For Health Care Professionals: A Counseling Guide for Engaging Bereaved Mothers/Birth Parents

Compliments of

Minnesota Milk Bank for Babies

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COVER PHOTOS AND PHOTO ABOVE: Northwest Mothers Milk Bank in Portland, OR.

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ABOUT THIS GUIDE

This guide is intended for health care workers who work with bereaved mothers/birth parents and families dealing with perinatal loss. This may include nurses, lactation consultants, physicians, registered dietitians, social workers, midwives, bereavement counselors, human milk bank workers, among other health professionals.

The purpose of this guide is to help health care workers appropriately and sensitively discuss lactation options for bereaved mothers/birth parents.

OBJECTIVES OF THIS GUIDE

Use of this guide will enable healthcare workers to:

► Understand the grief process for mothers/birth parents who have lost an infant.

► Understand the role of the health care worker in providing appropriate and sensitive support to bereaved mothers/birth parents.

► Provide accurate information to bereaved mothers/ birth parents on the lactation process during bereavement.

► Counsel mothers/ birth parents in a sensitive and comprehensive manner regarding the options for donating human milk during the bereavement process.

HOW TO USE THIS GUIDE

This guide serves as a quick reference for what health care workers can expect from bereaved mothers/ birth parents and families after losing their baby and how to provide lactation support for bereaved parents.

SECTION 1

BEREAVEMENT AND GRIEF: AN OVERVIEW

What is bereavement?

► Bereavement is the state and experience of loss after a loved one has died. ►

The loss of a baby can occur at any stage of pregnancy, or any time after birth.

► Figures 1 and 2 illustrate the five types of infant loss at different points during pregnancy and after birth.

Figure 1. Perinatal loss during pregnancy.

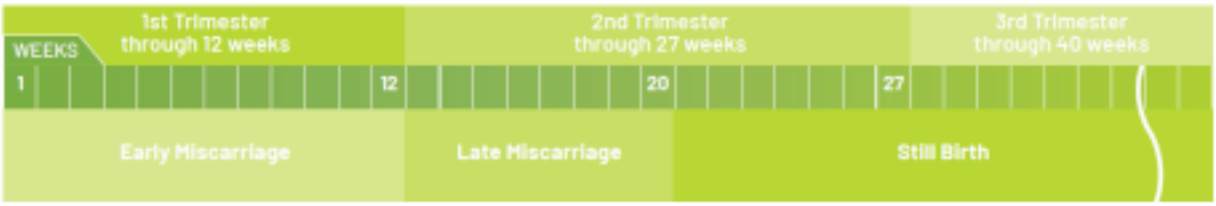
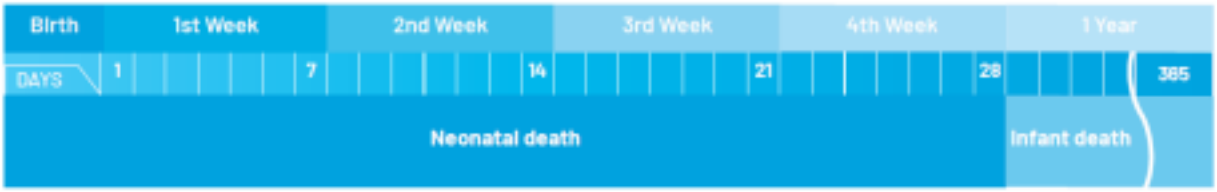


Figure 2. Loss after birth.



What is Grief?

A basic understanding of grief will help you best care for bereaved mothers/ birth parents and their families. Grief is a natural and normal response to loss and a means of healing after a loss. [1] Everyone experiences grief differently. [2,3] Perinatal loss is a high-risk factor for individuals to develop complicated grief. [2,4] Acute symptoms of grief after perinatal death will likely decrease within the first year. Complete recovery from grief after perinatal death can take several years. [5] Individuals may not necessarily "recover" from grief but develop a new way to live. [3] There are many different theories to explain how individuals grieve. Grief after perinatal loss can be more complicated than other types of grief since parents often have no or very limited time with the child and because the "natural order of life" is

disrupted when a child dies before the parent. [4] There is no correct way to grieve; mothers/ birth parents, fathers, and other family members may grieve very differently. [6,7]

THE SIX "R'S" OF MOURNING IN PERINATAL BEREAVEMENT (ADAPTED) [4,8]

Avoidance phase: Individual avoids recognizing the loss. This can be complicated by societal resistance to recognize the existence and death of the baby. Confrontation phase: Parents must fully experience the pain of this event by **reacting, recollecting, re-experiencing, and relinquishing**, but this is especially difficult in the case of perinatal loss. Parents can have difficulty reacting to being separated from the child, especially because the child can be seen as an extension of themselves. There can be

problems recollecting and re-experiencing the relationship with the infant because parents do not have many memories or experiences with the child. Difficulty relinquishing attachments to the child can emerge because this also means relinquishing connections to parenthood.

