# PEDIATRIC NEWBORN MEDICINE CLINICAL PRACTICE GUIDELINES

## Bereavement Support for CWN Families



Implementation Date: October 2019

**Clinical Practice Guideline:** Bereavement Support for CWN families

**Points of emphasis/Primary changes in practice**:

1. Well-established protocols in place at BWH for Neonatal Palliative Care, Religious Support for Parents of Critically Ill or Stillborn Infants, and Care of the Patient/Family Experiencing Pregnancy/Neonatal Loss. (policies available within Department of Nursing)
2. Bereavement follows loss; hence, the goal of "Bereavement Support" is to enhance follow-up with families as parental grief continues for several weeks/months after the death of their infant(s).

**Rationale for Change**: To enhance and standardize the Bereavement Services in CWN at BWH

| | |
|---|---|
| **Clinical Guideline Name** | Bereavement Support for CWN Families |
| **Effective Date** | |
| **Revised Date** | |
| **Contact Person** | |
| **Approved By** | Clinical Practice Council ____<br>Department of Newborn Respiratory ___<br>Department of Newborn Medicine ____<br>Department of Neonatal Nursing __9/11/19__ |
| **Keywords** | |

**This is a clinical practice guideline. While the guideline is useful in approaching standardized and enhanced bereavement care for families experiencing loss, clinical judgment and / or new evidence may favor an alternative plan of care, the rationale for which should be documented in the medical record.**

**I. Purpose**: The purpose of this clinical practice guideline is to standardize and enhance bereavement care to families experiencing neonatal loss for 12 months after the infant's death.

**II.** All CPGs will rely on the NICU Nursing Standards of Care. All relevant nursing PPGs are listed below.

HAPM 1.11.1 Fetal/Newborn Death
WNH I.3 Care of an Infant with A Life Limiting Condition or Illness
WNH M.2 Bringing Infant from Patient Care Unit to Morgue
WNH P.3 Care of the Patient/Family Experiencing Pregnancy or Neonatal Loss
WNH R.3 Religious Support for Parents of a Critically Ill or Stillborn Infant

**III.** Definitions: ***Grief*** – "a symptom of bereavement"; the emotional reaction that follows the loss of a valued other; or a normal response characterized by intense and deep sorrow that may be manifested in psychological, physical, behavioral, or social ways." (Fenstermacher paper). ***Mourning*** – "an expression of bereavement that is time-limited and dynamic, differing from person to person and over time." (Fenstermacher paper). Bereavement – there is no specific definition; vaguely defined as loss through death. Grief is used a synonym for bereavement, when bereavement is a much more global process.

V Bereavement theories

a. Classic – resolution of grief and detachment from the deceased loved one (Davies 2004)
b. Modern thoughts

i. Bereavement is a process that is unique to each person and INCLUDES maintaining the loved one's memory
ii. Grief can be a catalyst for personal change ("a re-framing of self")

**IV**. Bereavement influences (see also attachment 1)

a. Antecedents
   iii. Primary event: unexpected loss of infant
   iv. Secondary event: loss of "dreams" – dreaming about parenthood is about, future hopes for baby, etc
b. Attributes – main attribute is grief (personal experience involving potentially a multitude of emotions – sadness, irritability, depression, anger, etc), but there are many modifiers
   v. Situational modifiers
      1. Number of living children
      2. Surviving twin
      3. Recurrent loss
      4. Subsequent pregnancies
      5. Other stressful life events
   vi. Internal modifiers
      1. Attachment – "without attachment or bonding [to the baby], there can be no sense of loss or bereavement"
      2. Gender – men and women grieve differently
      3. Personality traits – different personal traits can influence how a person grieves during bereavement (shame, guilt, blame, envy)
   vii. External modifiers
      1. Culture – How neonatal loss is perceived by culture, faith, and tradition can influence parents' actions during bereavement
      2. Bereavement support – help, caring during difficult time helps parents with the degree of grief intensity and duration of bereavement (lessens)
      3. Attachment – "without attachment or bonding [to the baby], there can be no sense of loss or bereavement"
      4. Gender – men and women grieve differently
      5. Personality traits – different personal traits can influence how a person grieves during bereavement (shame, guilt, blame, envy)
c. Outcomes
   viii. Bereavement has no set end point
   ix. Families can struggle with guilt, finding a redefined sense of self, marital issues, sense of inadequacy

x. Goal – have families develop their own "meaning to the experience"

