



Pregnancy Loss and Infant Death Alliance

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Position Statement

Bereaved Parents' Right to Self-Determination Regarding Their Baby



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Position

Bereaved Parents' Right to Self-Determination Regarding 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.

Executive Summary

When a baby dies during pregnancy, birth, or following delivery, healthcare providers have the unique opportunity to support parents in their desire to spend time with their baby. Many bereaved parents report treasuring the time they spent with their baby, and experts assert that memories and mementos created during this time can facilitate the grieving process. Because of the potential benefits, parents have the right to see their baby if they wish, regardless of condition or gestational age.

However, not all parents want to spend time with their baby after death, and there is no published, empirical data that justifies insisting that reluctant parents do so. Because parents vary on whether, when, and how they want to spend time with their baby, each parent should be able to determine for her- or himself how best to proceed.

Determining for themselves whether, when, and how to spend time with their baby affirms the parents' bond with their baby and acknowledges their ability to make decisions about what's best for their family. Being in charge of whether or when to spend time with their baby can also restore some sense of control over what happens to them even as they face the trauma of their baby's death. Healthcare providers must remain unbiased, neither urging parents to see their baby nor discouraging parents from doing so, and support parents in whatever they choose to do.

To support each parent's self-determination, the healthcare provider should be informative and reassuring, and make the baby freely available so that parents can set their own pace for making decisions and spending time with their baby.

Background and Significance

In the past few decades, increased awareness and sensitivity to the special needs of newly bereaved parents has changed hospital-based intervention— from *shielding* parents from the death of their baby to *supporting* parents through the experience. As a result, the modern standard of care is to offer grieving parents repeated and extended opportunities to have close contact with their baby.



Implications for Practice

Most bereaved parents report that close contact with their baby is an invaluable experience for which they feel grateful. Particularly when access to their baby is limited to pregnancy and then curtailed too soon by death, contact offers parents their only chance to "meet" this child. Contact of their choosing allows the parents to transform their bond from the unseen-but-loved baby in the womb to the visible and held child in their arms, and to establish the particular identity of this child in their family.

- Not all parents want contact with their baby after death, but when parents *do* want contact, they must be able to spend sufficient, quality time with their baby, on their own terms, or they may feel burdened with regret and thwarted in their desire to demonstrate their tender, loving care. This missed opportunity is yet another loss to endure.
- Parents can find it meaningful to demonstrate their love in physical ways, including touching, examining, holding, cuddling, and kissing their baby. Parents can also find comfort in rituals such as baptism or blessing, bathing and dressing the baby, and collecting keepsakes, such as locks of hair, foot and hand prints, and photographs. Ritual co-created in the moment can be especially meaningful to all who are bearing witness to the experiences of this family with their special baby. Bereavement photography should be relational and personal, with parents taking the lead on the types of photos they choose. Photos may be taken by family members themselves, professional perinatal bereavement photographers who provide a free service to parents, or by staff members trained in using a hospital camera. Spending time with their baby in ways that hold meaning for them and creating meaningful memories, including keepsakes, can help parents feel connected to their child, and loving contact with their baby can meet intense biological, psychological, and spiritual needs.
- Parents also report that these experiences can help them acquire positive memories and comforting mementos of their baby's life. These memories and mementos also serve to affirm their baby's existence and can help parents process and feel validated in their grief. These final experiences and moments with the baby might also be shared with family and friends, building a community around the baby's memory.
- Memories can be shared post-discharge with other grieving families with whom it might be beneficial for the family to interact. Rather than feeling alone, abnormal, or "crazy" for being so bereft, parents can feel acknowledged and comforted.
- Because parents vary on whether, when, and how they want to spend time with their baby, they must be supported in making their own decisions and doing what they believe is best. Healthcare providers have a responsibility to inform parents of the option to see their baby, to discuss the possibilities for how to spend that time and what other parents have found helpful, and to offer



reassurances for their concerns. The baby should remain freely available to the parents as most are initially in shock, and they require time and support to explore this opportunity. Even for parents who decline at first, knowing that their baby continues to be available allows for continued conversations about it and gives them the freedom to reconsider their options.

- If a baby's appearance has been affected by anomalies, early gestational age, or having been dead for longer than a few days, parents can still benefit from seeing their baby, particularly when the healthcare provider can openly and honestly describe the normal and beautiful parts of their baby's body, and then explain any anomalies or deterioration. Even when their baby is undeveloped, deteriorated, or has anomalies, parents tend to focus on the special beauty in their baby, looking through the eyes of love and seeing past what others may find difficult to view.
- When death occurs early in pregnancy through miscarriage, parent self-determination remains a focal point of care. It is important for clinicians to recognize that the meaning of early miscarriage varies; therefore, careful assessment is necessary to determine how this particular woman and her family have come to make sense of the experience. Most refer to the loss as a baby, but others do not. No matter the meaning, researchers have found that women need to be sure that death is confirmed, usually by ultrasonogram, before making treatment decisions.

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Contributors

Kathy Adzich, BA

Founder, Jakob's Room Project
www.trustingthejourney.com

Deborah L. Davis, PhD

Developmental Psychologist and Writer
Denver, Colorado

Todd Hochberg, BA

Bereavement Photographer
Touching Souls Photography
www.touchingsouls.org

Karen Kavanaugh, PhD, RN, FAAN

Elizabeth Schotanus Professor of Pediatric Nursing
Wayne State University

Kathie Kobler, MS, APN, PCNS-BC, CHPPN, FPCN

Pediatric Palliative & Supportive Care
Center for Fetal Care
Advocate Children's Hospital

Catherine A. Lammert, RN

Education Coordinator (retired)
Share Pregnancy and Infant Loss Support, Inc.

Irving Leon, PhD

Clinical Psychologist
Adjunct Associate Professor of Obstetrics and Gynecology
University of Michigan Health System

Rana Limbo, PhD, RN, CPLC, FAAN

Associate Director and Senior Faculty Consultant
Resolve Through Sharing®
Bereavement and Advance Care Planning Services
Gundersen Medical Foundation, Inc.

Darryl Owens, MDiv, BCC, CT

Women's Services Chaplain/Grief Counselor
Clinical Chaplain II, University of North Carolina Hospitals

Janet N. Press, CNS, MSN, CT, RN-C

Perinatal Obstetrical Coordinator
Central New York Region
Perinatal Bereavement Services Coordinator
Crouse Hospital