set
- Photographs (if consent provided)
- Molds of hands and feet
- Clothing and blanket (try to include clothing or blanket ADMs/guardian(s) have seen on the infant)

- Soother the infant used
- Miscellaneous medical equipment such as Electrocardiography (ECG) leads, saturation probe, phototherapy mask etc. that were worn by infant.

Spiritual, Cultural, and Religious Supports

Spirituality and religion are not the same. If the ADM, or guardian(s) does not identify as being part of a certain faith, they may still have spiritual beliefs and practices that are important to them. Spiritual care should be routinely offered to all families recognizing each family will ultimately decide whether such support is appropriate for their situation. Use of hospital and community cultural ombudspersons should be supported in accordance to the family's wishes.

The health care team should:

- Ask which rituals or procedures are meaningful for a particular family, in a way that is respectful to the family's religious or spiritual beliefs.
- Discuss what the family would like, and when appropriate, help to organize or facilitate.
- Notify Spiritual Care Services as available or community clergy of the ADM's, or guardian's choice as soon as requested and as early on in the process as possible
- Offer additional resources such as multicultural health brokers, Aboriginal health liaison, and/or Northern Health Network nurses as available.

Cultural ceremonies and traditions should be supported whenever possible. Spiritual Care Services and/or social work may be of assistance in arranging certain rituals (blessings, baptisms, sweet grass ceremonies, etc.), keeping in mind that these practices may not always be possible in some hospital units. Please be informed of site, zone, and AHS policies regarding spiritual ceremonies involving burning substances.

Future Family Planning and Palliative Care Considerations

For some ADMs or guardian(s), the period immediately following the death of their infant will not be an appropriate time to discuss future family planning. ADMs or guardian(s) should guide the discussion about future family planning, if desired, including stressors, fears, anticipations, and hopes (see [Appendix D: Future Family Planning](#) for conversation guide). Health care providers should acknowledge the ADMs or guardian(s)' thoughts and feelings regarding the stress of future pregnancies and provide information for supportive organizations, if available.

ADMs or guardian(s) may wish to determine the reasons for their infant's death and if there may be risks for future pregnancies such as a genetic condition. ADMs or guardian(s) may wish to undertake testing or investigations before trying to become pregnant again.

ADMs or guardian(s) should be directed to resources and persons to contact if they are ready to have such discussions. The MRHP should consider referrals to their primary care physician, medical and genetic specialists or counselors or provide resources for additional information on future family planning.

Community Resources

ADMs or guardian(s) should be advised about burial/cremation options including hospital burial programs if they exist and the option of private funeral home arrangements. An up-to-date list of funeral homes should be provided to the family for their consideration. Special documentation is necessary if ADMs or guardian(s) choose to transport the body in their own vehicle.

A list of up to date bereavement supports / counseling services based on the family's geographical location should be made available to ADMs or guardian(s) to assist with the grieving and healing process.

Refer family for bereavement follow-up through bereavement registry if available in the geographical area where they live.

Definitions

Advance Care Planning means a process which encourages people to reflect and think about their values regarding clinically indicated future health care choices; explore medical information that is relevant to their health concerns; communicate wishes and values to their loved ones, their alternate decision-maker and their health care team; and record those choices.

Alternate decision maker means a person who is authorized to make decisions with or on behalf of the patient. These may include, specific decision-maker, a minor's legal representative, a guardian, a 'nearest relative' in accordance with the *Mental Health Act* [Alberta], an agent in accordance with a Personal Directive, or a person designated in accordance with the *Human Tissue and Organ Donation Act* [Alberta].

Health care provider means any person who provides goods or services to a patient, inclusive of health care professionals, staff, students, volunteers and other persons acting on behalf of or in conjunction with Alberta Health Services.

Health record means the Alberta Health Services legal record of the patient's diagnostic, treatment and care information.

Goals of Care Designation means one of a set of short-hand instructions by which health care providers describe and communicate general care intentions, specific clinically indicated health interventions, transfer decisions, and locations of care for a patient as established after consultation between the most responsible health practitioner and patient or alternate decision-maker.

Guardian means, where applicable:

For a minor:

- a) as defined in the Family Law Act [Alberta];
- b) as per agreement or appointment authorized by legislation (obtain copy of the agreement and verify it qualifies under legislation; e.g., agreement between the Director of Child and Family Services Authority and foster parent(s) under the Child, Youth and Family Enhancement Act [Alberta]; or agreement between parents under the Family Law Act; or as set out in the Child, Youth and Family Enhancement Act regarding Guardians of the child to be adopted once the designated form is signed);
- c) as appointed under a will (obtain a copy of the will; also obtain grant of probate, if possible);
- d) as appointed in accordance with a Personal Directive (obtain copy of Personal Directive);

- e) as appointed by court order (obtain copy of court order; e.g., order according to the Child, Youth and Family Enhancement Act); and,
- f) a divorced parent who has custody of the minor.

Most responsible health practitioner (MRHP) means the health practitioner who has responsibility and accountability for the specific treatment/procedure(s) provided to a patient and who is authorized by Alberta Health Services to perform the duties required to fulfill the delivery of such a treatment/procedure(s) within the scope of his/her practice.

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Appendix A: Palliative Care Conversations

1. The goal of the health care team should be to guide the family through their palliative care journey, acting as a support to assist the family in meeting their needs.
 - a. Health care professionals should never assume what the family needs.
 - b. Health care professionals should be cautious to avoid imposing their values, beliefs, traditions, and attitudes about health and death during the discussions.
2. Grief is a normal reaction throughout this experience. Families will experience grief before and after an infant dies as they will have a series of losses throughout the process. The health care team should normalize this grief response for the family and acknowledge the emotions the family is experiencing.
 - a. Grief is experienced and manifested in a variety of ways as families grieve. The health care team should be present and attentive to walk with the family through the process based on where they are at. Attempting to diminish the grief being experienced unjustly diminishes and minimizes the losses.
 - b. Families benefit from health care professionals who are compassionate, non-judgmental, demonstrate a sense of caring, and are attentive to their needs.

