

Pregnancy Loss and Infant Death Alliance

Supporting those whose work supports bereaved families.

Practice Guidelines: Offering the Baby to Bereaved Parents

Related PLIDA Position Statements:

- Bereaved Parents Holding Their Baby: After their baby dies, it is the parents' right to decide how much time, if any, to spend with their baby, and to determine when and how to use this precious time.
- Offering the Baby to Bereaved Parents: When a baby dies, parents should be offered their baby within the context of an empathic relationship, where the health care provider engages parents in periodic conversations, eliciting their thoughts and feelings about spending time with their baby, and then supports the parents in doing what they believe is best, whether or not they elect to spend time with their baby.

Guidelines for the Bereavement Care Provider

First and foremost, cultivate an empathic relationship with parents. Ask them about the pregnancy, and particularly for early pregnancy loss or pregnancy termination, listen to the parents' conceptualization of this event, so that you are able to honor their perceptions and wishes. Whenever parents see their loss as "the death of our baby," ask them about their baby and provide care accordingly. Also inquire about their physical well-being and comfort. Cultivating an empathic relationship with parents gives them a caring context within which to process their experiences and emotions, and thoughtfully explore their options.

<u>Understand the benefits parents can experience in spending time with their baby.</u> For grieving parents, contact with their baby can

- validate their role as parents to this child,
- offer opportunities to express their love and devotion (such as holding, kissing, bathing, dressing) and engage in rituals (such as blessing, baptism, naming ceremonies),
- cultivate cherished memories (such as how their baby looked and felt) and keepsakes (such as hair, footprints, photographs),
- rally the support of family and friends who can meet their baby too,
- help them process the traumatic events surrounding their baby's death as they share this parenting
 experience with others, including other grieving families in post-discharge support settings, and
- allow for a more gradual goodbye.

All of these benefits can foster productive grieving for those parents who want and need contact, memories, and keepsakes. If denied this experience, some parents will harbor lasting and significant regrets. However, for parents who do not want or don't feel the need for contact, they may not reap these benefits, and some may harbor lasting regrets if pressed to have contact with their baby. Understanding the complexities of perinatal bereavement and the long term effects of contact with the baby requires further systematic research. In any case, the complexities underline the importance of individualizing care for each parent.

<u>Work to individualize care.</u> Every parent is unique, every family is different, and you will encounter much variety in parents' responses and desires. So rather than trying to fit parents into a rigid protocol, or deciding whether they should see their baby, or directing their involvement with their baby, ask parents about their needs and preferences and accommodate each family's process and timeframe.

- Some parents will know right away whether or not they want to see their baby; others need time to weigh their options.
- Some parents will decide not to see their baby; others will welcome the opportunity.
- Some parents will embrace their baby without hesitation, others will be more cautious about seeing, touching, or holding their baby.

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- Some parents will need more time with their baby; others will need less.
- Some parents will want to keep the baby with them for extended periods; others will want short or multiple viewings on different days.
- Some parents will find your presence reassuring; others will want privacy.
- Some will want family and friends to see their baby; others will prefer to be alone with their baby.

Parents benefit from making their own decisions in their own time. And if parents decide to see their baby, they benefit from pacing themselves instead of having arbitrary constraints placed on them.

<u>Follow the parents' lead.</u> Be an unbiased sounding board for their thoughts and feelings, offer them options and individualized guidance, address their concerns, and leave the decision-making to them. By listening, responding, and respecting parents' choices, you are

- honoring their self-knowledge,
- recognizing their competence to navigate this difficult terrain; even as they may feel temporarily incompetent, your confidence in them can be a reassuring boost,
- giving them room to make satisfying choices,
- averting the regrets that can accompany being directed or pushed,
- reminding them that they can still exert some control over what happens after their baby dies, and thereby
- alleviating trauma and the accompanying feelings of helplessness.

<u>Practice cultural and religious sensitivity.</u> In some cultures, close contact with a dead body is prohibited, while in other cultures, it is considered the highest form of respect to remain with a body until burial.