Accommodation phase: This phase requires **readjusting** to the new reality without forgetting the old one and **reinvesting** in a new life. Parents may have difficulty readjusting and reinvesting because of the nature of relationships between parents and children and their inability to fully experience parenthood.

What to expect at onset of bereavement

There are many emotions that bereaved parents might feel after the loss of their baby. Every parent will have a different reaction. The following are some examples of what a bereaved parent might express initially after the loss of their baby:

► Difficulty accepting the loss, especially since the death of a child before the parent goes against the natural order of life. [4,6,9,10]
► Guilt or feelings that it is their fault that their baby did not survive. [11,12] ► Shock, anger, and disbelief. [2]
► Difficulty making decisions. [13,14]
► Uncertainty of how to proceed or what questions to ask. [13]
► Not wanting to be around healthy babies.
► Desire to know why baby died.
► Belief that parent can hear their baby crying or have a sense that their baby is present. [2]
► Apathy and disinterest. [2,11]
► Depression. [11]

► Physical symptoms such as pain and gastrointestinal upset. [2]

BOX 1. ASSESS THE NEEDS OF YOUR PATIENT

- Mothers can lose a baby at any stage of pregnancy.
- This means some mothers may not have had much or any antenatal education.
- Some mothers will be knowledgeable about lactation; others may need assistance.

How to help parents begin the grieving process

If possible, provide parents the opportunity to "parent" their child.[14] This may include:

► Arranging alone time with baby.
► Allowing parents to hold their baby in their arms.
    • This may not be desired by all parents, but they should have the option and support from health care staff. [5]
► Expressing milk. [15-17]
    • This may be helpful for some mothers/birth parents to feel connected to parenthood and begin to heal. [15,16]If possible, provide parents with the opportunity to create memories with their child. [6,13]

You can support this by encouraging and facilitating:

► Taking photos. [5]
► Creating footprints or handprints.[5]
► Collecting locks of hair.
► Arranging alone time with baby.
► Storing breast milk. [15]

SECTION 2

THE ROLE OF THE HEALTH CARE WORKER DURING BEREAVEMENT

Empathy and sensitivity

As a health care worker, it is important that you are empathic and sensitive after the loss of a child.

► Show parents that you care about their child. [6,13]
    • It is okay to show your tears.
► Encourage parents to see their baby, without being forceful.

    • Also, give them the opportunity to change their mind if they do not want to see their baby.[4]
► If parents do want to see the child:
    • Set expectations for what the child will look like. Pictures can be provided if desired by parents.
    • Stay with the parents and only leave them alone with their infant when they are ready.

► Treat every family individually and respond to their needs.[13]
► **Table 1** contains sample statements to use and to avoid when acknowledging the loss of bereaved families.

Time and space

Give parents time and space to process their loss. [13] Do not rush the family's decision-making, their time spent with baby, or your time spent with the family.

Table 1. Sample statements for counseling bereaved families.

DO SAY	DO NOT SAY
I am so sorry for your pain.	*You can always have another child.*
I am here if you need someone to talk to.	*At least you know you can get pregnant.*
I am so sorry for your loss, I know there is nothing I can say to make you feel better.	*Everything will be okay, it was meant to be.*

Practical help [13]

► Answer all questions from the family.
► Provide family resources for additional information and support services when desired.
- *Teardrops with Milkdrops: Lactation Options After the Loss of Your Baby* brochure offered by the Minnesota Milk Bank for Babies.
- See also "Section 7: Additional Resources."

► Help the family make simple choices and decisions, such as reminding them to eat or helping them make funeral arrangements. [13]
► Assist family in making decisions by providing guidance without pressuring.

[12] **Communication**

► Be forthcoming with information about the parents' baby. [1,13,14]

► Acknowledge their loss directly and sensitively.
► Do not try to avoid talking about their grief.
► Use the same terminology the parents use to refer to their baby (e.g., by name, "baby", "infant", "fetus") and their loss (e.g., "death", "loss").