3. Questions should not be avoided but rather, should be answered openly and honestly.
4. The use of accurate, simple, and straightforward language is important when communicating with family after the death, avoiding the use of medical jargon.
5. It is acceptable and welcomed to show emotions during the conversations.
6. Some suggestions of phrases to say include:
 - a. I'm sorry for your loss.
 - b. I don't know what to say, but I am here for you.
 - c. Do you have any questions? We can talk again later.
7. Some phrases to avoid include:
 - a. It's best this way.
 - b. It could be worse.
 - c. You can have more children.
 - d. Time will heal.
 - e. It's good your infant died before you got to know him or her.

Appendix B: Addressing Goals of Care

This appendix outlines the recommended approach for how to organize and proceed with conversations relating to the Goals of Care for NICU patients and their families. Please refer to AHS Advance Care Planning and Goals of Care Designation Policy and toolkit for additional information and resources.

Process:

1. A Goals of Care conversation is initiated when a member of the medical team or the patient's surrogate decision maker (usually their ADMs/parents/guardian(s)) believe that that the Goals of Care Designation (GCD) for a patient should be changed.
2. Prior to a meeting with the ADMs, a multidisciplinary team meeting should be held whenever appropriate (see Table 1).
3. The meeting with an infant's ADMs should be scheduled shortly after the team meeting (see Tables 2 and 3).

Table 1. Multidisciplinary Team Meeting

Objectives	<ul style="list-style-type: none"> • To allow collaborative care • To facilitate discussion, sharing of facts, opinions and recommendations between different team members • To clarify the role of individual team members in discussing goals of care with the family
Why?	<ul style="list-style-type: none"> • To ensure that team members feel heard and have the opportunity to contribute • To enhance consistent messaging when any member of the team is communicating with the family • To prevent overloading the family with different messaging and multiple difficult conversations
Who should attend?	<ul style="list-style-type: none"> • Primary physician. Where possible, a consistent staff physician (or designate) should be present at all Goals of Care discussions.

	<ul style="list-style-type: none"> • Neonatal Nurse Practitioner (NNP), fellow, clinical assistants or resident caring for the infant as appropriate • Primary bedside RN. Where possible, a consistent RN should be present at all Goals of Care discussions. • Charge RN • Social worker • Consultants (depending on clinical scenario) – ex. dietician, pharmacist, respiratory therapist, palliative care, spiritual care, neurology, cardiology as appropriate • ASSIST team member(s)
Where?	Quiet and private room, away from patient bedside whenever possible
When?	To be held after a member of the medical team or the patient's ADM/guardian suggests that the GCD should not be R1. This meeting should take place prior to a meeting with the ADMs/parents/guardians
Who will organize?	The primary Physician and/or charge RN will coordinate with the rest of the team members to organize a meeting.
Documentation	Discussion should be documented on the patient's chart to allow continuity of care.

Table 2: Team/Family Meeting

Possible Objectives	<ul style="list-style-type: none"> • To establish trust/relationship with ADMs • To share information • To introduce conversation about types of care that may be pursued for their infant • To make a decision about the Goals of Care <p>Note: It may take several conversations to arrive at a clear plan. A Goals of Care conversation does not always have to end with a decision about the Goals of Care designation.</p>
When?	After a team meeting, initiated by ADM/parent/guardian or member of the team proposing that R1 may not be an appropriate GCD.
Who should attend?	At least: <ul style="list-style-type: none"> • ADMs/Guardian(s) and supports (if possible/desired)

	<ul style="list-style-type: none"> • Primary physician or a delegate (NNP/fellow) Where possible, a consistent physician (or representative) should be present at all Goals of Care discussions. • Charge RN/primary bedside RN. Where possible, a consistent RN should be present at all Goals of Care discussions. • Social worker <p>May also include:</p> <ul style="list-style-type: none"> • NNP, fellow or resident caring for the infant • Charge RN • Other providers as deemed necessary/helpful (e.g. dietician, pharmacist, social work, respiratory therapy, palliative care/ASSIST team, spiritual care, specialty care, psychologist)
Where?	Quiet and private room, away from patient bedside whenever possible.
When?	After team meeting
Who will organize?	The primary physician and/or charge RN will coordinate to organize a meeting.
Documentation	Discussion should be documented in the patient's record to allow continuity of care recognizing that documentation includes more than a GCD.

Table 3. Proposed Meeting Guide for Family/Team meetings

Component Detail	Sample Language
Introduction	
<ul style="list-style-type: none"> • Invite all present to introduce themselves by name, role 	<p>“Thanks to everyone for coming today. Perhaps we can start by having each of us introduce ourselves... I’ll start...”</p>
Statement of Meeting Purpose	
<ul style="list-style-type: none"> • Describe goals/purpose/intention of the meeting and ask others to confirm this plan 	<p>“The main reason we are coming together today is to....” “Does everyone agree that this is what we’re here to discuss? Are there other things we should cover?”</p>
Parental Perspective	
<ul style="list-style-type: none"> • Invite ADMs/guardians to share what their understanding of how their infant is doing. • Inquire about how they are feeling about what is happening. Provide an empathetic response and a commitment to help. • Gently correct any misunderstandings, add information that they do not seem aware of. Be truthful about the infant's current status 	<p>“What is your understanding of [Infant’s name]’s condition?”</p> <p>“It can be very scary to have an infant in an intensive care unit. How are you feeling about what is happening?”</p> <p>“I know this is really difficult to talk about, but it’s very important that you have information about how your infant is doing”</p>
Allow time for reflection and processing of information	
<ul style="list-style-type: none"> • Pacing of information is really important. ADMs or guardian(s) may need time to process what they’ve heard. • Leaving ADMs or guardian(s) to contemplate the above may be enough for the first discussion. 	<p>“I’ve shared a lot of information with you so far. Do you need some time to think about this? Are you ok to proceed with the meeting? There are some other things I’d like to discuss, if you are ok to do so”</p>

