

Newborn Critical Care Center (NCCC) Clinical Guidelines

Neonatal Palliative Care Guidelines

TABLE OF CONTENTS

Purpose / Definitions / Process	Page 1
References	Page 4
APPENDIX A: Algorithm – Fetus with Life-Threatening Condition	Page 5
APPENDIX B: Family Meeting Tips	Page 6
APPENDIX C: Family Meeting Tool	Page 8
APPENDIX D: NCCC Family Meeting Documentation	Page 10
APPENDIX E: Guidelines for Withdrawal of Life Sustaining Therapies and What to Do after a Death in NCCC	Page 12

PURPOSE

These guidelines will assist in providing proactive, comprehensive, and holistic care to infants whose disease process is not amenable to cure-oriented interventions.

DEFINITION OF PALLIATIVE CARE

“Comprehensive pediatric palliative care...aim[s] to ‘relieve suffering, improve quality of life, facilitate informed decision making, and assist in care coordination between clinicians across sites of care.” NeoReviews 2015.

PROCESS

Identify if the patient is a candidate for palliative care by assessing the infant’s diagnosis and prognosis.

Antenatal Identification:

- a. The Center for Maternal Infant Health will request neonatal consult for pregnant mothers with infants with a presumed life-limiting diagnosis.
- b. Assess fetus’ condition, antenatal testing, prognosis, parental understanding of the diagnosis, and parental wishes regarding post-delivery infant care as part of the consult and document in the mother’s medical record. Consider involving the NBN team at this stage if the family has elected for provision of palliative care starting in the delivery room.
- c. Please refer to the Palliative Care Algorithm for Providers in [Appendix A](#) for how to proceed with newborn care after delivery of the infant.

Neonatal Identification:

- a. Inform a neonatal attending of the need to discuss a potential candidate.
- b. Gather information to describe the issues involved in the potential candidate. The neonatal attending of record, primary case manager, and primary nurse should take the lead in assuring that all of the appropriate data has been obtained. However, any member of the NCCC team can assess and gather data (including parents, physicians, nurses, nurse practitioners, respiratory therapists, pharmacists, case managers, therapists, and chaplains).

Provide care for infants receiving palliative care in the NCCC

A. *Conduct Initial Family Meeting:*

Plan a family meeting to discuss the infant's medical condition and ascertain the family's understanding and goals for their infant. The timing of this first meeting should be individualized to support the family's needs. If the family has other children, talk with them about having someone care for those children during the family meeting so that they may focus on the discussion of their baby's care. An attending or fellow should facilitate discussion of these items (See [Appendix B](#) for additional tips):

- a. Clarify the family's understanding of the infant's condition and goals of care.
- b. Assess the family's preferences.
- c. Communicate all information to the family in a clear, sensitive, unhurried manner, and in an appropriate setting away from the bedside. It may also be helpful to have access to records, X-Rays, etc. to aid in communication.
- d. Assure the family that decision making by the healthcare team will incorporate their preferences.
- e. Assess for additional family needs or barriers (not limited to those listed below; See [Appendix C](#) for a tool to help ask these questions)
 - Cultural, Spiritual, & Religious
 - Transportation
 - Lodging
 - Childcare
 - Employment obligations
- f. Establish and document clear, realistic, and appropriate goals of care.
- g. Obtain a DNR or specify other limitations of care, if appropriate.
- h. Consider the Stages of Grief and offer psychological consult, as needed.

B. *Family Meeting Documentation*

Document the discussion during the family meeting as a Significant Event Note (see [Appendix D](#)). It may be helpful to have a dedicated note taker, who is separate from the facilitator. If this is possible, the note taker should inform the family that they will be taking notes so the team will remember to share all their special requests and needs. Notes should be reviewed with family afterwards to ensure accuracy.

C. *Share Decisions with Team*

Neonatal attending of record and/or fellow should share the decisions made at the case conference with other health care team members (e.g., at sign-out, report, etc.). If questions develop, providers are to refer to the documentation in the Significant Event note in the patient's record.

