

GUIDELINES FOR FUNERAL DIRECTORS

PROVIDING CARE TO THE FAMILY
EXPERIENCING
PERINATAL LOSS, NEONATAL DEATH,
SIDS OR OTHER INFANT DEATH



The Bereavement Support Work Team of the National SIDS & Infant Death Program Support Center (NSIDPSC) created these guidelines. Also available, are standards for other types of professionals and a list of recommended materials on pregnancy loss and infant death. To obtain a copy of this document or other materials, please visit our web site at www.sids-id-psc.org or contact us at 1-800-638-SIDS (7437). The NSIDPSC is a cooperative project of the SIDS Alliance, Inc. and the Health Resources and Services Administration's (HRSA) Maternal and Child Health Bureau Sudden Infant Death Syndrome/ Infant Death Program.

BACKGROUND

The terms *perinatal death (including miscarriage and stillbirth)*, *neonatal death*, *Sudden Infant Death Syndrome (SIDS)*, and *infant deaths (ID)* encompass many types of pregnancy and early childhood losses. Following guidelines that outline standards of care is critically important to providing continuity of sensitive care to families experiencing these losses. Of the almost 4 million births in 1999, the National Center for Health Statistics reported 18,700 neonatal deaths, and 9,164 post neonatal deaths. Perinatal loss may occur in as many as 30% of pregnancies. When the loss of a child due to perinatal loss, SIDS or ID occurs, all normal components of grief – emotional disequilibria, physiological trauma, spiritual and mental disharmony – are heightened for parents, propelling them into one of life's major tragedies, the death of a child. Funeral directors and other mortuary professionals need guidelines to provide competent and sensitive care throughout the families' experience.

METHODOLOGY

The burial of infants and children is often a small segment of the average funeral directors experience. Therefore, the special needs of those families may not be given enough emphasis in mortuary schools. This document seeks to detail perinatal, SIDS, and other infant deaths with the goal of examining their special needs and making recommendations for necessary services. Please take special consideration of the possibility that young families dealing with the loss of a child may have limited experience with death or may have never made funeral arrangements.

Funeral directors have an important opportunity to influence the direction of recovery for parents and other family members by making the process special for those involved. With our mobile society, you may deal with a family who, at least initially, may have no support from their nuclear family, and may come to you even more lost, apprehensive and traumatized. You, the funeral director, must be alert and sensitive to the situation so you can assist the family in the most appropriate and beneficial manner.

GUIDELINES

1. The funeral director caring for the parents/family who have experienced a pregnancy loss or infant death can assist by doing the following:
 - Initially, find out all circumstances surrounding the infant's death. Information should be gathered such as cause of death, length of pregnancy, size of baby, history of previous miscarriages or early infant deaths and how long the child lived (if applicable). Other information to obtain is whether the family had time to spend with the infant at the hospital, was there some type of service, and was this death sudden or unexpected.
 - If the child has been named, use it when discussing the child.
 - Offer to contact the parents' religious leader, grief counselors or other bereavement specialists for emotional support while making funeral arrangements.

- The family may give you some insights on their wishes for the arrangements, but be prepared with a wealth of information that will meet the special needs of the family. Parents may make requests that you have never done before. Be supportive and open-minded as you try to meet their needs.
- Do not present adult funeral arrangements to parents/families suffering from the loss of an infant. Purchase or prepare special books, pictures and materials to show the family infant caskets, service choices, prayer cards, programs, register cards, clothing, floral arrangements and guidance with the cemetery. Be open to special arrangements such as placing the baby in a bassinet for the viewing and funeral, or decorating the casket with stuffed animals, flowers, or baby blankets.
- Support the family by anticipating questions they may have. Educate yourself on the causes of perinatal death, SIDS and other infant deaths.
- Keep in mind the siblings and grandparents as final arrangements are made. In accordance with the parent's wishes, include these family members in the process and the service if they are available.
- Ask the parents if they had the opportunity to see their child prior to coming to the funeral home. If not, prepare the parents by explaining what to expect before they see their child. Arrange clothing to cover any disfigurements.
- Offer the parents the opportunity to lay out their child's body for the viewing and funeral. They may wish to comb their child's hair a special way, choose their child's burial outfit, and dress their baby.
- Offer the parents a private viewing for family and friends.
- Offer to take a picture of the child once he/she is dressed and cosmetized. Also offer to take pictures of the child being held by family members.
- Ask if they would like to keep a lock of the child's hair, and if they have a special blanket in which to cover the child, and mementos from family members.
- Encourage the family to make the service as personal as possible. Suggest a memory table containing the child's favorite things, or items that pay special tribute to the child.
- Suggest special touches that will make the event memorable for siblings and grandparents also, such as placing pictures, favorite toys, gifts, poems and other keepsakes in the casket. Siblings may wish to help choose the burial outfit, or recite a poem at the funeral.
- Offer to perform a prayer service in the funeral home, hospital, chapel or church; or a graveside service, burial, or cremation if religious leader is not performing one.
- Ask if the family would like to be present for the closing of the casket and lowering of the vault, or whether they want to help cover the grave. Please check with the cemetery as to whether this coincides with their policies and procedures.

- While encountering families in various stages of grief, please remember that all families grieve differently.