Clinical Update	
<ul style="list-style-type: none"> • Explain the current status and the plan for the infant. • Describe what you are worried about immediately (if anything). Describe what you think might be a worry in the future. • Confirm that ADMs or guardian(s) have the information that they need. Inquire about any additional concerns. 	<p>“At this time [Infant’s name]’s major challenges are a, b, c...”</p> <p>“The current plan is to do x and y, and to look out for z”</p> <p>“We’re hoping that this plan will lead to a, b, and c. however, we can’t always predict how neonates may respond. It may be that d, e, or f occur.”</p> <p>“Do you feel like you have enough information about what is going on with your child?”</p> <p>“Do you have any questions about what I have said so far?”</p>
Probe for specific understanding (if necessary)	
<ul style="list-style-type: none"> • Depending on the purpose of the conversation, seek more information about ADMs or guardians’ views of specific topics. 	<p>“I’m wondering if you...</p> <ul style="list-style-type: none"> • “...are worried that [infant’s name]’s condition seems to be worsening despite everything we are talking about” • “... know what happens automatically in the NICU if an infant stops breathing or their heart stops” • “...have ever heard of a code or cardiac arrest”
Parental/family values, goals and hopes	
<ul style="list-style-type: none"> • Ask ADMs/guardian(s) about their values, goals and hopes for the child • Acknowledge the ADMs/guardians’ feelings and emotions 	<p>“It is important for us to understand what is important to you and your infant’s care”</p> <p>“We want to match what we know about your infant’s health and condition with what is important to you regarding your infant’s treatment and future”</p>

	<p>"Are you able to tell us now any thoughts or feelings you may have about medical interventions for your child?"</p> <p>"It is OK to be angry...sad..."</p>
If seeking agreement on GCD	
<ul style="list-style-type: none"> • Explain the Goals of Care Designation to ADMs/guardian(s) and its intention. • State current GCD and indicate whether a change in this GCD may be considered. • Propose alternate GCD and provide rationale 	<p>"Have you heard of a Goals of Care Designation? This is something that every patient in hospital has. It is a way for patients, families and health care providers to have a clear plan for how best to care for patients"</p> <p>"At this stage, your infant's goals of care designation is [X] which means we are focusing on [making sure infant has the best chance of getting better; ensuring that infant feels as comfortable as possible; etc.]"</p> <p>"Based on what I've heard from you today, it sounds like...</p> <ul style="list-style-type: none"> • "...we should keep this designation as is" • "The designation [Y] best aligns with what we know about your infant's health and what is important to you. This means we focus on..."
Final check-in and Commitment to further Conversations	
<ul style="list-style-type: none"> • Ask if ADMs/guardian(s) have any further questions or requests. • Make a commitment to keep the ADMs/ guardian(s) informed as things move along 	<p>"Do you have any other questions that I can help with before we end our meeting?"</p> <p>"We realize this may be a lot to take in right now. There will be other chances for us to talk about this more in the future"</p> <p>"Are there any other supports like spiritual care that you might want...?"</p> <p>"Shall we plan meet again on....."</p>

Adjournment	
<ul style="list-style-type: none"> • Thank everyone for their participation in the conversation. • Let them know who they can contact if they have additional questions. 	<p>"Thanks for meeting with us today. If you have any question, you can</p> <ul style="list-style-type: none"> • ".....Get in touch with me by [insert method]." • "...raise them with your infant's care team"

Notes on Communication Strategies and Language

Regarding Resuscitation

Asking ADMs/ guardian(s) what they understand about resuscitation, codes and/or what happens if an infant's heart stops or if he or she stops breathing often allows you to tell ADMs/ guardian(s) what a code entails. These measures are intended for illnesses and conditions that we think may be reversible. We should stress that we err on the side of doing everything for every infant if we are uncertain; however, there are situations in which we think that the infant is really not going to be able to recover, or has irreversible illness/injury. In those situations, there is a risk of causing harm or discomfort rather than benefit. Using the language of protecting their infant from unhelpful and painful interventions, rather than withholding a treatment, is actually more honest and medically appropriate.

Resuscitation and the GCD

Rather than going through particular pros and cons of various components of care (CPR, intubation, etc.) it is likely much more productive to start with a big picture - life, hopes and fears of the ADMs/ guardian(s). We can explain we are trying to match what we know about the infant's condition/health and the ADMs'/ guardians' values and beliefs to the right treatments for their infant.

Reframing the request to do everything

Initially, doing everything may have meant trying all available treatments. However, if those treatments are failing to make the infant better, or actually causing harm to the infant, then doing everything might change its focus to protecting the precious intimacy and time between ADMs/ guardian(s) and the infant. Language that ADMs/ guardian(s) use is often around giving up and gentle redirection can help them reframe difference between giving up, and trying too hard to change something that cannot be changed.

Understanding Parental Values

Consider asking ADMs/ guardian(s) “how do they view a good life, and what does quality of life mean to them?” It can be helpful to encourage them to think about their thoughts and conversations before they had an infant that was really sick. It is okay to let them know that some ADMs/ guardian(s) who would normally focus on quality of life might flip into a life at all costs way of thinking as their infant is in crisis. Help them identify what’s *usually* true for them. Can they find ways to step back from the panic and emotion to see what they really think, or what they might think down the road? Do they need a break from the bedside to be alone and away for a few hours or days as a couple? What do they fear right now? What do they fear if their infant doesn’t survive? Most ADMs/guardian(s) can respond to this.

