



Helping After Neonatal Death
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HAND's Mission

To help parents, their families, and their healthcare providers cope with the loss of a baby before, during, or after birth

HAND's Services

Peer support groups
Telephone support
Hospital visitation
Quarterly newsletter
Lending library
Web site
Community education
Publications
Service of Remembrance

HAND is a California
Nonprofit 501(c)(3)
corporation

Guide for Professionals

The death of an infant is one of the most tragic events that can strike a family. Usually the death is unexpected and the parents are unprepared for the experience. Many times it will be their first encounter with death, especially one so close to their hearts.

As a caregiver, you are in a unique position to provide a level of care and sensitivity that can greatly affect the course of a family's grieving process. The following information has been assembled to assist you in meeting the needs of families who have experienced the death of an infant.

At the time of the loss...

- Recognize that their infant is unique and irreplaceable. Don't rationalize the loss with comments such as "You can have other babies" or "You have other children at home." Do say "I'm sorry", "This must be so hard" or "How can I help?"
- No matter the age of the baby, it is important to realize that parental bonding begins long before birth and that a newborn is already very much a part of his/her family.
- Reassure the parents that their expression of grief and the intense feelings associated with it are normal. Grief is not proportional to the size of the person who dies.
- Be real; share feelings of distress and sadness with the parents. These are not unprofessional behaviors. Parents greatly appreciate caring physicians, nurses or other health care workers who express their feelings.
- For babies that die at or shortly after birth, develop a system to flag the mother's room so that everyone on staff can be aware of what has happened. (Perhaps a special sticker or magnet can be placed on the outside of the hospital room door.)

Let parents know they may take their time

- There will be many decisions to make, but nothing needs to be decided immediately. There is no rehearsal when a baby dies. The moment passes and is gone forever. Families need to be comfortable with the decisions they make.



Encourage the parents to see their baby

- There are often fears about death and the baby's appearance. You can help set aside these fears by describing gently and honestly how their baby looks.
- Suggest that they hold and touch their infant and have some private time alone to say good-bye in an unhurried fashion. Parents who have taken the time to say good-bye in person seem to have an easier and more manageable grief. Holding their baby may prevent a lot of future regrets. Parents who have declined this offer have expressed deep and long lasting guilt and remorse. If they don't want to hold their baby immediately, give them some time and make the offer again (even if this means having a staff member make a trip to the morgue).
- Wrap the baby in a clean, warm baby blanket. It will show that you cared enough to handle their child tenderly and with respect.
- If the baby died at or shortly after birth, encourage the parents to name their baby and use the name when referring to the child. A name provides an identity, a means of talking about his little person and can help facilitate the grieving process. If the family chooses not to name their baby, be careful to always refer to the child by the appropriate sex.
- Emergency Room Personnel — Please be aware of any local county coroner protocols concerning deaths that require investigation.

Take Pictures

- Most hospitals try to routinely photograph infants who die. Even if the family chooses not to see their baby, these pictures should be kept in their file should they change their minds.
- Suggestions:
 - Take more than one picture
 - If possible use a camera using negatives (the pictures will maintain their integrity and it will be easier to obtain quality copies)
 - Take some with the baby wrapped in blanket, some with the baby unwrapped (if possible), some with the parents holding the baby
 - Be sensitive to lighting and think about how the baby can look its best. For most parents, these pictures will be a cherished, permanent and tangible memory of their child.

Mementos

- If these items are not offered to the family, let them know that they may ask for them:
 - Pictures
 - The blanket that wrapped their baby
 - A lock of hair
 - Certificates: birth, death, baptismal
 - Handprints/footprints
 - Hospital name band and name card



Information

- The parents will probably have a lot of questions. Be approachable and accessible to them – both in the hospital and afterwards. Grieving parents may need to ask the same questions over and over again before they are able to fully understand what has happened.
- Please be patient and realize that most of the parent's energy is directed toward coping and they may be functioning at a minimal level.
- Some parents may not know what to ask, or what information may be helpful to them in the days and weeks ahead. Your experience and expertise will be invaluable. Consider sharing some of the choices other parents have made. Most importantly, assure the family that you will be available to answer any questions that may come up at a later date.