D. *Multidisciplinary Discussion*

Discuss the case at the Tuesday multidisciplinary rounds. If time is a factor, arrange for the attending of record, primary case manager, primary nurse, chaplain and others as identified based on infant's care needs/team (e.g., Center for Maternal & Infant Health) to discuss the case outside of multidisciplinary rounds. The Supportive Care Team may be a helpful resource for navigating discussions with families about options for palliative care. Consulting the Supportive Care Team is often particularly helpful for identifying potential resources for hospice care outside of the hospital.

E. *Conduct Follow-Up Family Meeting*

Plan a follow-up meeting with the family to address additional questions, finalize the plan of care and discuss whether to transition to palliative-directed care. An attending or fellow should facilitate discussion of the below items.

- a. Assess the family's physical, emotional, and spiritual needs.
- b. Identify family's needs and preferences.
- c. Collaborate with family to decide type of palliative care plan and limitations:
 - Discharge home with family
 - Discharge home with services (hospice, home health nursing)
 - Transfer to a long term care facility (depending on availability)
 - Limitations of care (specify)
 - Withdraw of life sustaining support (see [Appendix E](#) for specific guidelines)
 1. Planned withdrawal: (include date and time)
 2. Specification of family and friends to be present: (specify)
 3. Specific requests prior to withdrawal of intensive care (walk outside, etc)
 4. Religious preferences: (chaplain, baptism, service in chapel)
 5. Location of withdrawal: (bedside, sleep room, designated outdoor areas, other)
- d. Identify the family member who will serve as the primary contact person. Ask the family at what frequency they would like to be contacted.
- e. Identify the primary provider(s) who will communicate with the family.
- f. Review plans and recap discussion.
- g. Consider the Stages of Grief and offer psychological consult, as needed.

F. *Follow-Up Family Meeting Documentation*

Document (Physician or NP) family's expectations in the medical record regarding care goals and limitations on medical interventions.

G. Initiate the NCCC Palliative Care Epic Order Set

H. Document family communication in the daily progress notes

I. Communicate with Charge Nurse to facilitate continuity of care

J. *Update new caregivers regarding the palliative care plan*

It is the off-going service team's responsibility to share the palliative plan of care with the incoming team (attending/fellow).

K. The off-going team should prepare the family for change in care team.

L. *Changes to Palliative Care Plan*

It is the responsibility of a new care team to address the desire to change the care plan with the family, including specification of reasons for doing so, as well as reviewing the case and proposed changes with the previous care team. This is in an attempt to reduce the family's confusion and anxiety surrounding changes in care.