Parental Perspectives on Comfort

Are ADMs/guardian(s) satisfied that their infant is as comfortable as he/she can be? If not, this needs to be addressed before they will be able to engage in further conversation.

Supporting a Substituted Judgment

Invite ADMs/guardian(s) to explore care from the infant’s perspective. If they could trade places with their infant, would they feel that it would be a good enough situation for

themselves, or are there things we are doing to/for their infant that they don't think they would truly want, if it was happening to them?

Guilt and Moving Forward

Addressing guilt is important. Every ADM/guardian will feel guilty about something. Explore this. It may be the source of their guilt is something they misunderstand and is easy to rectify, sometimes it will be deep-seated and resistant to intervention

Consider how ADMs/guardian(s) will look back on this time. What stories will they tell themselves and others about it? Let ADMs/guardian(s) know you are really trying to help them find a way forward that they will be comfortable with, years later when they remember how they came to the decisions they did.

Appendix C: Discontinuing Mechanical Ventilation

There is no consensus on the best way to discontinue mechanical ventilation in the context of end-of-life care (see Table 1 for two described approaches).

It is important to discuss the extubation process with the family, and to prepare them for what they might see and hear.

ADMs/guardian(s) should be offered the choice of holding the infant before, during and/or after the extubation, and for any amount of time that they would like. They should not feel rushed during any stage.

Let them know which member of the team will be extubating the infant.

Explain that the timing of death is unpredictable. Some infants die within minutes of an extubation, while others may live hours to days to weeks.

Explain how their infant may gasp or struggle to breathe following extubation and that the team will work with the family to assist the infant in staying comfortable through that process. The health care provider should explain to ADMs/guardian(s):

- How their infant may gasp or struggle to breath.
 - It is important to differentiate between respiratory distress and known breathing reflexes (agonal breathing). Avoid the term agonal breathing with families, as it may project that the infant is suffering or in agony. ADMs/ guardian(s) should be prepared for the possibility of deep gasping breathing followed by irregular periods of apnea. Describe this pattern of breathing as a lower brainstem reflex, or simply a reflex. Reassure the family that, as best as we know, if this were to happen, the infant is not struggling, nor uncomfortable.
 - Respiratory distress is increased work of breathing, which can be appropriately treated with opioids to relieve discomfort and/or air hunger

- It is common that the infant may gasp a few times after extubation regardless of the approach, as part of the transition of removing breathing support. If this is ongoing, comfort measures will be provided.
- How their infant may have difficulties managing their secretions.
 - Noisy breathing may be common following extubation as the infant may inconsistently swallow saliva or other oral secretions.
 - Secretions may be suctioned if the infant appears uncomfortable
- How the infant's colour is expected to change over time.

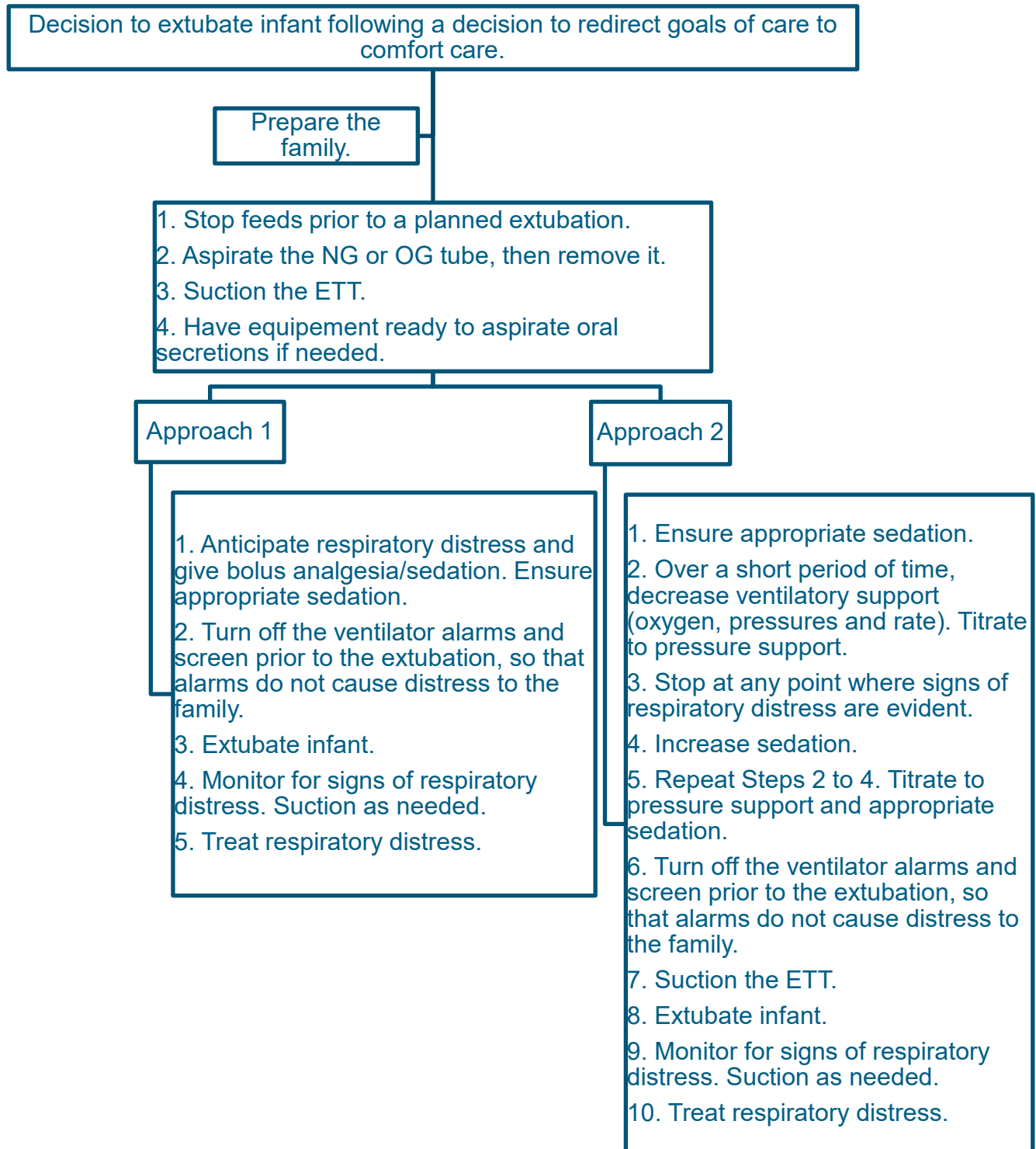
Answer any questions that family members may have.

