

GUIDELINES FOR MEDICAL PROFESSIONALS

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 (MCHB) 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 four 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. These guidelines were developed to help healthcare professionals provide competent and sensitive care throughout the families' experience.

METHODOLOGY

Parents and families are especially vulnerable at the time of loss because of the physiological changes and the psychological trauma sustained. Both parents experience unfamiliar feelings and may be unaware of their own needs at the time of the loss. They often require assistance in making decisions. Hospital policies regarding the death of a child during pregnancy or infancy should provide support and sensitive guidance for parents throughout the decision-making process, allowing for individual expression of grief.

Personnel in all units/clinics who may interact with the parents and their families who experience a loss should have a policy for providing care when the death occurs. Areas requiring such a policy include settings where infant losses are managed, especially the Labor and Delivery, Neonatal Intensive Care Unit, Nursery, Antepartum Care, doctor's offices, clinics and emergency departments. Policies are used in the orientation of new personnel, provided to members of the multidisciplinary team, and are available for use as reference material. These policies underscore the rights of parents and their families to make decisions regarding their care and the care of their babies who have died.

Healthcare providers who care for women and families who experience a loss need to be educated on how to provide sensitive and thoughtful grief support. They should assume a leadership role in educating other health care professionals who care for these families as well as ancillary personnel who come in contact with the families. Optimally, the healthcare team needs to lead an interdisciplinary approach to providing care throughout the woman's hospital stay because continuity in care facilitates grief work. The parents' individual responses and needs are the basis for their plan of care, and mechanisms must be in place to ensure continuity of care after discharge.

GUIDELINES

1. In hospital staff (e.g. labor & delivery, neonatal intensive care unit, nursery, emergency departments) can assist parents/family who have experienced a pregnancy loss or infant death by doing the following:¹

- Develop and utilize a tool (See Appendices for sample tools) to assist all healthcare professionals to incorporate the standards of care in keeping with the policies of the health facility.
- Assume a professional posture that will let the parents know that the healthcare providers are available and willing to approach the topic of death with them.
- Convey the cause of death in a clear, non-technical manner. If the cause is not known, parents should receive information about whether or how the cause might be determined at a later date (i.e. through post-mortem tests, etc.). The healthcare professional should not speculate or offer opinions regarding the cause of death, but convey only the known medical facts.
- Provide counseling to the parents by an experienced staff professional about autopsy and/or the need for any further testing in a manner that is sensitive to the family's cultural and religious beliefs.
- Offer parents the opportunity to see their baby. If there is disfigurement, the infant should be presented to the parents clothed or wrapped in such a way as to optimize his best physical characteristics. Later the infant is unclothed and any defects are explained. Healthcare professionals should be aware that, in keeping with certain religious or cultural beliefs – or simply as a matter of preference – the parents might decline to see their baby. Healthcare professionals should “take their cues” from the parents and respect their wishes in this matter, but only after giving information about the long term pros and cons of spending time with their baby.
- Offer parents the chance to perform tasks such as bathing and dressing the baby to increase their otherwise limited opportunities to enact these parenting roles.
- Provide parents with any personal items that have been in direct contact with the infant. If the parents do not want these items initially, they should be recorded and stored, and parents should be informed as to how they may obtain them at a later date.
- Take pictures for the record and the future, unless a religious or cultural belief prohibits picture taking. Healthcare professionals should be aware that, in keeping with certain religious or cultural beliefs the parents might not allow their baby to be photographed. Again, healthcare professionals should “take their cues” from the parents and respect their wishes. If possible the baby should be photographed in such a manner as to emphasize his positive physical characteristics. Parents may decide to accept pictures later.
- Give parents oral and written information regarding burial and cremation, and allow them sufficient time to make decisions. When an early pregnancy loss –such as an ectopic pregnancy, miscarriage, blighted ovum, etc – occurs, parents should be given the opportunity to make their own arrangements for the remains.
- If parents experiencing an early pregnancy loss decline to make their own arrangements, the hospital should inform the parents orally and in writing of the facilities' disposal protocol.
- Allow parents the opportunity to change their minds within a given time frame about decisions they have made, including decisions about whether to see or photograph the infant, possession of his personal effects, and the manner of final internment. Inform parents about the grieving process and how the individual responses of mother, father,

and other family members may differ. Parents with other children should be given guidance on informing, involving, and dealing with the grief reactions of siblings.

