Parents' Needs and Rights When a Baby Dies

BY SR. JANE MARIE LAMB, OSF

Perinatal death—including miscarriage, ectopic pregnancy, stillbirth, or newborn death—can have a devastating impact on the parents, who often become confused and bewildered in this time of emotional crisis. The average parents are unaware of their needs and options at this time of loss. It is imperative, therefore, that hospitals draw up guidelines so they can fulfill their responsibility to these families and provide them with the support and resources they need.

Team effort and administrative support are essential to ensure supportive care. During hospitalization nearly every department provides some aspect of care for these parents and their families. This widespread involvement calls for hospital-wide educational programs that inform and sensitize staff in how to respond to these families. In addition, written information on the parents' options and rights can empower them to express their needs and make decisions despite their confusion, vulnerability, and emotional paralysis.

Establishing Guidelines

The grief experience is universal, yet each person has his or her own personality, history, and coping style. Hospital guidelines regarding perinatal deaths must be based on respect for privacy and individual needs and responses.

The **Box** on p. 53 offers some sample "rights" for parents and babies that hospitals can use as a handout to parents and a springboard to draw up their own guidelines. The need for this document came to light when parents and care givers, finding that hospitals were insensitive and unyielding to what seemed like reasonable requests, contacted the National SHARE Office for supportive materials. SHARE, a member of the SSM Health Care System, is a pregnancy and infant loss support center based at St. Joseph Health Center, St. Charles, MO, with more than 200 chapters internationally. It serves as a resource for bereaved parents, group leaders, and care givers. In response to this need, SHARE has revised and expanded the rights for national distribution, based on a document first developed by the Perinatal Bereavement Team at Women's College in Toronto.

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The term "rights" is not used as a mandate for the bereaved, nor as a militant statement of demands. It is an affirmation for parents who wish to be involved with their baby, to make decisions based on informed consent, and to assume the parenting role in meaningful ways despite the tragic circumstances. Every minute is significant, every decision important for the future peace and healing of these parents. Many, however, are afraid to request anything our society might consider morbid, unusual, or weird. This document serves as a guideline to their possibilities and options and gives them "permission" to follow their parenting instincts within the limits of state, local, and hospital policies.

In response to the rights, care givers and institutions have the responsibility to provide parents information about their options and to allow them time and support for decision making. However, the decision must always be left to the bereaved. Care must be taken to provide the options—the needed information for decision making—without making the parents feel guilty about their choices. Sensitivity and respect for the individual are paramount in this highly emotional and vulnerable time.

Respecting Parents' Rights

The following guidelines for care givers were developed over six months as staff persons at SHARE explored the rights with the hospital ethics committee. These suggestions are intended as a starting point for hospitals establishing guidelines for dealing with perinatal deaths.

To See, Hold, and Touch Their Baby

- Offer parents the opportunity to see, hold, or touch their baby. Allow time for them to reconsider their decision, and take into account individual differences and needs.
- Take care to avoid "protectionism"; allow

parents to make their own decisions.

- Prepare parents for what they can expect to see (e.g., discoloration, peeling skin, anomalies). Focus on the positive and familial features seen in the baby.

To Have Photographs of Their Baby Taken

- Discuss with families the significance of pictures in bereavement.
- Include family members in the picture if possible.
- Pay attention to the baby's position, clothing, and coverings.[1]
- If parents do not want to see the pictures right away, give them the photos in an envelope or keep them on file—identified, sealed, and held as confidential.
- Consider developing a consent form for picture taking.[2]

To Be Given as Many Mementos as Possible

- Be creative in providing mementos, and listen to families' requests.
- Consider a certificate or recognition of life for framing if no birth certificate is issued, especially after a miscarriage.[3]

To Name Their Child

- Provide suggestions for names when indicated.
- If the sex of the baby is unknown, encourage parents to follow their intuition or to use a name appropriate for either gender.
- Have a naming service—a bonding experience that can facilitate closure.[4]

To Observe Cultural and Religious Practices

- Learn what is important to the parents by asking questions and encouraging them to discuss their customs.
- Where fulfillment of their specific wishes is not possible, explore alternatives that are acceptable and comforting to the parents.[5]

To Be Cared for by an Empathetic Staff

- Allow parents to express their feelings, and really listen.
- Be aware of current concepts of support for perinatal loss. Encourage ongoing education for involved staff.
- Respect parents' needs and wishes, even when you do not understand.
- Keep options open for as long as possible and, when indicated, give parents extended time to consider those options.