Table 1: Approaches for discontinuing Mechanical Ventilation

	Approach 1	Approach 2
Summary	<ul style="list-style-type: none"> ● Extubation from current settings. 	<ul style="list-style-type: none"> ● Decreasing ventilator support prior to extubation while analgesia/sedation is titrated.
Pros	<ul style="list-style-type: none"> ● Avoids prolonging death. 	<ul style="list-style-type: none"> ● Provocation of respiratory distress symptoms prior to extubation allows the team to make sure that the infant has appropriate analgesia/sedation. ● Likely to cause hypoxemia and hypercarbia, which can increase sedation. ● Reduces risk of infant having symptoms of distress after extubation. ● Minimizes risk of patient suffering.
Cons	<ul style="list-style-type: none"> ● Increased risk of having to urgently titrate sedation in response to respiratory distress after extubation. 	<ul style="list-style-type: none"> ● Must avoid the term weaning, as this term is associated with decreasing medical intervention as the patient's clinical picture improves.

		<ul style="list-style-type: none">• Could be seen as prolonging death.• May not be tolerated by fragile patients.
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Truog, 2001 and Muson, 2007



Appendix D: Future Family Planning and Palliative Care Situations

While some parents may wish to become pregnant again soon after their infant dies, others may need more time before they are emotionally or physically ready. The fear of another loss may make it difficult to become pregnant again.

Parents may feel a need to protect each other from their thoughts, feelings, and anxieties about subsequent pregnancies. Encourage parents to discuss their needs and concerns with each other or with someone who is able to offer such supports.

In some cases, another pregnancy may not be possible due to medical problems and/or it may be dangerous for a woman to become pregnant again. It is important for parents to discuss this with their physician or other health care provider.

In some cases, parents who had fertility treatments to become pregnant may not be able to afford future fertility treatment.

Parents should be directed to available resources for support for pregnancy after miscarriage or neonatal death, sexual relationships after death of an infant, and so forth as available.

Parents may have concerns about the timing of subsequent pregnancies due to risks, concerns about ability to conceive, sexual difficulties, and so forth.

Health care providers should reassure parents that there is no right time to try to get pregnant again and to consult with their physician when would be a good time for them.

Information should be provided about the mother's need for physical healing as well as illness experienced during pregnancy.

Health care providers can encourage families to care for themselves both emotionally and physically.

Addendum 1: Pharmacological Measures for Palliative Care



Table 1: Pharmacologic Measures for Managing Agitation, Pain and Respiratory Distress

Medication	Mechanism of action	Pharmacodynamics / Pharmacokinetics	Indications	Recommended doses	Adverse effects
<p>sucrose (analgesic)</p>	<ul style="list-style-type: none"> The potential mechanism includes activation of endogenous opioid system through taste receptors on the tip of the tongue. 	<ul style="list-style-type: none"> Maximum effect: 2 minutes Duration: 3 to 5 minutes 	<ul style="list-style-type: none"> Pain Mild analgesia during minor procedures (venipuncture, NG tube insertion, ET suctioning, IM or subcutaneous injection). 	<p>24% sucrose solution (oral):</p> <ul style="list-style-type: none"> Greater than 1500g: 0.75 to 1 mL 1000 to 1500g: 0.25 to 0.5 mL Less than 1000g: 1 to 2 drops on tip of tongue <p>Maximum 6 doses of sucrose per day</p> <p>Administer dose approximately 2 minutes prior to painful procedure.</p> <p>The beneficial effects can be improved when used in conjunction with non-pharmacologic measures.</p>	<ul style="list-style-type: none"> Safety of long-term use has not been studied. One study raised the concern of frequent dosing (greater than 10 doses per day in the 1st week of life) and worse neurodevelopmental scores. No systematic or published reports of NEC associated with sucrose use