- Likewise, some religions specify that a body needs to be buried or cremated in a short time window, which may affect the parents' ability or need to be with their baby.
- Assess each family's practices, keeping in mind that they may or may not wish to observe their traditions.
- Never assume—always ask.
- Remember that even if parents look, talk, and act like you, they may hold very different beliefs and preferences.
- To find out their wishes, you might ask, "Can you tell me about your family's traditions when someone dies?" or "Are there any religious or cultural traditions that you would like to observe?" or
- "It would be helpful for me to know what is most important to you as you consider spending time with your baby."
- If parents want guidance from elders or religious practitioners, help them receive this counsel, while letting them know that you will honor whatever the parents themselves decide to do.
- As you build a rapport with each parent, you can gauge what types of information and support are welcome.

<u>Honor the parent-baby bond</u>. Central to your mission is to honor the parent-baby relationship, and make room for each parent to nurture their baby and/or their baby's memory.

- Observe and acknowledge the unique bond each parent feels with her or his baby, no matter the gestational age or whether the baby lived after delivery.
- Whether they want contact or not, you can affirm their baby's existence and importance by acknowledging their baby's life and their loving bond. Ask them to tell you about their baby, the pregnancy, their dreams for this child, and how they plan to honor their baby's memory. "Tell me about your baby (pregnancy, delivery, dreams.)" "Have you thought about doing (making, buying, keeping) anything special to remember this baby by?"
- Many parents find it comforting to hear that they have been, and always will be, this child's mother or father. Refer to them as such.
- If parents elect to spend time with their baby, step back so that the parents can bathe, groom, dress, and generally take care of their baby whenever possible. Even if the mother is bed-bound, you can ensure her proximity and participation—all of these activities can take place on her lap or next to her. For many parents, taking care of their baby is a meaningful and memorable way for them to nurture and feel close to their little one.

• Parents who see their baby can also find it therapeutic to play a primary or participatory role in clipping locks of hair, making molds or prints of tiny hands, feet, and other body parts, or making photographs of their baby. Collecting these mementos provides additional opportunities to feel close to their baby and lets parents have a creative role in determining what their keepsakes look like.

<u>Engage parents in open-ended conversations</u> about their baby and their options. When you listen to parents, you are able to accompany them as they evaluate their options, communicate their needs, and figure out what is best for themselves. For some hesitant parents, simply having an opportunity to express their feelings and tell their story can help them recognize the benefits of seeing their baby. For others, the chance to share their thoughts and feelings can affirm their decision to not view their baby.

- In general, rather than dispensing advice or directing, ask them what they are feeling and thinking about with regard to their baby, the circumstances, and their options. It is far more therapeutic for them to gather their own insights than to have you set the pace or plan.
- Ask, "Have you thought about seeing your baby?" or "How do you feel about seeing your baby?" This will help them consider what they want and need.
- Resist directly asking "Do you want to see your baby?" as this will only elicit a simple "yes" or "no" answer.

During these conversations, listen to their thoughts, desires, and feelings about their baby and their ideas about having contact.

- Let them know that they can hold, undress, dress, bathe, rock, and photograph their baby, and that you can provide a rocking chair, disposable cameras, blankets, clothing, a small tub, and bathing accessories.
- As they consider contact with their baby, ask them how they would want to use this precious time.
- Let parents know that friends and other family members can be involved in rituals, photographs, and keepsakes. Parents can find it comforting to be surrounded by loved ones, including the baby's siblings, grandparents, aunts, uncles, and family friends. By inviting others into the circle, parents
- are essentially holding their baby inside a loving community, which can help them hold onto their baby's memory.
- Whether or not they want contact with their baby, tell them, "I'm here to listen if you'd like to talk about your baby, your pregnancy and delivery, and how you're doing."
- About their baby's name, ask the open-ended question, "Had you picked out names for this baby?" Find out the meaning or source of this name, and then ask "Do you feel comfortable using this name for this baby?" If they are considering saving the intended name for a future baby, reassure them that many other parents have done the same, and the measure of their devotion is not the particular name they choose, but the care they are taking to pick the best name for this child.
- If they choose a name, use it when referring to their baby.

When you engage with and listen to parents, you are better able to understand—and respond to—their needs and wishes.