**V.** Currently available supports at BWH
- a. Bereavement room on CWN 5 – across from labor room 14. Multiple support pamphlets are available.
- b. Bereavement cart located in Neighborhood 4 of NICU
- c. Once a year, Remembrance Service – typically last Sunday in October
- d. Memory boxes
- e. Photography services
- f. Certified bereavement coordinators/councilor
- g. Social Services and staff make phone call & send cards to family after infant's passing
- h. NICU Family Support Specialists

**VI.** Immediate Steps after Death – Bereavement Checklist **(APPENDIX 1)**
**VII.** Detailed Outline of Bereavement Steps **(APPENDIX 2)**
**VIII**. Sample Physician Follow Up Phone Call **(APPENDIX 3)**
**IX**. Sample Bereavement Letter **(APPENDIX 4)**
**X**. Immediate Bereavement Support Services list **(APPENDIX 5)**
**XI**. Example of Bereavement Form to be filled out by nursing at time of infant's death **(APPENDIX 6)**
**XII. FOLLOW UP MEETING:** A follow-up meeting should be offered with the primary teams (both NICU and Obstetrical) and the family to review pertinent clinical issues, autopsy reports, and to provide further emotional support and comfort.
- a. Members of these teams may include (depending upon location of infant – L&D, NICU, and/or WBN):
  - i. Primary Attending
  - ii. Fellow
  - iii. Resident
  - iv. NNP or NICU PA
  - v. Primary nurse
  - vi. Medical Social Worker
  - vii. Respiratory Therapist
  - viii. Chaplain
  - ix. Infant's PCP if the family has older children
  - x. NICU Family Support Specialist
- b. A typical time for follow up is 4-12 weeks after the death of the patient. This may be held in an office off the CWN floor. If it is not possible to meet in-person then communicate with the family by phone.
- c. The nurse should fill out bereavement form (located in NICU bereavement cart) and leave in NICU assistant nurse manager's mailbox (if infant was located on CWN 9, 10 or NICU). The form should include all above mentioned members of the team and any comments concerning the parents' grief process. This allows the bereavement team to coordinate follow up.

d. NICU attending should fill out physician form – Appendix 1 (located in NICU bereavement cart) and leave in Physician Bereavement Binder on Bereavement Cart in NICU.
e. Primary Social Worker should call within 3-7 days after infant's passing.
**f. NICU attending physician should communicate with OB attending re: availability and date for a multidisciplinary Follow-Up Meeting at 2 months post-death (prior to calling family).**
g. Attending physician should call 4 weeks after time of death to offer a family meeting to discuss pertinent clinical issues review autopsy reports and offer words of support. Autopsy results may also be discussed on the phone per parents' wishes.
h. RN/MSW/MD/RT and chaplaincy (if involved) will call/send a card at **6 months** and on the **one-year anniversary of the infant's death**.
i. Examples for composing a condolence letter or speaking with the family can be found in **Appendices 3 and 4.**

**XIII: Additional key points:**

a. There are few instances in which an infant receiving palliative care is in the WBN. Medical staff should strongly consider having this infant on the NICU service (with an assigned NICU attending/fellow/LIP) as the primary service providers.
b. **Of note, any lines (including ETT) that are present when the infant dies should NOT be removed after death. Because the death is reportable to the office of the Medical Examiner, state statute provides *"The body of the deceased shall not be moved, and the scene where the body is located shall not be disturbed, until either the medical examiner or the district attorney or his representative either arrives at the scene or gives directions as to what shall be done at the scene." (MGL ch. 38 s. 4).* Up until the infant passes away, the parents have autonomy to make decisions for care, and if palliative measures include removal of tubes, this can be and should be supported.**