Pharmacologic Measures for Managing Agitation, Pain and Respiratory Distress

Medication	Mechanism of action	Pharmacodynamics / Pharmacokinetics	Indications	Recommended doses	Adverse effects
<p>acetaminophen (analgesic)</p>	<ul style="list-style-type: none"> Not fully elucidated, believed to inhibit the synthesis of prostaglandins in the CNS and work peripherally to block pain impulse generation. Produces antipyresis from inhibition of hypothalamic heat-regulation center. 	<ul style="list-style-type: none"> Onset of action: PO less than 1hr Duration: PO 4 to 6hrs Half-life: approximately 7 hrs (3 to 11 hrs). Metabolized in the liver, excreted in urine. Rectal absorption is variable and prolonged. 	<ul style="list-style-type: none"> Pain Mild to moderate pain; adjunct for severe pain 	<p>ORAL:</p> <ul style="list-style-type: none"> PMA 28 to 32 weeks: 10 to 12 mg/kg/dose every 6 to 8 hours; maximum daily dose: 40 mg/kg/day PMA 33 to 37 weeks or term neonates less than 10 days: 10 to 15 mg/kg/dose every 6 hours; maximum daily dose: 60 mg/kg/day Term neonates greater than and equal to 10 days: 10 to 15 mg/kg/dose every 4 to 6 hours; do not exceed 5 doses in 24 hours; maximum daily dose: 75 mg/kg/day <p>RECTAL:</p> <ul style="list-style-type: none"> PMA 28 to 32 weeks: 20 mg/kg/dose every 12 hours; maximum daily dose: 40 mg/kg/day PMA 33 to 37 weeks or term neonates less than 10 days: Loading dose: 30 mg/kg; then 15 mg/kg/dose every 8 hours; maximum daily dose: 60 mg/kg/day Term neonates greater than and equal to 10 days: Loading dose: 30 mg/kg; then 20 mg/kg/dose every 6 to 8 hours; maximum daily dose: 75 mg/kg/day 	<ul style="list-style-type: none"> Hepatotoxicity with excessive doses or prolonged use (greater than 48 hours) of therapeutic doses. There are no studies reporting on the long-term effects of use in neonates. <p>*More common in preterm neonates</p>

Pharmacologic Measures for Managing Agitation, Pain and Respiratory Distress

Medication	Mechanism of action	Pharmacodynamics / Pharmacokinetics	Indications	Recommended doses	Adverse effects
<p>morphine sulfate (narcotic)</p>	<ul style="list-style-type: none"> ▪ Binds to opioid receptors in the CNS causing inhibition of ascending pain pathways. ▪ Decreases responsiveness of respiratory center to hypoxia and hypercapnia 	<ul style="list-style-type: none"> ▪ Peak effect: IV = 20 min, PO = 1 hr ▪ Duration: IV and PO = 3 to 5 hrs ▪ Half-life: <ul style="list-style-type: none"> ○ preterm neonates = 10 to 20 hrs ○ Term neonates = 4.5 to 13.3 hrs ▪ Steady state reached by 24 to 48 hours. ▪ Metabolized in the liver, excreted in urine 	<ul style="list-style-type: none"> ▪ Pain Moderate / severe pain ▪ Respiratory Distress Reduce symptoms of respiratory distress. 	<ul style="list-style-type: none"> ▪ Oral: 50 to 100 mcg/kg/dose, repeated every 3 to 4 hours as required. ▪ Sublingual, Buccal: 50 to 100 mcg/kg/dose repeated every 3 to 4 hours as required (<i>limited data, hydrophilic therefore poorly absorbed - presumed bioavailability around 20%</i>). Use oral solution to administer dose. ▪ IV Bolus, subQ: 20 to 100 mcg/kg/dose IV, repeated every 4 to 8 hours as required. ▪ IV Continuous Infusion: 10 to 20 mcg/kg/hr IV. <p>Respiratory distress: lower end of dose range may be sufficient.</p> <p><i>Titrate the dose as needed to reach comfort</i></p>	<ul style="list-style-type: none"> ▪ Respiratory depression ▪ Decreased gastrointestinal motility ▪ Hypotension* ▪ Urinary retention ▪ Tolerance with prolonged use.

*More common in preterm neonates

Pharmacologic Measures for Managing Agitation, Pain and Respiratory Distress

Medication	Mechanism of action	Pharmacodynamics / Pharmacokinetics	Indications	Recommended doses	Adverse effects
<p>fentaNYL citrate (narcotic)</p>	<ul style="list-style-type: none"> ▪ Binds to opioid receptors in the CNS, increases pain thresholds, alters pain reception, and inhibits ascending pain pathways. ▪ Causes less histamine release compared to morphine. 	<ul style="list-style-type: none"> ▪ Onset of action: IV almost immediate (2 to 3 minutes) ▪ Duration: IV 30 to 60 min ▪ Half-life: 1 to 15 hrs ▪ Metabolized in the liver, excreted in urine ▪ Intranasal: absorption and plasma concentration comparable with IV administration. ▪ Transient rebound in fentaNYL serum concentration may reflect sequestration and subsequent release of fentaNYL from body fat 	<ul style="list-style-type: none"> ▪ Pain Moderate / severe pain ▪ Respiratory Distress Reduce symptoms of respiratory distress. 	<ul style="list-style-type: none"> ▪ Intranasal: (<i>limited data</i>) 1 to 2 mcg/kg/dose repeated every 5 to 10 minutes up to three doses in 30 minutes. <i>Refer to "Administration of intranasal fentaNYL".</i> ▪ IV Bolus: 0.5 to 3 mcg/kg/dose IV, repeated every 2 to 4 hrs as required. ▪ IV Continuous Infusion: 0.5 to 3 mcg/kg/hr IV. <p>Respiratory distress: lower end of dose range may be sufficient.</p> <p><i>Titrate the dose as needed to reach comfort</i></p>	<ul style="list-style-type: none"> ▪ Respiratory depression ▪ Hypotension (less than morphine) ▪ Chest wall rigidity, occasionally associated with laryngospasm (reversible with naloxone) ▪ Urinary retention ▪ Hypothermia. ▪ Tolerance with prolonged use.

