

## **Caring for Families Experiencing Stillbirth: A unified position statement on contact with the baby**

### **Preamble**

Stillbirth is recognized as one of the most traumatic experiences a parent can go through and may be associated with long-lasting psychosocial effects. Additionally, parents may have had limited or no previous experience with death. They are typically fearful and confused about what to expect and what options are available to them.

Seeing and holding a live baby after birth is a normal parental response. Seeing and holding a stillborn baby is also a normal response, and there is much evidence that doing so can be a valuable and cherished experience. Parents benefit from support and individualized guidance as they make their own decisions about how much time to spend with their baby, and as they determine when and how to use this time.

### **Position statement**

Prior to the 1970s, standard hospital practice in the aftermath of stillbirth was to discourage or disallow bereaved parents from seeing their deceased baby. However, in the late 1970s, providers of maternity care began to pay attention to bereaved parents' requests to see their expected baby, and a body of research emerged which resulted in a shift of practice standards.<sup>1-3</sup> For the next 30 years in most western countries, bereaved families were encouraged to see and hold their baby.

Since 2002, this practice has been questioned following publication of one study which concluded that for some parents, seeing their baby's body results in long-term negative psychological outcomes.<sup>4</sup> This small study has affected bereavement care in some countries, such that some providers of maternity care no longer encourage or guide bereaved parents to have contact with their stillborn baby. This reversal of practice standards is troubling because there is virtually no evidence that discouraging parents from seeing their baby is helpful to their long-term emotional health.

In fact the many studies and guidelines published both before and since 2002<sup>5-24</sup> demonstrate that parents can benefit from spending time with their baby, as they acquire affirming experiences and cherished memories. Conversely, when parents do not see and hold their baby, many express deep regret. Furthermore, in many cultures there are widely accepted customs and rituals involving holding and caring for the body of a deceased loved one of any age. These traditions assist the bereaved in recognizing the reality of the death, saying goodbye, and grieving the loss.<sup>25-30</sup>

Parents normally see and hold their baby after a live birth. It is therefore counterintuitive to suggest that parents would not benefit from nor wish to see their baby after stillbirth. Whether and how to spend time with their deceased baby is a very personal decision, and it is important to ensure that all parents are given enough support and information to enable them to make informed choices.

## Recommendations

As international leaders in the perinatal bereavement caregiving community, we make the following recommendations to policy-makers and practitioners who work with families experiencing stillbirth. These recommendations are based on: a) empirical studies, b) anecdotal wisdom, c) direct practice experiences of interdisciplinary clinicians, and d) the advocacy work of grassroots organizations led by bereaved parents.

1. Provide a standard of care that reflects the parents' natural desire to see and hold their baby after birth. This means not asking closed-ended questions such as, "Do you want to ...?" Parents will usually reply "no" to such questions but they don't mean "no" forever, just "no" for now.
2. **After bad news is broken:** Begin by aiming to foster a sensitive relationship with the parents. Gauge their needs by having open-ended conversations about their experience, their baby, and their care. Understand that parents will be shocked and will not be able to take in or say too much at this time. Keep information about their options simple and offer it in both written and verbal forms. During this time, if parents express reluctance to see or hold their baby, sensitively explore their fears and concerns, including the likely appearance of their baby. Assure them that you will be with them as they meet their baby.
3. **During labour and birth:** If parents have not raised any concerns about contact with their baby, then proceed just as naturally and respectfully as you would with any parents who wish to see and hold their expected newborn.
4. **Following the birth:** Provide gentle, individualized guidance when parents are meeting their baby. Most parents feel emotionally overwhelmed and this can affect their ability to make prudent decisions, consider the long-term consequences of their actions, or advocate for themselves. If necessary, normalize contact with their infant by sharing how other parents find that saying hello to their babies affirms the baby's importance and offers cherished memories. Modeling, such as cuddling and speaking softly to their baby, can be a powerful, affirming demonstration that may offer parents a path to spending time with their infant.
5. If parents decline to see or spend time with their baby, respect and fully support their wishes. Continue to engage in sensitive conversations with the parents about their baby and experience. Explain that they can change their minds at any time up to burial or cremation. Collecting mementos for these families may still be appropriate, with their consent. The family may choose to take the mementos with them, or the facility can keep them for possible collection at a later date.

When acting on these recommendations be mindful of the shock, trauma, and grief inherent in experiencing the death of a baby. Consider the parents' need to take their time with emotional processing, decision-making, and desired contact with their baby. Each parent's personal values, cultural traditions, and religious beliefs may also influence the amount of time spent with a deceased baby or occasionally preclude contact. Provide care in a manner that is intentional, unhurried, calm, respectful, and culturally sensitive.

Ideally these recommendations would be conducted by well-trained, experienced personnel, with mentoring in place for inexperienced personnel. We also recommend that those providing direct care participate in ongoing professional development and study resources offering ways to support families, build relationships, and discuss options in open-ended conversations. Finally, we recommend the establishment of well-planned, evidence-based bereavement care policies, protocols, and guidelines in all clinics and hospitals where stillbirth might occur, and administrative support for ongoing implementation.