**References:**

1. Blunnhuber, K., Nash, S., Meier, D., Weissman, D., Woodcock, J. (2008). Putting evidence into practice: Palliative care. © BMJ Publishing Group Limited.
2. Gardner, S.L, Carter, B.S., Enzman-Hines, M., & Hernandez, J.A. (Eds.). 7th ed., 2011, Merenstein & Gardner's Handbook of Neonatal Intensive Care, Mosby Elsevier: St. Louis.
3. Williams, C., Munson, D., Zupancic, J., Kirpalani. (2008). Supporting bereaved parents: practical steps in providing compassionate perinatal and neonatal end of life care – A North American perspective. Seminars in Fetal & Neonatal Medicine, 13, 335-340.

## Appendix 1: Physician Checklist for Newborn Death

(not part of medical record)

PATIENT NAME:_____MRN:_____
DATE OF BIRTH:_____DATE OF DEATH:_____
PRIMARY CAUSE OF DEATH:_____
RELATED DIAGNOSES:_____
_____
ATTENDING covering at time of death:_____
ATTENDING on service (if different):_____NOTIFIED: YES / NO
FELLOW covering at time of death:_____
FELLOW on service (if different):_____NOTIFIED: YES / NO
PRIMARY LIPs/RESIDENTS/CONSULTANTS:
_____NOTIFIED: YES / NO
_____NOTIFIED: YES / NO

| | **Initials of Person Completing Task** | **COMMENTS** |
|---|---|---|
| **Call Medical Examiner**<br>• **1-617-267-6767**<br>• Call **before** asking for autopsy consent | | Case (circle): accepted rejected<br>Medical Examiner Name:<br>_____ |
| For **Organ Donation**, call New England Donor Services<br>• **1-800-446-6362** | | Name of Donor Services Contact:<br>_____<br><br>Organ Donor (circle): yes no |
| **Autopsy**<br>• Call ME first<br>• If parents consent, form signed | | Parents consented (circle):<br>Yes No<br><br>Autopsy consent form signed |
| **REPORT OF DEATH**<br>• **Death certificate completed** | | Process:<br>• Complete paper death certificate & take to Admitting office (call x25521)<br>• Admitting enters info on Internet & brings you the printed Certificate<br>• SIGN BEFORE YOU LEAVE |
| **EPIC DEATH NOTE COMPLETED** | | |
| Call **OBSTETRICIAN** | | OB name: |
| Call **PRIMARY PEDIATRICIAN** | | Pediatrician name: |
| If infant was a transport, Call **REFERRING PHYSICIAN/HOSPITAL** | | |
| **Please leave in Physician Bereavement Coordinator Binder on Bereavement Cart in NICU** | | |
| **Please notify NICU leadership of infant death** | | Email: NICUbereavement@bwh.harvard.edu |

## APPENDIX 2: Detailed List of Bereavement Steps

**Immediate Steps -- Neonatal Death:**

1. **Pronounce the death**
Evaluate tone, spontaneous respiratory effort and heart sounds. Listen for a full minute as a baby may continue to have a very low heart rate for many minutes after they have stopped breathing. Document the date and time of death in the chart and note the clinical findings e.g. "no heart beat or spontaneous respiratory effort". **Of note, any lines (including ETT) that are present when the infant dies should NOT be removed after death. Because the death is reportable to the office of the Medical Examiner, state statute provides *"The body of the deceased shall not be moved, and the scene where the body is located shall not be disturbed, until either the medical examiner or the district attorney or his representative either arrives at the scene or gives directions as to what shall be done at the scene." (MGL ch. 38 s. 4).* Up until the infant passes away, the parents have autonomy to make decisions for care, and if palliative measures include removal of tubes, this can be and should be supported.**

2. **Inform the Medical Examiner**
*(617) 267-6767 (open 24 hrs)*
All newborn deaths must be reported to the Medical Examiner. The Medical Examiner has the prerogative to accept any case. They may perform an autopsy on a case even if the parents decline for personal or religious reasons.
Tips when speaking with the Office of the Medical Examiner:

- Have the following information available:
- Date and time of birth
- Date and time of death
- Maternal information
- Cause of death (what you intend to write on the death certificate, e.g. periventricular hemorrhagic infarction due to extreme immaturity).