*More common in preterm neonates

Pharmacologic Measures for Managing Agitation, Pain and Respiratory Distress

Medication	Mechanism of action	Pharmacodynamics / Pharmacokinetics	Indications	Recommended doses	Adverse effects
<p>midazolam (sedative, hypnotic)</p>	<ul style="list-style-type: none"> ▪ Potentiates Neuro-inhibitory pathways mediated by GABA ▪ Causes dissociative state allowing patients to tolerate unpleasant procedures 	<ul style="list-style-type: none"> ▪ Delayed elimination in neonates compared to pediatric patients ▪ Peak plasma concentration: 0.5 to 4 hours ▪ Onset of action: IV 1 to 5 minutes ▪ Duration: 2 to 6 hours ▪ Half-life: 4 to 12 hours (up to 22 hours in premature neonates) ▪ Bioavailability: approximately 50% with sublingual, buccal and intranasal administration. 	<ul style="list-style-type: none"> ▪ Conscious sedation: Depressed consciousness that “allows protective reflexes to be maintained” e.g. Agitation, Respiratory Distress, sedation for comfort while NPO 	<p>Intranasal: 0.1 to 0.3 mg/kg/dose repeated every 2 to 4 hours as required. <i>Refer to "Administration of intranasal midazolam".</i></p> <ul style="list-style-type: none"> ▪ Sublingual, Buccal: 0.1 to 0.3 mg/kg/dose repeated every 2 to 4 hours as required. Use undiluted 5 mg/mL IV solution to administer dose. ▪ Continuous Infusion: 10 to 60 mcg/kg/hr IV ▪ IV Bolus: 50 to 150 mcg/kg every 2 to 6 hrs as required. To be administered slowly to prevent hypotension <p>Respiratory distress: lower end of dose range may be sufficient. <i>Titrate the dose as needed to reach comfort</i></p>	<ul style="list-style-type: none"> ▪ Apnea ▪ Respiratory depression ▪ Hypotension* ▪ Seizure like activity (myoclonus)* ▪ Nasal administration may have a burning sensation

*More common in preterm neonates

Pharmacologic Measures for Managing Agitation, Pain and Respiratory Distress

Medication	Mechanism of action	Pharmacodynamics / Pharmacokinetics	Indications	Recommended doses	Adverse effects
<p>LORazepam (sedative, hypnotic)</p>	<ul style="list-style-type: none"> Potentiates Neuro-inhibitory pathways mediated by GABA 	<ul style="list-style-type: none"> Highly lipid soluble Onset of action: within 5 minutes Peak serum concentration: 45 minutes Duration: 3 to 24 hours Half-life: Term neonates 18 to 73 hours (mean 40 hours) 	<ul style="list-style-type: none"> Conscious sedation Agitation, Respiratory Distress Oral alternative to midazolam 	<ul style="list-style-type: none"> Intranasal: 0.03 to 0.1 mg/kg/dose repeated every 2 to 8 hours as required (<i>limited data</i>). Refer to "Administration of intranasal LORazepam". Buccal/Oral/IV: 0.03 to 0.1 mg/kg/dose repeated every 2 to 8 hrs as required (<i>limited data for buccal route, use oral solution</i>). <p>Respiratory distress: lower end of dose range may be sufficient.</p> <p><i>Titrate the dose as needed to reach comfort</i></p>	<ul style="list-style-type: none"> Apnea Respiratory depression Neurotoxicity Hypotension* Seizure like activity (myoclonus)* Contains benzyl alcohol which has been implicated in gasping syndrome in neonates
<p>methadone (narcotic)</p>	<ul style="list-style-type: none"> Binds to opioid receptors in the CNS, causing inhibition of ascending pain pathways, altering the perception of the response to pain, produces generalized CNS depression. N-methyl-D-aspartate (NMDA) receptor antagonism. 	<ul style="list-style-type: none"> Onset of action: 30 to 60 minutes Duration: 6 to 8 hours, increases to 22 to 48 hours with repeated doses (first few doses, short half-life; repeated doses, slowly released from liver and tissue where it is retained). Half-life: 16 to 25 hours. 	<ul style="list-style-type: none"> Pain Severe Pain 	<ul style="list-style-type: none"> In an <i>opioid naïve patient</i> - start 0.1 mg/kg/dose every 4 hours for 2 to 3 doses, then every 6 to 12 hours. 	<ul style="list-style-type: none"> Recommend consultation of ASSIST team. Respiratory efforts may be depressed. Prolonged QT associated with high doses. ECG required prior to initiation and dose titration.

		<ul style="list-style-type: none">▪ Steady state achieved at 3 or more days after initiation.▪ Inhibits tolerance by multiple mechanisms.▪ Metabolized in liver, excreted in urine.			
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*More common in preterm neonates

Medication	Intranasal Administration Information
<p>fentaNYL citrate (narcotic)</p>	<ul style="list-style-type: none"> ▪ Less than 2.5 kg, prepare 10 mcg/mL solution as follows: <ul style="list-style-type: none"> ○ ADD 1 mL of fentaNYL 50 mcg/mL IV solution to 4 mL of NS to obtain 5 mL of fentaNYL 10 mcg/mL solution. Mix well. ○ Transfer solution to a medication cup. ▪ Greater than or equal to 2.5 kg, prepare 25 mcg/mL solution as follows: <ul style="list-style-type: none"> ○ ADD 2 mL of fentaNYL 50 mcg/mL IV solution to 2 mL of NS to obtain 4 mL of fentaNYL 25 mcg/mL solution. Mix well. ○ Transfer solution to a medication cup. <p>Administer WITHOUT nasal atomizer</p> <ul style="list-style-type: none"> ▪ Draw up dosage in a 1 mL oral syringe (preferable). ▪ Lean baby's head back slightly. ▪ Insert oral syringe tip into the nare and administer slowly (drops) over 15 to 30 seconds. ▪ Ideal volume per nostril is 0.1 to 0.3 mL. Volumes higher than this should be split between the two nostrils. <p>Administer WITH nasal atomizer</p> <ul style="list-style-type: none"> ▪ Nasal atomizer has a dead space volume which varies between brands. ▪ Draw up dosage + min 0.2 mL (sufficient to prime nasal atomizer) in a 1 mL needleless IV syringe. ▪ Connect needleless IV syringe to nasal atomizer. ▪ Adjust volume to ordered dose (this will prime nasal atomizer and account for volume lost in dead space). ▪ Lean baby's head back slightly. ▪ Place tip snugly against the nostril (the foam tip may need to be pushed back slightly to fit a small nare). ▪ Briskly, squirt medication into nare. ▪ Ideal volume per nostril is 0.1 to 0.3 mL. Volumes higher than this should be split between the two nostrils.