To Be with Each Other

- Allow the fathers overnight accommodations in the same room with the mothers when possible.
- Reexamine and, if necessary, revise hospital policies to avoid excluding fathers (e.g., during ultrasound to confirm the death of a baby).[6]

PARENTS' AND BABIES' RIGHTS

Rights of Parents When a Baby Dies

- To be given the opportunity to see, hold and touch their baby at any time before and/or after death within reason.
- To have photographs of their baby taken, and made available to the parents or held in security until the parents wish to see them.
- To be given as many mementos as possible, e.g., crib card, baby beads, ultrasound and/or other photos, lock of hair, feet and hand prints and record of weight and length.
- To name their child and bond with him or her.
- To observe cultural and religious practices.
- To be cared for by an empathetic staff who will respect their feelings, thoughts, beliefs and individual requests.
- To be with each other throughout hospitalization as much as possible.
- To be given time alone with their baby, allowing for individual needs.
- To be informed about the grieving process.
- To request an autopsy. In the case of a miscarriage, to request to have or *not* to have an autopsy or pathology exam as determined by applicable law.
- To have information presented in terminology understandable to the parents regarding their baby's status and cause of death, including autopsy and pathology reports and medical records.
- To plan a farewell ritual, burial and cremation in compliance with local and state regulations and according to their personal beliefs, religious or cultural tradition.
- To be provided with information on support resources which assist in the healing process, e.g., support groups, counseling, reading material and perinatal loss newsletters.

Rights of the Baby

- To be recognized as a person who was born and died.
- To be named.
- To be seen, touched and held by the family.
- To have life-ending acknowledged.
- To be put to rest with dignity.

To Be Given Time Alone with Their Baby

- Before leaving the parents alone, let them know you will be available, and encourage them to determine the length of time they desire with their baby. (If you must set a time limit, make that clear and provide a later opportunity to be with their baby.) Negotiate when their expectations and yours differ.
- Allow the parents privacy so their time will be more intimate and spontaneous.

To Be Informed of the Grieving Process

- Provide general information and simple, informative, printed material regarding common grief experiences.
- Provide an environment where crying and expression of feelings are accepted and encouraged.
- Do not assume parents are not grieving because they do not cry or verbalize feelings. Take care not to impose guilt on those who do not grieve.
- Encourage the couple to maintain open, ongoing communication with each other.
- Communicate to the parents as a couple, rather than separately.

To Request an Autopsy and to Choose Whether to Have a Pathology Examination

- Provide information about autopsies so parents can give informed consent.
- Explain that the information from an autopsy may help them in a subsequent pregnancy.
- Clarify procedures regarding pathology examinations with miscarriage; often the care giver views the surgical permit as permission for the pathology examination and dissection, whereas the family does not understand the extent of the consent signed. Additional clarification is needed regarding methods and means of disposition.

To Have Information Presented in Understandable Terminology

- Be aware of parents' difficulty comprehending during a crisis. Repetition and opportunity to ask questions is imperative.
- Speak in simple language without talking down to them.

To Plan a Farewell Ritual, Burial, or Cremation

- Keep in mind the significance of the farewell ritual—it may be their *only* ritual to replace a lifetime of rituals for their child.
- Provide resources for planning farewell rituals, and encourage creativity.[7]
- Know local and state regulations, as some parents may choose unconventional options. Provide parents with written information regarding local regulations. If their requests are within regulations, do not restrict their wishes.[8]
- Draw from or consult with persons who are familiar with practices of the family's cultural group. Study cultural traditions and rituals of persons in your community.

To Receive Information on Support Resources

- Find out what support groups are available in your area, and consider expanding or providing resources to address unmet needs.[9]
- Make follow-up telephone calls to parents at established intervals and at anniversary times, with in-between calls made as needed.
- Be aware of grief counselors in the area (not all counselors are prepared to work with grieving parents).
- Develop a lending library and provide booklets, reading lists, and addresses of perinatal loss newsletters.[10]

Explore options with parents, letting them know how comforting it has been for others to see, touch, or hold their baby.

Respecting the Baby's Rights

To Be Recognized

- Recognize the baby as a human being, regardless of gestational age.
- Avoid insensitive terminology, such as "fetal tissue" and "products of conception."
- Recognize the baby's life and death by providing a written document (e.g., birth certificate or a certificate or recognition of life).
- Refer to the baby by name.

To Be Named

- Encourage parents to name their baby, without setting a time limit.
- When needed, suggest names for the baby, but leave the decision to the parents.

To Be Seen, Touched, and Held

- Explore options with parents, letting them know how comforting it has been for others to see, touch, or hold their baby. Should the parents choose not to, never force them.
- In presenting the baby, use a soft, warm, colorful blanket, just as you would with a live baby.
- Respect privacy and individual needs during this precious time.

To Have Life Ending Acknowledged

- Assist in preparing a formal or informal farewell ritual.
- Acquaint the parents with birth and death announcements and other ways of acknowledging their baby's birth and death.[11]
- Inform them of potential ways of memorializing the baby (e.g., memory book or box; plaque with the baby's name; personalized headstone; planting of a tree, rose bush, or perennial flowers; personalized crafts with name, date, and other information; memorial services at significant times in the weeks, months, and years to come).