- If acceptable to the parents, incorporate family and friends into the plan of care and assist them in supporting the mother/father/immediate family by waiving hospital visitation rules, educating friends and family about the range of emotions and responses of bereaved parents, and offering concrete suggestions on how they can support the parents. Include grief support that is respectful of cultural and religious beliefs, as well as individual requests.
 - Ensure that the hospital has a mechanism for follow-up with the family, including assessment of each member's coping style, adaptation and support system, and follow up with information on the cause of the loss, including diagnostic evaluations (e.g., genetics testing, autopsy results) and advice relevant to subsequent pregnancy.
 - Arrange for post-discharge follow-up for the family. Follow-up should include telephone calls, referral to support groups, home visits, written materials, a follow-up survey, and referral for counseling.
2. Parents are likely to have a stronger bond with clinic staff than with the staff of the Emergency Room or the Labor & Delivery Ward who cared for them in the hospital. They may have increased expectations and hopes of you and your staff. This can be an opportunity to aid them, help them find resources, and be supportive of them in their crisis. The follow-up office/clinic visit is one of the most difficult things the parent(s) will face since their baby has died. Clinic staff can help parents who have experienced a pregnancy loss or infant death by:²
- When the loss occurs elsewhere, be sure you have a system in place through which the doctors and the hospital can alert you.
 - When the patient comes back for a follow-up visit, the staff needs to know that there has been a loss. Use a sticker of some sort to code the chart so that all personnel who skim it will be alerted that a loss has occurred.
 - Be careful of the words you use while in the room or out in the hall (the walls are thin, the parents can hear you) abortion (even spontaneous) is an emotionally charged word. Even though the correct medical term for the event is spontaneous abortion it may be preferable to use the term miscarriage instead, in order to avoid possible confusion and pain.
 - Offer to let the mother sit in an exam room in case waiting in the lobby with other expectant parents and new babies is too painful for her.
 - Encourage the father to come for the follow-up visit. He needs to review what has happened, discuss his concerns and questions, and hear about any preliminary results of the test.
 - When greeting the mother/father let them know that you understand they have had a loss. "I'm sorry to hear about..." is a good start. It's helpful if you tell them some of your feelings, such as being upset, disappointed, or shocked. This will show your humanity and genuine concern. Your sensitivity, openness, honesty, and compassion are important at this time.

- Say the baby's name out loud. If you are unsure of the name, ask if they named the baby, even if it was miscarried. Many people now name their miscarried babies. Maybe they already had a name or nickname. Ask if they have pictures or mementos of their baby. You may be one of the few people who ever dare to take this much interest.
- Ask the mother if she wishes to tell what happened, about her labor, etc. Ask the father for his view of what happened. For the parent(s) it's often nice to know that someone is interested and will listen. You must recognize their parenthood and validate the experience by asking questions as if the baby had lived. Most people will want to retell their labor story, especially those who have had a baby die, since so few will ever ask. Be prepared for tears and silence at difficult moments.
- Ask what kind of support they are getting and how the children and relatives are handling this.

3. 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 the *Standards And Guidelines For Professional Nursing Practice In The Care Of The Woman And Newborn: Guidelines For Providing Care To The Family Experiencing Perinatal Loss And Fetal Death* (5th edition) developed by the Association of Women’s Health, Obstetric and Neonatal Nurses (AWHONN) and the *Guidelines for Perinatal Care* (4th edition, 1997) developed by the American Academy of Pediatrics (AAP) and the American College of Obstetricians and Gynecologists (ACOG).
2. Guideline 2 was developed by Sherokee Ilse. Wintergreen Press.
3. 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.
4. Developed by Suzanne Bronheim. National Center for Cultural Competence, Georgetown University Child Development Center. Washington, D.C.
5. Appendices were developed by Sherokee Ilse. Wintergreen Press.

ADDITIONAL RESOURCES

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APPENDIX I: SAMPLE PATIENT PERMISSION/AUTHORIZATION FORM FOR MISCARRIAGE⁵

I (we) represent that I am (we are) the parent(s) of the miscarried fetus/baby and are entitled to make decisions about testing, and disposition of the remains.

I (we) authorize the following:

	Yes	No
External testing only, or	_____	_____
External and Internal testing, or	_____	_____
No testing on the remains	_____	_____

Choose one of the following:

____ I (We) will control disposition and take care of our own arrangements

_____ Name of funeral home (if required), or

____ Hospital may handle the disposition

- Disposition is handled in the following manner: _____
- I (We) do____ do not ____want to know how the hospital handles/disposes of the remains (unless the law requires that the hospital gives details to the families).

Signed: _____ Witness: _____ Date: _____

Signed: _____ Witness: _____ Date: _____

Signed: _____ Witness: _____ Date: _____

Hospital use: _____ Patient took remains Date: _____

_____ Funeral home has been called

Remains picked up on _____ (date)

This form is a sample form to be adapted for your hospital use. **Please have an attorney review your final form before implementation.** Please give patients a copy of the form before they leave, whether they take the remains of their baby or not.