3. **Call the New England Donor Services (formerly New England Organ Bank)**
*800-446-6362*
Call their number and give them details of the infant.
They will decide if there are tissues that may be suitable for transplant. Typically, the only tissues that the NEDS will consider are corneas and heart valves. Most often the case is declined. In cases they believe are suitable for tissue transplant, they will contact the family directly and ask permission. You should not ask permission for organ transplant as that creates the perception of a conflict of interest, however you should alert the family that they will receive a call from NEDS if you know this to be true, so that it does not come as a surprise to them. **They will call the family**.

4. **Ask the family for autopsy consent**
It is always a delicate and difficult conversation. Find language that works for you. There are now many options on the autopsy form. You should go through these with the family. The family may request that only certain organ systems are examined. Tissues may be removed for histological examination – the family may refuse this. The family will decide if any removed tissues are to be returned to them (the funeral home) for disposal, or if the hospital may dispose of them.

5. **Complete the Death Certificate**
Massachusetts now has electronic death certification. BWH has simplified the process for practitioners:

- You will continue to complete the death certificate
- □ Take this to the Admitting office (under escalator in 75 Francis St (x25521 or (617) 732-5521)
- They enter the information on the Internet
- They bring you the printed Certificate
- YOU MUST SIGN THIS BEFORE YOU LEAVE
- If you are on your way out, let the Admitting Office know, and go in there to sign the certificate before leaving.
- Example: Periventricular Hemorrhagic Infarction/Intraventricular Hemorrhage due to: Extreme Prematurity. Associated Conditions: Intra-uterine Growth Restriction

6. **Complete a summary of the baby's stay**
The Attending physician is responsible for dictating the summary for the baby that has died This should summarize the reason for admission, and description of the medical course and death. Please include the cause of death noted on the death certificate, if an autopsy is being performed, and the results of the calls to the NEOB and the Office of the Medical Examiner. The goal is to dictate this summary within 24 hours of the death.

7. **Inform medical staff who have contact with the family**
It is a courtesy to inform the mother's Obstetrician, and their Pediatrician (if there are older siblings), and the Primary Neonatologist. Please also send email via NICU Bereavement address.

8. **Provide Staff support**
It is important to find a time shortly after the death of a newborn, to review the case with the staff, including attendings, RNs, RTs, and trainees. This debriefing session can help improve medical care and support staff. Staff should also be made aware of resources including the Physician support group, and the Employee Assistance Program. A multidisciplinary ethics debriefing can be considered after complex care deaths.

9. **Immediate bereavement support**
The MSW will share bereavement resources with the family.
Appendix 5

All families should be offered:
 Memory box which includes “certificate of life”, footprint pads, “Now I Lay Me Down To Sleep” professional photography with consent from parents.

 Bereavement materials which are either located in the bereavement cart in the NICU or in the bereavement room on L & D.

o When Hello Means Goodbye booklet

o Topic specific brochures from RTS (e.g. talking with children about perinatal loss, grandparent’s grief, loss of a multiple, etc). Brochures are available in both English and Spanish.

o When there are siblings, provide information about bereavement support programs (e.g. The Children’s Room) or connect family with Child Life Specialist from community palliative care agency (e.g., Care Dimensions)

- See Nursing Policy WNH P.3 Care of the Patient Family Experiencing Pregnancy or Neonatal Loss

10. **Lactation**
Notify the NICU lactation consultant if the mother is currently breastfeeding or pumping. The appropriate support can be given to help her donate her breast milk, stop pumping, or dispose of frozen milk.

11. **Disposition of remains**
Hospital policy
HAPM 1.11.1
 Massachusetts state law dictates that all live born infants **regardless of gestational age must be buried/cremated. This is the responsibility of each family. BWH will not take responsibility for these dispositions.**
 Social Work can assist family with making these arrangements.
 The deceased infant will remain in the BWH morgue until the family has made burial/cremation arrangements. The funeral home will then come to BWH to pick up the baby and to prepare him or her for disposition. If a family would like special clothing/items to accompany the baby to the funeral home, the items can be given to the OB Admitting Office in the lobby with a note attached to them. The funeral home will be given the items when they come for the baby.