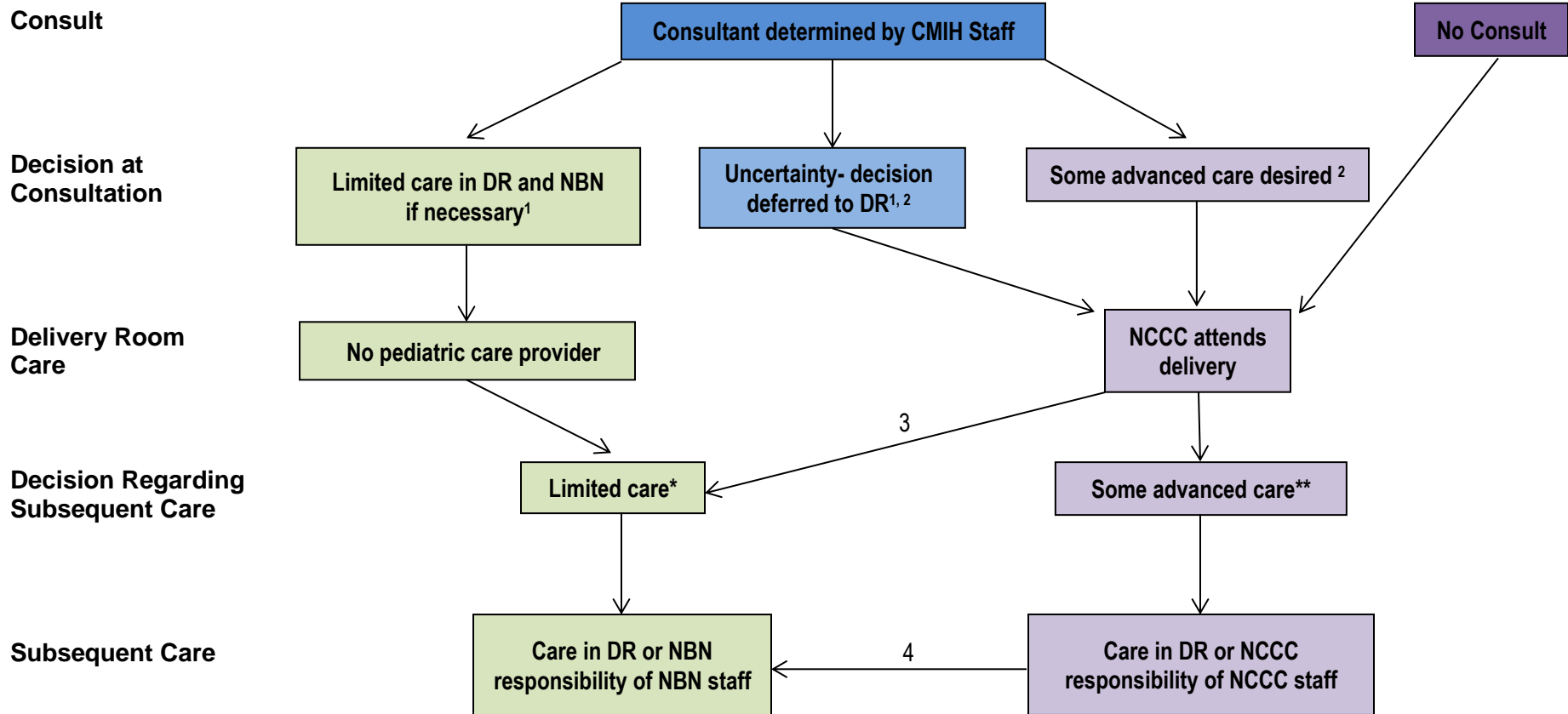
M. When time has come for withdrawal of life sustaining therapies, reference [Appendix E](#) for guidelines.

References:

1. Haug S, Dye A, Durrani S. End of Life Care for Neonates: Assessing and Addressing Pain and Distressing Symptoms. *Frontiers in Pediatrics*. 2020; 8.
2. Bidegain M, Younge N. Comfort Care vs Palliative Care: Is there a difference in Neonates? *NeoReviews*. 2015; 16(6): 333-339.
3. Harris LL, Douma C. End-of-Life Care in the NICU: A Family Centered Approach. *NeoReviews*. 2010; 11(4): 194-199.
4. Niehaus J, Maurer S. NICU Communication: The Many Disguises of Opportunity. *NeoReviews*. 2018; 19(9):526-532.
5. Premedeva I, Gardham A, Faller A, et al. Fifteen-minute consultation: How to approach the withdrawal of neonatal intensive care. *Archives of Disease in Childhood- Education and Practice*. 2021.
6. Tewani KG, Jayagobi PA, Chandran S, Anand AJ, Thia EWH, Bhatia A, Bujal R, Khoo PC, Quek BH, Tagore S, Chua MC. Perinatal Palliative Care Service: Developing a Comprehensive Care Package for Vulnerable Babies with Life Limiting Fetal Conditions. *Journal of Palliative Care*. 2021.
7. Vig PS, Lim JY, Lee RWL, Huang H, Tan XH, Lim WQ, Lim MBXY, Lee ASI, Chiam M, Lim C, Baral VR, Krishna LKR. Parental bereavement - impact of death of neonates and children under 12 years on personhood of parents: a systematic scoping review. *BMC Palliative Care*. 2021;20(1):136.
8. Kopelman AE. Understanding, avoiding, and resolving end-of-life conflicts in the NICU. *Mt Sinai J Med*. 2006 May;73(3):580-6.
9. Fine RL, Whitfield JM, Carr BL, Mayo TW. Medical futility in the neonatal intensive care unit: hope for a resolution. *Pediatrics*. 2005 Nov;116(5):1219-22.
10. Levetown M, Carter BS. *Palliative care for infants, children and adolescents. A practical handbook*. 1 ed. ed. Baltimore: The Johns Hopkins University Press.; 2004. 399 p.
11. <http://changingminds.org/disciplines/change management/kubler ross/kubler ross.htm>.