Medication	Intranasal Administration Information
<p>midazolam (sedative, hypnotic)</p>	<ul style="list-style-type: none"> ▪ Use midazolam 5 mg/mL IV solution for intranasal administration. <p>Administer WITHOUT nasal atomizer</p> <ul style="list-style-type: none"> ▪ Draw up dosage in a 1 mL IV syringe ▪ Transfer solution to an oral syringe (preferable). ▪ Lean baby's head back slightly. ▪ Insert oral syringe tip into the nare and administer slowly (drops) over 15 to 30 seconds. ▪ Ideal volume per nostril is 0.1 to 0.3 mL. Volumes higher than this should be split between the two nostrils. <p>Administer WITH nasal atomizer</p> <ul style="list-style-type: none"> ▪ Nasal atomizer has a dead space volume which varies between brands. ▪ Draw up dosage + min 0.2 mL (sufficient to prime nasal atomizer) in a 1 mL needleless IV syringe. ▪ Connect needleless IV syringe to nasal atomizer ▪ Adjust volume to ordered dose (this will prime nasal atomizer and account for volume lost in dead space). ▪ Lean baby's head back slightly. ▪ Place tip snugly against the nostril (the foam tip may need to be pushed back slightly to fit a small nare). ▪ Briskly, squirt medication into nare. ▪ Ideal volume per nostril is 0.1 to 0.3 mL. Volumes higher than this should be split between the two nostrils.
<p>LORazepam (sedative, hypnotic)</p>	<ul style="list-style-type: none"> ▪ Prepare 0.5 mg/mL solution as follows (a more concentrated solution may be prepared if dose greater than 0.3 mg): <ul style="list-style-type: none"> ○ ADD 0.5 mL of LORazepam 4 mg/mL IV solution to 3.5 mL of NS to obtain 4 mL of LORazepam 0.5 mg/mL solution. Mix. ○ Transfer solution to a medication cup. <p>Administer WITHOUT nasal atomizer</p> <ul style="list-style-type: none"> ▪ Draw up dosage in a 1 mL oral syringe (preferable). ▪ Lean baby's head back slightly. ▪ Insert oral syringe tip into the nare and administer slowly (drops) over 15 to 30 seconds. ▪ Ideal volume per nostril is 0.1 to 0.3 mL. Volumes higher than this should be split between the two nostrils. <p>Administer WITH nasal atomizer</p> <ul style="list-style-type: none"> ▪ Nasal atomizer has a dead space volume which varies between brands. ▪ Draw up dosage + min 0.2 mL (sufficient to prime nasal atomizer) in a 1 mL needleless IV syringe. ▪ Connect needleless IV syringe to nasal atomizer ▪ Adjust volume to ordered dose (this will prime nasal atomizer and account for volume lost in dead space). ▪ Lean baby's head back slightly. ▪ Place tip snugly against the nostril (the foam tip may need to be pushed back slightly to fit a small nare).

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| <ul style="list-style-type: none">▪ Briskly, squirt medication into nare.▪ Ideal volume per nostril is 0.1 to 0.3 mL. Volumes higher than this should be split between the two nostrils. Slowly administer medication over 15 to 30 seconds. |
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Pharmacologic Measures for Managing Oral Secretions

Medication	Mechanism of action	Pharmacodynamics / Pharmacokinetics	Indications	Recommended doses	Adverse effects
<p>atropine (anticholinergic)</p>	<ul style="list-style-type: none"> Blocks the action of acetylcholine at parasympathetic sites in smooth muscle, secretory glands, and the CNS; increases cardiac output, dries secretions 	<p><i>Based on limited information</i></p> <ul style="list-style-type: none"> Onset of action: 15 to 30 minutes. Rapidly absorbed. Duration: approximately 4 hours Metabolized in the liver and excreted in urine. 	<ul style="list-style-type: none"> Inhibit salivation and reduce excessive secretions. 	<p>Sublingual: 1 to 2 drops of 1.0% ophthalmic solution, every 4 to 6 hours.</p>	<ul style="list-style-type: none"> Facial flushing Constipation Urinary retention Tachycardia ECG changes Dry eyes
<p>glycopyrrolate (anticholinergic)</p>	<ul style="list-style-type: none"> Blocks the action of acetylcholine at parasympathetic sites in smooth muscle, secretory glands, and the CNS; indirectly reduces the rate of salivation by preventing the stimulation of acetylcholine receptors. 	<ul style="list-style-type: none"> Onset of action IV: within 1 minute. Half-life IV: 21.6 to 130 minutes. Oral absorption poor. Excreted in urine. 	<ul style="list-style-type: none"> Inhibit salivation and reduce excessive secretions. 	<ul style="list-style-type: none"> Oral: 40 to 100 mcg/kg/dose, 3 to 4 times daily. IV Bolus, subQ: 4 to 10 mcg/kg/dose every 3 to 4 hours 	<ul style="list-style-type: none"> Drowsiness, irritability, restlessness and mood changes. Dry mouth or thick secretions Urinary retention Flushing Constipation

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