Teach parents about the grief process

- Give the parents anticipatory guidance regarding what they might experience during the period of acute grief — somatic complaints, feelings of unreality, loneliness, depression, guilt, anger, irritability, loss of routine patterns, preoccupation with the child that died, insomnia, and difficulty with friends and family.
- Warn parents about sudden and dramatic emotional shifts.
- Tell them there may be differences in the style and length of grieving between the mother and the father.
- Parents don't forget, but as time passes the pain lessens. Warn them that even when life seems to be back to normal, there may still be some unexpected and painful reminders such as anniversary dates and some holidays. It's not unusual for parents to continue to experience occasional moments or days of sadness throughout their lives.

Referrals

- Offer the parents telephone numbers of mortuaries close to their home. Encourage both parents to be involved in this decision making process. This will be the last thing, as parents, they will ever be able to do for their child.
- Provide the names and numbers of support groups for parents who have experienced the death of a child. It may be very difficult for parents to reach out for support at this time. Offer to make that first call.



For the patient being seen in a physician's office

- Realize that returning to an obstetrician's or pediatrician's office can and will be very difficult.
- If possible, schedule the appointment at the time when the patient won't have to sit in a waiting room with pregnant women or families with new babies.
- Set up a system to flag charts so that on return visits everyone is aware of the situation.
- Offer referrals to appropriate support groups - offer to make the first call.

Follow-up of these patients is essential and should be done at these times:

- At the time of death
- Two or three days after discharge
- Two to four months after the death (This is critical because the hardest times are usually not when the death occurs but often months later. Support has dropped off, the shock has worn off, and the reality of the child's death has set in).
- On the one year anniversary of the child's death.

A special note to medical and office personnel:

- Parents always appreciate hearing from people who cared for and remember their child. Please try to call the parents sometime during the first several months to see how they are or to simply say, "I was thinking about your son/daughter today and I wanted to give you a call." This conveys to the family that their child was more than just another patient to you and is remembered. This can be especially true for families whose baby died at, or shortly after delivery, because the hospital staff may be the only people, other than the parents, who spent any time with their child while he/she was alive.
- If a phone call is not possible, consider sending them a card or a letter of condolence that expresses the same kind of message.

Special Cultural Considerations

- It is important for all parents to know that their child received the best of care and that everything that could have been done for the child, was. This is especially true for families concerned about cultural and/or socioeconomic issues.
- Be sensitive to language barriers. Many parents have left the hospital not fully understanding the cause and/or contributing factors to their child's death. Try to share any information you can in a manner that will be easy for them to understand. If parents are monolingual in another language, or if English is their second language, every effort should be made to find translator fluent in both languages, with the appropriate medical background. In crisis situations, family members should not be asked to translate for each other.
- Be sensitive to cultural differences. Not all cultures express grief or respond to death in the same manner.



Care for the Caregiver

- Bereaved parents have the expectation that professionals are aware of and understand the parental grief process. In reality, most of us have had very little training regarding bereavement and the very special nature of infant loss
- Caregivers do grieve for the death of their patients and often experience shock, isolation, guilt and anxiety. (Some of the same symptoms we warn newly bereaved parents about)

To maximize your coping skills consider the following suggestions:¹

- Accept your own feelings. No one is expected to handle every situation that is thrown his or her way every day
- Ask for help from co-workers. Consider working in teams (e.g. one person does the paperwork and the other interacts with the family)
- Schedule staff meetings to review the case and allow staff to share their feelings
- Consider attending the funeral and/or sending a card or letter to the family. This will provide you with some closure and will be appreciated by the family
- Attend a bereavement support group. These groups are a tremendous resource for caregivers as well as parents
- Share your feelings with co-workers or others who understand confidentiality and the grief process
- Remind yourself that you did the best you could with the information you had at the time
- Seek professional help if you get stuck at any stage in the grief process or you feel unable to carry out the duties of your job over time

¹ From *When the Bough Breaks - Working With Families Who Have Experienced The Death of an Infant (A Guide For Healthcare and Other Professionals)* by Heidi B. Olson. Used with permission.