**APPENDIX II: SAMPLE MISCARRIAGE, STILLBIRTH AND INFANT DEATH
NURSING CARE PLAN**⁵

Mother's Name: _____ Baby's Name: _____
Father's Name: _____ Doctor: _____
Sibling's Name/Age: _____ Primary Nurse: _____
Religious Preference: _____ History of Previous Loss: _____

Present Loss

Miscarriage _____ Date & Time of Delivery _____
Stillborn _____ Sex _____ Weight _____ Length _____
Neonatal Death _____ Lived (for how long) _____
Weeks Gestation _____

At Admission

(√ to indicate completion)

Diagnosis made _____ by ultrasound _____ by _____
(Date) (Doctor)

- Offered to call support persons (other family members, friends, clergy)

- Contacted patient's minister _____ declined at this time ____ Family will contact _____
- Hospital Pastoral care notified by nursing staff _____
(date / time)
 - 1) Pastoral care will visit _____
 - 2) Pastoral care talked with patient/patient will call back when ready for visit _____
- Social Services notified by nursing staff _____
(date / time)
 - 1) Social Services will visit _____
 - 2) Social Services contacted patient/patient will call back if services needed _____
- Flagged room _____ Chart _____ Patient room on 2N _____
- Genetic studies ordered _____ Pathologist notified _____
Pathologist request placenta _____ fetus _____ or both _____ to lab
- Explain recommended surgical procedure (if any) _____
- Consent form signed? _____
- Have parents signed disposition papers? _____

APPENDIX II: SAMPLE MISCARRIAGE, STILLBIRTH AND INFANT DEATH
NURSING CARE PLAN (continued)

At Delivery/Death

(√ to indicate completion)

- Parental consent to photograph baby? (Y/N)
- Saw baby: Mother _____ Father _____ Other _____
- Touched/Held baby: Mother _____ Father _____ Other _____
- Offered private time with baby _____
- Picture taken _____ offered _____ given _____ on file _____
- Footprints made _____ offered _____ given _____ on file _____
- ID Bands/Name card made _____ offered _____ given _____ on file _____
- Lock of hair cut _____ offered _____ given _____ on file _____
- Baby blanket offered _____ given _____
- Pastoral Care offered _____ patient's own _____ Hospital Chaplain notified _____
- Baptism/Blessing offered _____ declined _____ performed by _____
- Pediatrician notified _____ N/A _____
- Social Services visit 1 _____ visit 2 _____ (if needed)
- Room assignment discussed with patient _____
- Birth/Death Certificate discussed _____ completed _____
- Souvenir birth certificate offered _____ given _____ on file _____
- Autopsy discussed _____ permit signed _____ refused _____
- Options for disposition of body explained _____ family arranged _____ burial _____
cremation _____
- Mortuary contacted _____ Name and by whom _____
- Date/Time of Service _____ In Hospital _____
- Body to Pathology _____ morgue _____ Taken by _____ received by _____
- Discussed medical/hormonal changes likely to occur in mother. _____ (ex: breast engorgement, mood swings, and post partum depression)

**APPENDIX II: SAMPLE MISCARRIAGE, STILLBIRTH AND INFANT DEATH
NURSING CARE PLAN (continued)**

At Discharge

- Information materials given (Materials may be given at most appropriate time)
Parents Letter_____ *Silent Birth*_____ Reading List_____ Laser
Print_____ *Empty Arms*_____ *A Father's Story*_____ Funeral Home
List_____ What Friends and Family Can Do_____ Grieving
Grandparents_____ Sibling_____ Support Group Information_____ *Planning a
Precious Goodbye*_____ Other_____
- If baby is going to a funeral home, be sure release of body is signed_____.

Follow Up Plan Instituted

- Made referral to public health center or home care facility_____.
- Sent card/letter in one month: sent by_____ date_____.
Six months: sent by_____ date_____.
One year: sent by_____ date_____.
- Sent evaluation of hospital services and care_____.
- If parents refused pictures/mementos, sent reminder that items are being kept and are available to be picked up_____.
- Call to check in on family: who_____ when_____.

Additional Discharge Recommendations:

- Remind patient to eat well and increase fluid intake. Grieving at best is difficult; physical pain and discomfort will cause added stress.
- Encourage patient to talk about her/his feelings. This is an important event in their lives and it will not go away just because they ignore it or try to forget it.
- Encourage mother to spend some time alone with her partner. Healing will begin when the two of them are communicating their feelings with each other.
- Encourage mother/couple to be specific about their needs when others ask what they can do to help. Tell them if you need errands run, help with preparing food or any other tasks that will help you in the first few days at home. Remember they really do want to help.

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