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## References

1. Giles PF. Reactions of women to perinatal death. *Aust N Z J Obstet Gynaecol*. 1970;10(4):207-210.
2. Kennell JH, Slyter H, Klaus MH. The mourning response of parents to the death of a newborn infant. *N Engl J Med*. 1970;283(7):344-349.
3. Lewis E. Mourning by the family after a stillbirth or neonatal death. *Arch Dis Child*. 1979;54(4):303-306.
4. Hughes P, Turton P, Hopper E, Evans CD. Assessment of guidelines for good practice in psychosocial care of mothers after stillbirth: a cohort study. *Lancet*. 2002;360(9327):114-118.
5. Lovell A. Some questions of identity: late miscarriage, stillbirth and perinatal loss. *Soc Sci Med*. 1983;17(11):755-761.
6. Rådestad I, Steineck G, Nordin C, Sjögren B. Psychological complications after stillbirth--influence of memories and immediate management: population based study. *BMJ*. 1996;312(7045):1505-1508.
7. Trulsson O, Rådestad I. The silent child--mothers' experiences before, during, and after stillbirth. *Birth*. 2004;31(3):189-195.
8. Cacciatore J, Rådestad I, Frederik Frøen J. Effects of contact with stillborn babies on maternal anxiety and depression. *Birth*. 2008;35(4):313-320.
9. Barr P, Cacciatore J. Problematic emotions and maternal grief. *Omega (Westport)*. 2007;56(4):331-348.
10. Cacciatore J. Stillbirth: patient-centered psychosocial care. *Clin Obstet Gynecol*. 2010;53(3):691-699.
11. Cacciatore J. The unique experiences of women and their families after the death of a baby. *Soc Work Health Care*. 2010;49(2):134-148.
12. Wijngaards-de Meij L, Stroebe M, Stroebe W, et al. The impact of circumstances surrounding the death of a child on parents' grief. *Death Stud*. 2008;32(3):237-252.
13. Cacciatore J. The silent birth: a feminist perspective. *Soc Work*. 2009;54(1):91-95.
14. Rådestad I, Christoffersen L. Helping a woman meet her stillborn baby while it is soft and warm. *British Journal of Midwifery*. 2008;19(9):588-591.
15. Schott J, Henley A, Kohner N. *Pregnancy Loss and the Death of a Baby: Guidelines for Professionals*. 3rd ed. Sands UK / Bosun-Publications; 2007.
16. Flenady V, Wilson T. Support for mothers, fathers and families after perinatal death. *Cochrane Database Syst Rev*. 2008;(1):CD000452. doi:10.1002/14651858.CD000452.pub2.
17. Pregnancy Loss and Infant Death Alliance. Practice Guidelines: Offering the Baby to Bereaved Parents. 2008. <http://www.plida.org/pdf/PLIDA%20Guidelines%20Offering%20Baby.pdf>. Accessed May 4, 2011.
18. Primeau MR, Lamb JM. When a baby dies: rights of the baby and parents. *J Obstet Gynecol Neonatal Nurs*. 1995;24(3):206-208.
19. Rådestad I, Surkan PJ, Steineck G, Cnattingius S, Onelov E, Dickman PW. Long-term outcomes for mothers who have or have not held their stillborn baby. *Midwifery*. 2009;25(4):422-429.
20. Limbo R, Kobler K. The tie that binds: relationships in perinatal bereavement. *MCN Am J Matern Child Nurs*. 2010;35(6):316-321; quiz 321-323.
21. Gold KJ, Dalton VK, Schwenk TL. Hospital care for parents after perinatal death. *Obstet Gynecol*. 2007;109(5):1156-1166.

22. Brabin PJ. To see or not to see: that is the question. Challenging good-practice bereavement care after a baby is stillborn: the case in Australia. *Grief Matters: Australian Journal of Grief and Bereavement*. 2004;7(2):28-33.
23. Christoffersen L. Parents experience and the use of the Norwegian public health service previous to, during and after stillbirth: a pilot project. 2009 [link to English abstract <http://www.lub.no/id/22706C42B07BE677C1257689004ED9EB>, Paper in Norwegian] Accessed May 4 2011.
24. Davis DL. Reflections on the *Lancet* Stillbirth Study. *The Forum: Newsletter of the American Association of Death Education and Counseling*. 2004;30(2):4-5.
25. Beder J. Mourning the unfound: how we can help. *Fam Soc*. 2002;83(4):400-404.
26. Boss P. *Ambiguous loss: learning to live with unresolved grief*. Cambridge, Massachusetts: Harvard University Press; 1999.
27. Worden JW. *Grief counseling and grief therapy: a handbook for the mental health practitioner*. New York: Springer Pub; 2008.
28. Cooke MW, Cooke HM, Glucksman EE. Management of sudden bereavement in the accident and emergency department. *BMJ*. 1992;304(6836):1207-1209.
29. Chapple A, Ziebland S. Viewing the body after bereavement due to a traumatic death: qualitative study in the UK. *BMJ*. 2010;340:c2032.
30. Paul R. Viewing the body and grief complications: the role of visual confirmation in grief reconciliation. In: Cox GR, Bendiksen R, Stevenson RG, eds. *Complicated grieving and bereavement: understanding and treating people experiencing loss*. Amityville, New York: Baywood; 2002.

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