<u>Engage parents in conversations proactively</u>, when possible. If the baby has died before birth, or if the baby is likely to die during or shortly after delivery, ask the parents, "Have you thought about seeing your baby?" so that they can think proactively about how to make the most of this time.

- For instance, you'll know whether to hand the baby to the parents immediately after delivery. You'll also be giving
- mother and father time to:
- confront the unknown and become informed;
- make a decision and come up with creative ideas;
- · decide whether to have family and friends present;
- consider their other children, as including their baby's siblings can be particularly touching, meaningful, and beneficial.
- Remind parents that making plans can help them prepare and can offer guidance to their health care providers. Assure them that these plans are not set in stone, and they are free to adjust to unforeseen circumstances or change their minds and improvise.

<u>Continually assess</u> what the parents are thinking and feeling with regard to seeing their baby. In your ongoing conversations with parents about their baby, listen to their thoughts, feelings, and ideas, and continually assess where they are in their decision-making process.

- What are their feelings about holding their baby?
- Have they ever seen a dead body before?
- What are their fears?
- What are their regrets?
- What do they want from this opportunity?

Then you can tailor your guidance and support to fit their needs.

<u>Utilize a checklist</u> that makes room for qualitative answers. Rather than simply checking "yes" or "no," document the parents' thoughts, feelings, and fears, as well as your responses. These notes can help you and your team assess and respond to their needs for time, information, support, and reassurance. These notes can also assist you in providing a comprehensive and compassionate continuity of care.

Offer unbaised, balanced information that helps parents figure out what is best for themselves. During your conversations with the parents, tell them, "Some parents find it comforting and helpful to spend time with their baby, while others decline, and the choice is yours to make." If the parents are worried that seeing their baby is strange or morbid, you can inform them that some parents would rather remember their baby as what they imagined during pregnancy or as the live baby they once held, but many parents find it reassuring to see their baby and express their love and nutruing in physical ways.

Let parents know that it is normal and natural for them

- to feel a connection to their baby,
- to be curious about what their baby looks like,
- to notice family resemblances,
- to be nurturing— cuddling, dressing, or bathing their baby,
- to want keepsakes such as a lock of hair, hand and footprints,
- to want photographs that record their baby's appearance and their love for this child, and
- to name their baby.

Reassure parents by addressing their fears or concerns. Parents can benefit from knowing that many parents feel uncertain or scared about seeing a dead body or a baby who might have an unusual appearance.

- Inquire, "Do you have any concerns about what your baby looks like?" Then you can address their fears by describing their baby's appearance, letting them know they may find family resemblances, and telling them that their baby will be brought to them, warmed and wrapped in a warm blanket.
- Inform parents of their baby's condition. Even the most fragile babies can be touched and held by parents if the body is carefully and respectfully prepared, and the parents are honestly and reassuringly informed about their baby's tiny size, discoloration, the delicate nature of their baby's skin, or bodily fluids.
- Comfort parents by telling them that their baby is treated with respect and dignity at all times.
- Whatever the baby's gestational age or condition, when you are open and accepting toward the baby's appearance and condition, this can be tremendously comforting and validating for parents.

Remain accommodating and impartial to the wide range of parental responses. Some parents will know right away that they want to see and hold their baby. Other parents will remain adamant that they do not wish to do so, preferring to remember their baby alive (whether before or after birth.) And some parents will be undecided and may simply need time to recover from delivery and the initial shock in order to come to a decision. Rather than trying to convince all parents to see their baby, focus on exploring the options with each parent.

- Be aware of your own biases, so that you can resist convincing or pushing them to do what you believe is best.
- Be mindfully accepting of all requests and actions by parents, particularly when their choices are different from what you believe to be most meaningful, or from what you've observed or experienced with other families.
- Encourage parents to communicate their needs and focus on helping parents figure out what's best for themselves.