12. **Fill out necessary Follow up forms. Physician – Appendix 1 and Nursing Appendix 5.**

13. **Consider sending condolence letter. Sample in Appendix 4.**

14. **Bereavement phone call by MD 1 month after infant’s passing (Appendix 3 – sample). Offer a multidisciplinary follow up meeting to be scheduled at 2 months after infant’s passing.**

15. **Arrange multidisciplinary meeting with appropriate staff and family.**

# Appendix 3: Physician Bereavement Follow-up Phone Call

## I. Preparation

1) Know infant's name and sex
2) Know names of parents
3) Know whether autopsy requested

## II. Phone call

1) Privacy
   a) Talk in a private place
2) Have paper/pen available to take notes if family has questions
3) Conversation
   a) INTRO: "Hi, this is ____ from the NICU at Brigham & Women's Hospital. I was just thinking of you and wanted to check in to see how you are doing. Is now an ok time to talk?"
      i) If not a good time: "How about if I call you another time when it might be more convenient? What are some times that are usually good for you?"
      ii) If o.k. time to talk: "So, how are you managing? "
   b) MIDDLE: possible suggestions for conversation:
      i) how parent is spending his/her time
      ii) anything parent would like to talk about re: services that might have been held etc.
      iii) How is partner doing?
      iv) Are they seeing or do they wish to see any formal supports?
      v) Does parent have any unanswered questions about what happened? (Note: If parent has questions about the clinical care or other events during the NICU admission and you do not feel comfortable answering, offer to refer to Attending or other MD/NNP/PA whom the parent mentions as having been a support.)
      vi) Throughout the conversation, support any feeling that parent is having as part of the full range of human emotion…also look for any concerning thought process and if concerns, gently question if parent is concerned about their thoughts, and ask permission to have social worker call to say hello.
   c) CONCLUSION:
      i) You can say "I just wanted to let you know that I'm available if you have anything else you want to talk about, particularly because these conversations sometimes generate more questions."
      ii) One way to end the conversation is to say "It was good to talk with you, I'm glad we connected and I hope this time passes as gently as it can."
4) General Tips
      i) Silence may be helpful for parent and also for you to think about your next words

ii) If family member is angry, be a sounding board and allow them to vent. (It may be an appropriate time to notify Medical Director/Nursing Director/Patient Family Relations of family's anger)

(1) If family seems to be angry toward one person (e.g., obstetrician), encourage them to speak to that person directly

iii) Take notes if family has specific questions and outline a plan for getting back to them (For example, if family wants to know the autopsy results, let them know that you will try to figure out if they are back and you or a physician or NNP/PA will contact them later in the week).

iv) If family expresses guilt, validate that they did nothing wrong

## III. After Phone call

1) Place document conversation in infant's EHR. Note that provider should only access chart to document conversation.
2) If the provider has concern re: family coping (depressive symptoms, e.g.), the provider should notify the mother's attending obstetrician via a confidential email or message.

## References

1. Bell SE, Cadenhead K, Graboys TB. The Doctor's Letter of Condolence, *NEJM* 2001; 344: 1162-1164
2. NICU Bereavement Committee Beth Israel Hospital, https://www.bidmc.org/centers-and-departments/neonatology,
3. Zunin LM, Zunin HS, Zunin H. The Art of Condolence: What to Write, What to Say, What to Do at a Time of Loss. Harperperennial Library. July 1992.