2. General principles and approaches in caring for families from diverse cultures:

- The family as defined by each culture is the primary system of support and preferred point of intervention.³
- Families from diverse cultures have a unique set of stresses to which the system must be equipped to respond.³
- Individuals and families from diverse cultural groups make different choices that must be considered if services are to be helpful.³
- The dynamics of cross-cultural interactions must be acknowledged, adjusted to and accepted.³
- Recognize that important moments in the cycle of life are typically imbued with great meaning within cultures. Customs, beliefs, religious laws, and ceremonies are deeply connected with events such as birth and death. When the two come very close together in a life, the importance of culture in serving and supporting the family, friends, and community who have suffered the loss becomes especially critical.⁴
- Actions that might prove extremely comforting to some families may be prohibited and unsettling to others.⁴
- Approaching families with suggestions or actions that are not acceptable within their culture can actually intensify the grief and create a breach between caregivers and families.⁴
- Recognize that for some families who are new immigrants to this country, medical or other professional personnel are seen as authority figures. They also may not want to appear “un-American” and may be reluctant to share beliefs, practices, and customs from their own culture. It may help to have a “cultural broker” from their own culture who can assure them that their choices will be honored. If this is not possible, it is important for the professional to make clear that suggestions are just that and the family has choices that will be honored.⁴
- Recognize that there may be as much variation among individuals within a cultural, ethnic or racial group as there is between groups. Thus, use the information you gain to guide your questions and offers of service to families, but be sure to ask what the individual family prefers. There is no one-way to approach all families from a given cultural, ethnic, or racial group.⁴
- Familiarize yourself and any other staff with diverse cultural, ethnic, racial, religious, and linguistic groups served in your area. Connect with “cultural brokers” or leaders from those groups who are willing to share the customs, practices, and beliefs associated with an infant death within their culture. Also learn about traditional family structure and decision-making patterns. In some families it may be appropriate to ask the mother to

make major decisions. In others, the father must be approached as the decision-maker, or a spiritual or other leader in the community must be brought into the decision-making process.⁴

- Identify potential interpreters who can help you work with families who want such services and train them to ensure that they understand the terms you are using and thus correctly convey information to families.⁴

REFERENCES

1. Guideline 1 was adapted from: *Sudden Infant Death Syndrome: The Role of the Funeral Practitioner*, National Funeral Directors Association Inc.; *Helping Bereaved Parents: How Funeral Directors Serve When a Child Dies*, Funeral Monitor, 1995; *Child Death and the Role of the Funeral Director*, J. Norm Patterson, The Director, 1985; *Grief After SIDS*, National Funeral Directors Association, Inc.; and *Funeral Directors and Newborn Deaths*, Sherry Hutchins, Texas Director, 1990.
2. Cross, T., Bazon, B., Dennis, K. and Isaacs, M. (1989). *Towards a Culturally Competent System of Care: Volume I*. Washington, D.C. Georgetown University Child Development Center, CASSP Technical Assistance Center.
3. Developed by Suzanne Bronheim. National Center for Cultural Competence, Georgetown University Child Development Center. Washington, D.C.

ADDITIONAL RESOURCES

A Loving Goodbye Series:

Choosing a Cemetery

Choosing a Funeral Home

Planning the Service

Oklahoma SIDS Alliance

Scott Prough

P.O. Box 12282

Oklahoma City, OK 73157-2282

(800) 248-SIDS

A Loving Goodbye: A Guide to Arranging a Funeral for Your Baby. [Available in Spanish]

D. B. Sanders

California SIDS Program

5330 Primrose Drive, Suite 231

Fair Oaks, CA 95628-3542

(800) 369-7437 toll-free in CA only

(916) 536-0146, (916) 536-0167 fax

Bittersweet: Hello, Goodbye. =

Jean Marie Lamb

SHARE/

Pregnancy and Infant Loss Support

St. Joseph's Health Center

300 First Capitol Drive

St. Charles, MO 63301-2893

(800) 821-6819 or (314) 947-6164

(314) 947-7486 fax

Building Blocks Series: Helping Children Through the Funeral Process.

Charles A. Corr, Ph.D.

SIDS Resources Inc.

143 Grand Ave, St. Louis, MO 63122 (314)

822-2323, (314) 822-2098 fax

Comfort Us Lord, Our Baby Died.

[Available in Spanish]. =

Norman Hagley

Centering Corporation

7230 Maple Street

Omaha, NE 68134-5064

(402) 553-1200 (402) 553-0507 fax

www.centering.org

Cremation.

Paul Irion, Fortress Press. (Out of Print – check public libraries)

Have You Considered . . . ? Planning Your Child's Service (Revised Edition)

SIDS Foundation of Washington

4649 Sunnyside Avenue North, Rm. 348

Seattle, WA 98103, (206) 548-9290

(206) 548-9445 fax

Helping Children with Funerals.

Alan Wolfelt, Ph.D.

Batesville Management Services

One Batesville Boulevard

Batesville, IN 47006

(800) 622-8373, (812) 934-7788

(888) 876-7368 fax

Making Loving Memories.

Mary Lou Eddy and Linda Raydo Centering Corporation

7230 Maple Street

Omaha, NE 68134-5064

(402) 553-1200, (402) 553-0507 fax

www.centering.org

Planning a Precious Goodbye...After Miscarriage, Stillbirth, or Infant Death.

S. Ilse, S. Erling Martinez, M. J. Flynn

Wintergreen Press, 3630 Eileen Street

Maple Plain, MN 55359

(952) 476-1303 phone and fax

Thank You for Coming to Say Goodbye.

Janice Roberts, Centering Corporation,

1531 North Saddle Creek Road

Omaha, 68104-5064, (402) 553-1200 (402)

553-0507 fax

When A Baby Has Died.

National Funeral Directors Association,

13625 Bishop's Drive

Brookfield, WI 53005

(800) 228-6332, (414) 789-1880

(414) 789-6977 fax

= Christian focused literature

ACKNOWLEDGEMENTS

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