Reviewed October 2021 – Liguori / Price

APPENDIX A: FETUS WITH LIFE-THREATENING CONDITION



* Limited care = care that can be provided in the NBN (should be discussed with NBN provider prior to delivery)

** Some advanced care = care may be limited but beyond the scope of the NBN

1: NBN Staff notified upon admission of mother to L&D

2: NCCC Staff notified upon admission of mother to L&D

3: NCCC Staff at delivery contact NBN Staff to discuss further plan of care

4: Transfer of care after advanced care provided, whether in DR or NCCC to NBN. Transfer of care requires provider-to-provider conversation between NCCC staff and NBN staff.

Notes:

- No DNR order is needed if the prenatal consult dictates clear understanding of infant's condition by parents and their desire to pursue palliative care after delivery.
- All documentation by NCCC regarding further plan of care should be done on the delivery note.

APPENDIX B

Family Meeting Tips

End-of-life, palliative care conferences are difficult. They are difficult for not only the family of the critically ill infant but for the medical staff involved as well. These conferences require an intentional balance of both professionalism and compassion, as well as thoughtful consideration about how the family both receives and shares information. Said simply, end-of-life, palliative care conferences need to be taken seriously and prepared for thoughtfully. The following guidelines might be helpful:

- 1) Meetings are to be held in a quiet, private and comfortable place. The Family Resource Room or NCCC conference room are the best spaces in the unit to hold this kind of meeting. When possible, avoid conducting these meetings within the POD. Try to pass off the phone to another provider to avoid interruptions.
- 2) Meetings should include parents, grandparents, other relatives or support people the family indicates. In addition to the attending or fellow, the primary nurse, primary care provider, case manager, chaplain, and others as desired by the family should attend if possible. However, keep the number of staff present to a minimum – these are sensitive conversations and only those directly involved with the baby’s care should be included. Include an interpreter, as appropriate.
- 3) The way in which those present position/seat themselves is important. It sends a non-verbal message that all present in the room are equally important. In other words, no one person has the monopoly on what decisions are made and all are working as a team. The loveseat in the room is generally reserved for family (you may also let them walk in first and select their seating). If possible, try to have staff seated in chairs beside the family, so as not to have all staff situated on one side of the room – by including some staff next to the family, it shows support. The main facilitator should sit directly across from the parent(s) in order to maintain eye contact and engage with them as directly as possible. No one should be positioned against the door – doing so may make family members feel “trapped.” No one should be standing in the room (can be viewed as intimidating). Have tissues available.
- 4) Communication should be clear, accurate and empathetic. One way to show compassion during these conferences, in fact, is to be as candid and honest as possible. This allows a family to understand most fully what is being discussed. Talking around difficult issues or using vague language can be confusing and require more energy to interpret the facts.
- 5) Always begin the meeting by going around the room and allowing each person present to introduce themselves, saying their name and role.
- 6) Major problems should be reviewed. Family members will need time to process the information. When possible, lay terminology should be used to clarify medical diagnosis. Language should be nonjudgmental. Family should be supported in obtaining all the medical information they want, such as second opinions.
- 7) Ascertain the family’s understanding of the situation and/or decisions by using sentences like, “tell me what you heard me say” or “tell me what you understand is going on with your baby.” You may need to ask these questions more than once throughout the meetings. Family members sometimes understand best when issues are described one system at a time (e.g., brain, heart, lungs). You may also consider using pictures or other visual cues to help with explanations. Determining their understanding of each aspect of care is important. Also, different family members may understand things differently – make efforts to assess individual understanding (at least for the 2 primary caregivers).