► Communicate with other staff members to ensure clarity of information concerning the family's situation.
• This includes keeping an accurate record of what is discussed with the family.[13]

Continuing support

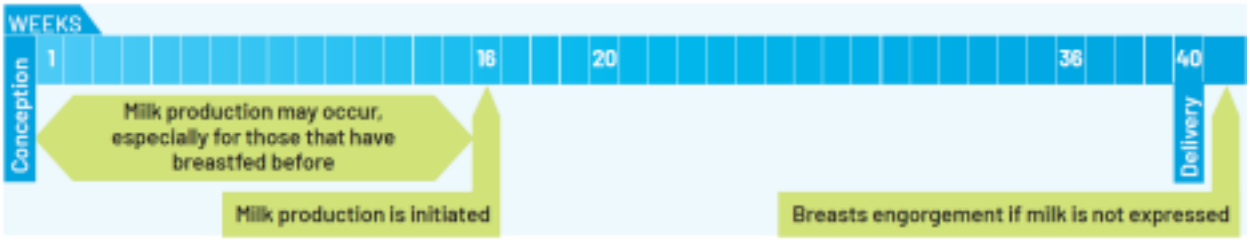
The grieving process will continue after parents leave your care. Offer community resources such as support groups, websites and print materials targeted specifically at bereaved parents. Use your hospital's resources, such as social services, to help with providing individualized resources for parents. [5,6,13] The *Minnesota Milk Bank for Babies* also provides a flyer that identifies community, regional, and national resource programs for families to consider.

SECTION 3

HOW TO PROVIDE LACTATION SUPPORT DURING BEREAVEMENT

Many mothers/birth parents may need lactation guidance after losing their child. Explain that lactation begins prior to delivery (see Figure 3) and that milk coming in is a normal process.

Figure 3. Milk production timeline during pregnancy and after delivery.[17]



There are many physical and emotional changes associated with milk production throughout the post-partum period. [16] Help prepare mother/birth parent for the effect of emotional changes associated with milk production. [16] Milk may be a reminder of

what they have lost, including the future they no longer get to have with their baby. Seeing and hearing other babies (such as in lactation support groups) may trigger milk letdown and serve as a reminder of what they have lost. Explain to bereaved mothers/

birth parents about the physiological changes that occur after delivery, such as milk production and the potential for engorgement. [16]

BOX 2. LACTATION SUPPORT: POINTS TO REMEMBER.

- Support should be offered quickly after the loss of a baby so that a mother has time to consider her options.[15]
- Initial lactation support should be carried out by someone who has already built rapport with the mother.
- Individualize support to the type of loss (e.g. miscarriage, stillbirth, neonatal death and infant death) and the needs of the individual mother.
- The stage of loss does not determine the length of the grieving process.

Lactation can be a difficult topic to discuss with a bereaved mother/birth parent and is just one part of the overwhelming and life-changing experience a mother/ birth parent is going through. Be sensitive to the needs of the mother/ birth parent when you bring up the topic of lactation. Do not assume that all mothers/birth parents want to suppress their milk supply immediately. (15)Instead, ask open-ended questions to determine what they want and what kind of information they may need to make a decision. Table 2 provides a list of statements and questions to use and to avoid when discussing lactation with bereaved mothers/birth parents.

Table 2. Sample statements and questions to discuss lactation.

Do say	Do not say
What questions do you have about your milk coming in?	*You don't have a baby to feed, so you should suppress your milk.*
When you are ready, I would like to talk to you about milk production and what to expect.	*You can always breastfeed your next child.*
Your body is going to produce milk because of hormones that are released after delivery.	*At least another baby can benefit from your breast milk.*
You can choose whether you want to do nothing, express your milk or suppress your milk supply.	*Even though your baby didn't make it, your breast milk can save another baby.*
Would you like more information about suppressing/expressing your milk?	*You have to express your milk.*
I can explain to you what to expect if you do nothing and how to manage engorgement.	*You have to suppress your milk.*
If you have any questions, I am happy to answer them now or whenever you think of them.	*Everything will be okay, it was meant to be.*

SECTION 4

HELPING A MOTHER/BIRTH PARENT WITH OPTIONS IN LACTATION DURING BEREAVEMENT

Guidance on how to counsel a bereaved mother/birth parent after the loss of an infant

There are general guidelines to follow when providing counseling to all bereaved mothers/birth parents.