# APPENDIX 4: PHYSICIAN BEREAVEMENT FAMILY LETTER SAMPLE

**A. Principles**

- Avoid statements intended to assuage grief such as "It was meant to be" or "I know how you feel"
- Avoid re-visiting clinical details of the illness (to avoid legal issues)
- Focus on the sadness of death
- Include any personal memories of the patient or family
- Point out that it was a privilege to have participated in the patient's care

**B. The Seven Components** (with examples in italics)

*Dear Mr./Ms.* [names]

**1. Acknowledge the loss**.

*While I was away this past weekend, I called in to the NICU and learned the sad news from Dr. X of [baby's name] death. I'm so sorry I wasn't available to you during the last moments of your baby's life.*

**2. Express your sympathy.**

*I would like to send my sincere condolences to you and your family.* OR, if you were there at the time of death……*Just a little note to say again how sorry I am about [baby's name]'s death or your loss.*

**3. Note special qualities of the deceased**.

This may not apply to newborns who die shortly after birth. May apply if the child dies after several weeks/months or if you learn about the death from another healthcare provider. Consider speaking to the "spirit of the baby." *He/she was a fighter, etc.*

**4. Recount a memory about the deceased**.

*I will always remember how (s)he……*

**5. Note special qualities of the bereaved**.

*Although I only had the opportunity to work with your family for a short time, it was my privilege to meet you (both) and to provide care for [baby's name].*
*I admire the way you both handled the challenges of making extremely difficult decisions about what was best for [baby's name].*

**6. Offer assistance.**

*Each person finds their way through these times of grief in different ways, but if you would find comfort from speaking (further) with me or if I can facilitate contact with another NICU staff member, please feel free to call me.*

**7. Close with a thoughtful word or phrase**.

*Please know that you are in my thoughts at this extremely difficult time.*

## APPENDIX 5: IMMEDIATE BEREAVEMENT SUPPORT RESOURCES

All families should be offered:

 Memory box which includes “certificate of life”, footprint pads, “Now I Lay Me Down To Sleep” professional photography with consent from parents.

 Bereavement materials which are either located in the bereavement cart in the NICU or in the Bereavement Room on CWN 5.

- o When Hello Means Goodbye booklet
- o Topic specific brochures from RTS (e.g. talking with children about perinatal loss, grandparent’s grief, loss of a multiple, etc). Brochures are available in both English and Spanish.
- o When there are siblings, provide information about bereavement support programs (e.g. The Children’s Room) or connect family with Child Life Specialist from community palliative care agency
- o BWH Bereavement Guide: Coping with Grief and Loss

 Some potential books for parents to read to siblings regarding death

- o *Something Very Sad Happened – A Toddler’s Guide to Understanding Death*
- o *The Invisible String*
- o *The Goodbye Book*

 See Nursing Policy WNH P.3 Care of the Patient Family Experiencing Pregnancy or Neonatal Loss https://hospitalpolicies.ellucid.com/documents/view/3301/active/

## Appendix 6: NURSING Bereavement Form to be filled out at Time of Infant's Death

**NEONATAL BEREAVEMENT FOLLOW-UP FORM**
Neonatal Intensive Care Unit
Brigham & Women's Hospital
Boston, MA

***Instructions:*** *The RN caring for the infant completes the first three sections of the Bereavement Follow-up Form and places this form in the folder with both cards and places the folder in the bereavement mailbox outside assistant nurses office.*

**Infant**

Baby's Name: Last Name after D/C (if different):

Date of Birth: Time of Birth: Birthweight:

Date of Death: Time of Death: Weight at Death:

Brief history of infant:

Please list any information about the baby and/or family that would be helpful to the staff in the upcoming months and years during interactions (i.e. family was visiting from out of town, baby had lots of drawings from siblings in her crib, there were always a lot of family visiting baby, etc.)

Were parents present at the time of death? Yes ☐ No ☐

Did the parents participate in post-mortem care? Yes ☐ No ☐

Memory box given to: ☐ Parents ☐ Social Worker ☐ Placed in Bereavement Cart

**NICU Caregivers**

Caregivers:
- Social Worker: _____
- Attending: _____
- Fellow _____
- NNP/PA _____
- Resp Therapist _____
- Primary Nurse _____
- Nursing Team _____
- Chaplaincy _____

**Family**

Mother's Name: Address:

Father's Name:

Names & ages of siblings:

Telephone number: ( )

**Follow Up Cards**

Do not write below this line

Date to send six month card: ____/____/____

Date to send month card sent: ____/____/____

Date to send one year card: ____/____/____

One year card sent: ____/____/____