- 8) If indicated, use words such as “death” and “dying”; euphemisms should be avoided.
- 9) The family should be asked their goals and hopes for the treatment.
- 10) When discussing palliative care, the family should know that they will not be abandoned and that some care will be continued. Terms such as “withdrawal of care” and “there is nothing else we can do” should be avoided. Instead, use language such as “We will continue to provide the most appropriate medical care for your infant. The baby’s treatment will include frequent assessments by nurses and physicians, feedings (if appropriate), adjustments of pain medications and making the baby comfortable” or “No further medical treatment will help cure your baby’s medical problems. We are changing the focus from curative care to improving the quality of life of your baby.”
- 11) If the transition to palliative care includes removal of mechanical ventilation, explain that the infant is dying and mechanical ventilation is neither beneficial nor recommended. This concept may take more than one discussion. Be patient with families and appreciate the seriousness of the decisions they are having to make about their baby’s life/death.
- 12) Discuss whether the family would like to consent for an autopsy. Explain that an autopsy is a medical procedure that is performed at UNC Hospitals to learn more about the cause or reasons for death. A complete autopsy will involve removal and examination of different organs of the body. An autopsy can be restricted to a certain portion of the body at the parents’ request. Incisions during the autopsy are planned to prevent any disfigurement. Autopsies are performed during weekdays and a full report is available to the physician in 6-8 weeks. There is no cost associated. If the family is interested in an autopsy, there is a consent form (HIM# 406s), located in the “Death Packet Sample” binder that should be filled out. There is an informational handout about autopsies in this binder that can be given to families.
- 13) Every effort should be made to listen carefully and answer the family’s questions. Emotions should be acknowledged and addressed. It is normal for families to express emotion through tears, silence, and perhaps raised or lowered voice. It is also okay to acknowledge your own emotions, but you should never be more emotional than the family. The family should not feel the need to comfort you.
- 14) Explain what to expect while the infant is dying. If appropriate, an estimation of timeframe should be given (i.e., hours or days). Acknowledge that uncertainty always exists about the exact timing of death, and that palliative care will be continued as long as necessary. Explain how the baby’s body might respond (i.e., what to expect to see, hear, etc – gasping and agonal breaths are normal physiologic responses and do not indicate pain or suffering). Assure the family that staff will remain present to offer information and updates as necessary.
- 15) Offer the possibility to talk to other parents who have experienced similar circumstances. [Consult with case manager, care coordinator, chaplain, or family support specialist to determine availability before offering this mechanism of support to the family.]
- 16) If family and staff agree on goals of care at the end of the meeting, summarize and clearly state the plan for treatment to confirm that everyone agrees with the plan moving forward. If goals of care cannot be agreed upon and further discussions need to happen, end the meeting by setting a date when those present will gather again and decide on shared goals.
- 17) Before the conclusion of the meeting, a next step should be established or a follow-up meeting if necessary. The parents should be asked when or if they prefer to meet again.
- 18) Document the meeting discussion and decisions as a Significant Event Note.

APPENDIX C

Family Meeting Tool

Discussing the limited life or possible death of an infant is not a conversation that can be perfectly crafted in advance; it is not a science either. Your own emotions, beliefs, and perspectives, as well as those of the infant's family, make these discussions especially difficult. Do not worry so much about getting these conferences "right"; rather enter these meetings hoping to communicate as directly as possible with the family by doing the best you can. Remember that while you might be the one responsible for facilitating the meeting, you are not the only one responsible for actively participating in it. The effectiveness of the meeting depends on both your communication of information to the family AND their communication with you. Trust yourself to do the best you can and allow yourself some room to make mistakes. If you are sincere and honest, aware of the seriousness of the conversation, and respectful of the circumstances in which this family finds themselves, your efforts will be received well. Finally, remember that however well you prepare for these meetings, you will likely make a mistake, say something less eloquently or sensitively than you had hoped, and/or illicit an emotional response from the family. This is okay.

INITIAL FAMILY MEETING

Clarify the family's understanding of the infant's condition and goals of care.

How do you feel your baby has been doing since we last met? Do you have new concerns or questions?

Assure the family that decision making by the healthcare team will incorporate their preferences.

Remember that while the medical staff manages the day-to-day carrying out/implementation of the decisions we made together about goals of care, your consistent input is necessary. You know your baby in a deeply personal way that we do not and your insight is valuable, particularly to allow us to provide the kind of care that you want for your child. It is our job to incorporate your preferences into the care of your baby at all times and when we feel we cannot do so due to medical/physical complications, we will let you know that we need to revisit our plan.