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- When parents are unsure about whether they want to see their baby, you can simply inform them of their options, address their concerns, and assure them that they can take their time to decide.
- Let parents know that their baby will continue to be available to them, if and when they are ready.
- Some parents will warm up to the idea over time and with your reassuring conversations about seeing a dead body or how normal their feelings are.
- Sometimes a baby's parents have different ideas and make different choices. Offer them the freedom to pursue their own experiences.
- Whatever a parent's choices and pace, continue to engage, listen, and support.
- Encourage parents to do what is meaningful to them. Some parents will have lots of ideas and engage freely in rituals and nurturing behaviors. Others will be grateful for your culturally sensitive suggestions or reassurance. If parents want to see their baby or are considering it:
- Ask parents about their ideas of how they might want to spend this time and then offer the support they need to carry out their desires.
- Describe what other parents have found meaningful to do during this time; doing so gives parents a framework and permission to think broadly about what they want to do.
- Offer ideas that expand on their own and fit with their expressed preferences; this individualized guidance can help them consider their options and explore the possibilities.
- Let parents know that they can stay with their baby for as long as they wish, and that they can have multiple viewings over time as well.
- Ask them if they want you to stay with them or if they'd rather have their privacy. Let them know that you are available and how to reach you.

<u>Find creative ways to honor the bond</u> between multiple babies. Many parents are keenly aware of the bond between babies who spent time together in the womb. Whether all of their babies are deceased or some are living, parents may want affirmation of this bond by having the opportunity to hold all of their babies together in their arms. Photographs of this time with the babies together can be treasured keepsakes.

Let parents know that their baby is always available to them. A significant way to individualize care is by making the baby freely available to parents for as long as they and their circumstances require.

- Keeping the baby available allows parents more time to move through the normal shock that can hinder decision-making or blur their memory of seeing the baby right away or only once.
- When you make the baby available to parents, they can determine when and how to spend time with their baby.
- Parents can decide whether to keep their baby in the mother's room continuously, or they can have the baby brought to them periodically.
- No matter how many days have passed since the death occurred, it can still be important and appropriate for parents to want to view or spend time with their baby, even as the body changes.
- Lengthy availability is especially important for mothers who experience a traumatic or surgical delivery, or who are in intensive care or at a different hospital due to their baby's transport.
- It is important to have an institutional policy in place whereby a baby is accessible to the parents for as long as the mother is hospitalized and until the parents consent to transfer to a funeral home or final disposition.
- There should be a process in place whereby a nurse, chaplain, or social worker can retrieve and warm the baby when the parents request.
- Follow-up with families who leave the hospital soon after their baby dies is critical, as they may be overcome with shock and trauma, and need at least a day to process the reality of their baby's death.
- Funeral arrangements for the baby may be completed prior to the mother's discharge or it could take several days up to a week, depending on the family's circumstances. The bereavement care provider should provide follow-up to the family and work individually with families who want their baby to stay at the hospital after the mother is discharged and final disposition for the baby is pending. The bereavement care provider can be instrumental in helping families transition to working with their funeral director to arrange additional time with the baby.
- Some hospitals will have the morgue space, staff time, and other resources available that support
- your efforts to individualize care even further by making the baby available to parents even after the mother is discharged and final disposition arrangements made for the baby.

- Your effort to individualize care will occur in the context of many factors, including the gestational age and condition of the baby, state policies, institutional procedures and facilities, and the parent's cultural or religious practices. For more related information that can guide policy, please refer to other PLIDA Position Statements and PLIDA Practice Guidelines.
- Respect the process of letting go. Letting go of their baby is a process, and for many parents, an
 important piece of this process is coming to the realization that the body is empty of life. As one mother
 said, "She feels different now. This is not her anymore. It is just her body now." Individualize care in
 order to give each parent the time they need to come to terms with this reality. Some parents need
 more time, some need less. For some parents, this process of letting go can involve multiple
 interactions with their baby over several days. Continued access to their baby can help parents face
 the reality of their baby's death within the context of their bond with their baby.

Know that your empathic relationship with parents can aid their adjustment. Whether parents want to see their baby or not, your kindness and understanding are key to supporting parents as they do the emotional, spiritual, and cognitive work they need to do. Providing follow-up care to parents after discharge is a natural extension of this relationship. Follow-up allows you to check in as their shock wears off and they're confronting the reality of their baby's death, and you can make the appropriate referrals to local and online support groups, professional counseling, and other resources. While families may be overwhelmed immediately after the baby's death, it is important to provide written information and access to these various discharge-support options, as well as the contact information for a hospital representative who might be available post-discharge to help with community support referrals.

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