► Follow the mother's/birth parent's lead during the discussion:
  • If she calls herself a mother/parent, do the same.
  • If she calls her baby by name, do the same.
► Observe her nonverbal communication:
  • If she seems uncomfortable, ask open-ended questions (e.g., "How can I support you right now? What questions do you have for me? What would you like to talk about today?") to allow the grieving mother/birth parent to steer the conversation.
  • If she seems uninterested in discussing lactation, consider providing the brochure *Teardrops with Milkdrops: Lactation Options After the Loss of Your Baby* to reference at another time.

• If she becomes upset, allow time to express her emotions and offer sympathy. ► Do not try to cheer her up:

► You are there to provide support and guidance.

► You will not be able to make her feel better, but you can help her to continue the grieving process.

What to tell a mother/birth parent after a miscarriage or stillbirth:

► Your body naturally starts the process of making milk at the 16th week of pregnancy. [17]

► From this point onwards, it is normal for your milk to come in, regardless of birth outcome. [17]

► It is okay and normal to feel emotional about the presence of your milk. [Encourage mother/birth parent to talk about this if desired.]

► Your breasts will likely become swollen and mildly tender (engorged) 2-5 days after delivery. You may begin to feel unwell or develop a fever when your milk comes in. This is the expected process that occurs after pregnancy and birth. [Remember that everyone experiences bereavement and emotions around milk expression differently.]

► You are not alone.

► You do not have to do anything about your milk supply, or you can choose to actively suppress your milk supply or to express your milk.

What to tell a mother/birth parent after a neonatal death or infant death: If the mother's/birth parent's milk has not yet come in, refer to guidelines above.

► It is natural and normal for your body to continue to produce milk after the loss of your baby.

► It is okay and normal to feel emotional about the presence of your milk. [Encourage mother/ birth parent to talk about this if desired.]

► You are not alone.

► You do not have to do anything about your milk supply, or you can choose to actively suppress your milk supply or express your milk.

If the mother/ birth parent has any stored milk in the freezer of the neonatal intensive care unit or at home:

► You can choose to take it home with you, have hospital staff dispose of it, or you may be able to donate it to a human milk bank.
► You do not have to make an immediate decision, but please let us know as soon as you have. Many milk banks, (including MN Milk Bank for Babies) will take milk from bereaved mothers/birth parents before the donor approval process is complete.

[Alert the appropriate staff that the mother/ birth parent is considering what to do with her milk, so that it is not thrown away before the mother/ birth parent makes her decision.]

Guidance on how to counsel a mother/ birth parent after she has made a decision about what to do with her milk supply

What to tell a mother/ birth parent who wishes to do nothing about lactation:

► Your breasts will likely become engorged.
► Engorgement is a natural process that signals the body to stop making milk. [16,20]
► Engorgement can cause pain, swelling and can lead to blocked milk ducts. Blocked milk ducts can lead to a breast infection called mastitis. [17,21]
► There are methods of reducing the discomfort associated with

engorgement. [See Box 4. Ways to manage engorgement.]

What to tell a mother/birth parent who wishes to suppress her milk supply:

► A safe way to suppress your milk supply is by gradually reducing hand expression or with the help of a breast pump.

If the mother/ birth parent has already initiated breast pumping:

► You can begin reducing the number of times per day that you spend pumping and the length of time you spend pumping.
► This will signal to your body over time to decrease milk production.

If mother/ birth parent has not initiated breast pumping:

► Expressing small amounts (5-10 mL) of milk by hand will relieve pressure and slowly reduce your milk supply.
► Expressing small amounts will not cause your body to produce more milk.

► If you stop pumping suddenly, your breasts may become engorged which can be painful and cause inflammation and possible mastitis. (See Box 4. Ways to manage engorgement.)

BOX 4. WAYS TO MANAGE ENGORGEMENT[15,20-22]

- Expressing small amounts of milk by hand or with a pump will relieve pressure in the breasts.
- Hot showers release small amounts of milk to help relieve pressure.
- Wear a bra that is comfortable (not too tight) to help carry the weight of the breasts.
- Place cold compresses on the breast for 20 minutes for comfort and to relieve swelling.
- Use crushed cabbage leaves as breast pads placed in a supportive bra to relieve minor discomfort.
- Over-the-counter anti-inflammatory medication can be used to alleviate pain.
- "Binding the breasts" (wrapping the breast tightly) is not recommended to suppress milk. This can lead to breast infection and plugged ducts.
- Seek medical advice in case of severe pain or inflammation.