Cultural, Spiritual, and Religious Needs

The NCCC is primarily designed for caring for very sick infants, and can be very overwhelming. Doing special things or surrounding yourself with items that are important and familiar to your family can be comforting. For example, some families like to hold special services, bring cherished items, take photographs, or invite important people to be with them. Is there anything we can do to make you feel more comfortable or anything we can provide that may help you?

Transportation

We think it is important for families to be here as much as they would like, whether it's to spend time together as a family or to meet with the NCCC staff to talk about your baby's medical care and be a part of decision-making. Is there anything that would make it difficult for you to be here as much as you would like? Do you have a way to get to the hospital?

Lodging

Some families like to stay-over at the hospital with their baby whenever possible, while others prefer to be at home. Have you thought about where you will rest? (If available, the NCCC has 3 private “care-by-parent” rooms. One may be offered to the family IF AVAILABLE.)

Childcare

Department of Recreation Therapy can help with/engage/babysit siblings when a patient is dying. Call 984-974-9341 to inquire if their assistance is available.

Employment

Some families may have difficulty getting time off from work to be at the hospital. In some instances, it helps to take your employer a note from the NCCC explaining the importance of your presence. Let us know if this is something that would be helpful to you.

Consider the Stages of Grief and offer psychological consult, if needed.

STAGES OF GRIEF	
Shock	Initial paralysis at hearing the bad news
Denial	Trying to avoid the inevitable
Anger	Frustrated outpouring of bottled-up emotion
Bargaining	Seeking in vain for a way out
Depression	Final realization of the inevitable
Testing	Seeking realistic solutions
Acceptance	Finally finding a way forward

Many feelings can come up during a stressful time such as this and we don't want you to handle them alone if you are overwhelmed. In addition to some of the resources you are already aware of in the unit, we also have staff members who specialize in helping mothers/fathers/families manage emotions, thoughts, and grief related to the hospitalization of their baby. Would meeting with this kind of staff person be helpful to you? Or would you like to see some more information on what kinds of services these consultants can offer?

Follow-Up Family Meeting

How do you feel your baby has been doing since we last met? How do you feel about the goals we set together then? Do you have new concerns or questions? Do you feel comfortable proceeding as we have been or do we need to revisit some decisions we made last time?

APPENDIX D

NCCC Family Meeting Documentation

Document the Family Meeting note as a Significant Event note. The following information is suggested documentation that should be included in the note:

NCCC FAMILY MEETING DOCUMENTATION (TITLE)

ATTENDEES:

Family Members/Legal Guardian

Healthcare Team:

Attending MD

NP/Fellow/Resident

Nurse

Subspecialists

Chaplain,MSW/Case Manager

Other:

PURPOSE FOR MEETING

Routine/update on known diagnoses

Update on new diagnosis

Discharge/Transfer planning

Palliative Care

End of Life Care

DNR – (Do not resuscitate)

STATEMENT REGARDING THE FOLLOWING:

Family's understanding of patient's condition and treatment plan

Concerns of family

Treatment goals/options

Family decisions

Other:

PLANS:

Consults:

MSW/Case manager

Chaplain

Palliative Care

Subspecialist: (specify service)

Withdrawal of life support (delineate timeframe and setting)

ORDERS

Do not resuscitate

Do not escalate care

Implement Palliative Care Protocol

Discharge to Hospice Care

Home Care referrals

Other:

TOTAL DURATION OF MEETING: _____ *minutes.*

APPENDIX E

Guidelines for Withdrawal of Life Sustaining Therapies and What to Do after a Death in the NCCC

A. DECISION – MAKING:

1. Parent/legal guardian selects withdrawal of life support
2. Contact case management (Christine Wesolowski, MSW, Chris Sellers, MSW, or Lindsay Logan, LCSW)
 - a. Text page Mon-Fri except holidays: 0830-1700
 - b. Leave phone message after hours
3. Contact chaplain services, if desired by family.
4. Contact Carolina Organ Donor Services to determine if there is any possibility of tissue donation: 1-800-252-2672.
5. Discuss with the family and plan the following:
 - a. Timing of withdrawal
 - b. Family members to be present
 - c. Chaplain services/clergy/service if any desired
 - d. Environment (Review options with family i.e. where: bedside, sleep room; holding of infant pre/post)
 - e. Notify Charge Nurse re: Bereavement cart
 - f. Mementos:
 - i. “Now I lay me down to sleep” pictures (Charge Nurse to coordinate, if desired)
 - ii. Family initiated mementos
6. Clarify DO NOT RESUSCITATE or DO NOT ESCALATE CARE orders (these should go into effect in the interim from decision-making point until actual withdrawal)
7. Clarify family’s wishes for IV/enteral feeds
 - a. Contact lactation services for mothers providing human milk
8. Discuss with family whether they would like to consent for an autopsy and clarify the timing for this (autopsies generally take place on weekdays and the patient’s body will be released to a funeral home only after the autopsy has been performed)
9. Clarify timing of Cremation/Burial Plans
10. Document in “Family Meeting” note
 - a. Selection of withdrawal
 - b. Plans clarified/Plans left undecided
 - c. DNR order

B. AT THE TIME OF WITHDRAWAL:

1. Clarify
 - a. Family members/caregivers desired present
 - b. Any meaningful service conducted if desired
 - c. Environment as desired
 - d. Consent for autopsy (consider leaving lines, endotracheal tube, or medical equipment devices in place, particularly if there is a chance that they contributed to the cause of death)

- e. Plan for cremation/burial
2. Nurse to initiate bereavement box
3. Medications:
 - a. Pain control - Opioid administration:
 - i. Fentanyl IV 3 mcg/kg/dose or continuous drip of 3 mcg/kg/hour
Repeat as needed, nurse to assess
 - ii. Morphine PO/IM/IV 0.1-0.2 mg/kg/dose or 0.3mg/kg/dose intranasal
 - b. Consider sedation – Benzodiazepine administration:
 - i. Midazolam IV 0.1 mg/kg/dose
4. Hold enteral feeds
5. Remove from monitors
6. Infant placed in family member arms, nurse caretaker arms or on warmer bed as indicated
7. Remove endotracheal tube from infant (unless decision is made to leave in place for autopsy)
 - a. RT to turn off ventilator
8. Remind family of your periodic return to check vital signs
 - a. Readdress desire for healthcare worker presence with family
 - b. Show nurse call button where appropriate
9. Obtain Death Packet from HUC
10. Pronounce infant – tell family infant has died
11. Death Note should include:
 - a. Plan for Withdrawal
 - b. Medications given to infant
 - c. Time removed from ventilator
 - d. Environment of infant following removal
 - e. Date/Time of Death (documentation of no HR, no RR, pupils fixed)
 - f. Bereavement box completed and document any bereavement plan specific to the family
 - g. Plan for autopsy
 - h. Plan for cremation/burial (Decedent Care Services (Phone: 966-4491, Pager 216-4236) can assist the family in understanding the next steps after a death)
12. Call Carolina Organ Donor Services: 1-800-252-2672. After calling CDS, fill out the Routine Referral for Anatomical Gift Form (MIM #223)
13. Fill out MD Death Packet completely (important information highlighted on sample sheet in binder, located in cabinets on front side of the unit):
 - a. Certificate of Death
 - b. UNC Hospitals Autopsy Request Form
 - c. UNC Hospitals Routing Slip – HUC to help
 - d. Routine Referral for Anatomical Gift Form (Will need to document name of CDS Coordinator who handles the referral)
 - e. Notification of Death form (to be sent to Neonatal Administration Office)
14. RN to fill out RN Death Packet
 - a. Mortuary Tag
 - b. Death Checklist (3 copy list)
15. Follow up with family (within 24 hours of death)

16. Follow up of family by parent support person as appropriate. The fellow on service will generally be responsible for writing a condolence letter to the family.
17. Determine need for debriefing or grief counseling for staff involved
18. Follow-up of autopsy results: identify attending and/or fellow responsible

KEY POINTS/CHECKLIST:

- Withdrawal plan in place
- Notify Chaplain
- Pain control/sedation given
- Withdrawal of support
- Death pronounced
- Death communicated to family
- Autopsy consent requested
- Cremation/Burial plan
- CDS (Carolina Donor Services) called
- Death packet completed
- Documentation (death note)