What to tell a mother/ birth parent who wishes to express her milk: ► You are in charge of how often and for how long you wish to express your milk. **If mother/ birth parent has never expressed milk before:**

► I can show you how to hygienically express milk by hand or how to use a

breast pump, depending on your preference.

[Demonstrate correct techniques and discuss options for getting a breast pump if desired.

If the mother/ birth parent wishes to collect her breast milk:

► You can keep your milk as a memory of your baby.
► You can keep your milk for a period of time and then dispose of it when you decide.
► You can apply to donate your milk to a human milk bank in memory of your baby.

What to tell a mother/ birth parent who is interested in milk donation:

► The safest and preferred method of milk donation is through a milk bank. [23] ► Donor human milk is given to vulnerable premature and low-birth weight infants who do not have access to their own birth parent's/mother's milk. ► To become a milk donor, you must complete a screening process. ► You may be able to donate milk that has already been pumped and stored. ► You can and should take time deciding what to do with your milk. ► Some women/birth parents choose to share their milk informally with other families.[23]

- This is not a regulated practice and may allow unsafe breast milk to reach babies.
- If you choose to share your milk informally, you should seek advice from a health care professional or lactation specialist on how to maximize safety.

(Provide brochure *Teardrops with Milkdrops: Lactation Options After the Loss of Your Baby* from the Minnesota Milk Bank for Babies.)

Notes: Most milk banks cover the cost of screening and shipping milk. Let parents know of this service.

If milk bank allows unscreened bereaved mothers/birth parents to donate milk for research or allows them to donate any amount of milk (no minimum) let parents know of this.

(The MN Milk Bank for Babies covers the cost for screening and shipping as well as accepts milk

from unscreened bereaved mothers that will be used for research.)

ONE BEREAVED MOTHER'S PERSPECTIVE:

"As a bereaved mother I would have liked the opportunity to donate milk whilst I came to terms with my loss. Simply letting my milk dry up was far too traumatic, and if I knew I could help other babies it would have helped me grieve."

SECTION 5

SUPPORTING MOTHERS/BIRTH PARENTS IN THEIR DECISION

Once a mother/ birth parent has decided how she wants to address lactation, she will need continued support in the decision. This support can come from simply asking the mother/ birth parent how she can be supported as well as letting her know what resources are available. Mothers/birth parents who choose to donate milk may need additional support when deciding to stop expression and/or milk donation.[16]

SECTION 6

HEALTH CARE WORKERS PRACTICING SELF-CARE

Caring for others who are grieving is humble and compassionate work, but it can become emotionally exhausting. As health care workers, it is completely normal to occasionally feel stressed and overwhelmed. When you feel overwhelmed, it is important to take time for yourself and engage in activities that help you deal with your emotions. Table 3 lists suggestions on practicing self-care at work and in your daily life.

Table 3. Ways for health care workers to practice self-care.

At work

- Check in with yourself regularly. It is important to identify signs of stress when they are present.
- Develop methods of dealing with the stress. Engage in activities that are relaxing and pleasurable to you.
- Allow yourself to make mistakes. Assess and review them and allow them to become a learning experience.
- Remember that you do not need to have to have an answer for everything or know what to say all the time.
- Seek support from your team. Turn to your co-workers or supervisors when you need to talk and express your feelings.
- Arrange debrief meetings to help you and your colleagues learn from both positive and negative experiences from working with bereaved families.
- If serious mental challenges arise, consider professional help. Seek the help of a counselor, psychologist or psychiatrist when needed.

In your daily life

- Get adequate rest and sleep.
- Exercise regularly.
- Eat balanced and wholesome food.
- Be kind to yourself.
- Spend time in nature; go out for a walk.
- Read a book.
- Awaken your sense of humor; laugh often.
- Practice relaxation, stretching the body, taking deep breaths.
- Have quiet time. Silence can bring your emotions and challenges into perspective.

SECTION 7

ADDITIONAL RESOURCES

Bereavement resources

Empty Arms- Bereavement Support
www.emptyarmsbereavement.org

International Stillbirth Alliance
http://stillbirthalliance.org/about-us/member-organisations/

March of Dimes
www.marchofdimes.org

Share- Pregnancy and Infant Loss Support
www.nationalshare.org

Hope for Grieving Parents- Minnesota Community Resources Provided by Minnesota Milk Bank for Babies

General lactation support and human milk bank resources

Human Milk Banking Association of North America (HMBANA)
https://www.hmbana.org

La Leche League International
https://www.llli.org

Kellymom
Kellymom.com

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