To Be Put to Rest with Dignity

- Offer the parents options (e.g., burial or cremation) for all babies, including those under 20 weeks.[12] Mothers and fathers need to know their options and hospital procedures for babies under 20 weeks.
- Examine past hospital practices and consider more sensitive options.[13]
- After autopsy or pathology examination, consider ways the baby can be made intact and carefully prepared for viewing when possible. Restore

the baby's dignity through careful suturing or cosmetic restoration.

- If the hospital has mass burial, inform parents of the time and place of the service and give them an opportunity to attend.
- Use plot markers to facilitate visits to the baby's grave by the parents.
- Let them know burial cradles are available for a reasonably priced, dignified burial of babies under 20 weeks.[14]
- When parents choose hospital burial, establish a waiting period of two to three months before burial so they can reconsider their decision.

A Creative Challenge

This article presents some challenges for hospitals to consider. Many hospitals have been creative in developing guidelines. As a result, staff in one hospital increased their awareness of practices in its crowded morgue; another hospital adapted its miscarriage burial policies to include burial of the placenta when there was no evidence of the baby.

Working with these concepts and establishing protocol will take time and careful consideration. The prevailing wisdom of yesterday will need to be replaced with present-day concepts. The parents' spiritual, emotional, and physical well-being

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THE FAREWELL RITUAL

The Importance of Ritual

The farewell ritual following the death of a baby is perhaps more significant than that of an adult, who has received recognition and left behind memories and friends who will mourn with the family. A personalized ritual, using the baby's name, can be the beginning of healing for the parents.

Parents often have deep feelings and a sense of what they want to express, but they may fear verbalizing those needs and wants to care givers. Care givers must give them permission to ritualize their feelings in actions that express the grief of loss and their love for this baby.

At one graveside service, while listening to Carey Landry's song "Isaiah 49: I Will Never Forget You," the baby's mother and father got up and walked to the casket, then cuddled next to each other on the ground with their heads resting on the base that held the baby's tiny burial cradle. Through the ritual, they experienced God's presence and the freedom to act their need to be close to their baby.

At the end of this service I invited their family and friends to come forward and say good-bye to the baby and to comfort the parents with a hug. Every person present hugged *both* parents, cried with them, and shared in their grief.

With a personalized ritual, those present are less likely to forget the baby and more likely to be available to the parents throughout the bereavement period. Once the numbness wears off, the parents need ongoing support. The hospital or parish can hold annual memorial services, recognizing the babies' life and death, or establish memorials through the dedication of a tree, a park, or a monument. Personal follow-up phone calls and visits by others who have had a similar experience allow parents to express their feelings, needs, and wishes, along their journey through the valley of darkness toward the promised fullness of life.

A Sample Graveside Service

Opening Prayer Lord God, we are gathered together at this time to share our faith. We are overwhelmed as we reflect on the mystery of life and death which we have just experienced.

Father, you are the source of all life. We thank you for sharing with us this power of creation and sending _____ into our lives. We thank you for this little person—special, sacred, and unique because he/she has been called to life. We find it hard to understand why you have chosen to again call _____ to *birth* into *eternal life.*

We ask, O Lord, that you comfort this little person in your arms. Bless, preserve, and keep him/her and grant to this precious child complete contentment and security in your love. Receive him/her into the kingdom which you have promised as the special inheritance of little children.

Scriptures

- Ecclesiastes 3:1-8
- Psalm 147:2-4
- Isaiah 66:12-13
- Mark 10:13-16

Family Readings

Song "Isaiah 49: I Will Never Forget You," by Carey Landry

Refrain: I will never forget you my people, I have carved you on the palm of my hand. I will never forget you, I will not leave you orphans, I will never forget my own.

Verse: Does a mother forget her baby? Or a woman the child within her womb? Yet, even if these forget, yes, even if these forget, I will never forget my own. (Repeat refrain twice.)

Closing Blessing and Committal O God, all that you have given us is yours. You have given us _____ for this very short time, and now we give our precious baby _____ back to you. Take _____ in your arms of loving care. Raise him/her up with all your people. Receive us also, your mourning people, raise us up during this painful journey. Help us to love and serve you in this world so that we may be united with our precious baby and with you in the world to come. Amen.

PATIENT PARTICIPATION

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stantively influence the movement to patient-centered care, she says.

Medical and nursing schools are beginning to recognize the need to train health professionals in new approaches, according to Orr. She suggests that, as hospital stays become fewer and shorter, physicians' offices need to meet patients' holistic needs for knowledge and a sense of community. Doctors' waiting rooms can provide "more than old magazines," offering information such as that provided by Planetree's consumer health network, which lists people willing to share their experiences with various diseases.

A Philosophical Shift

In developing the Planetree hospital units, a philosophical commitment to patient-centered care among board members and administrators has been essential, according to Cheryl Gelder-Kogan, Planetree's executive director. "We are asking them to go beyond cost-based analysis," she says. "Planetree is well aware of the financial pressures on hospitals. We work with hospitals to target their limited financial resources to areas that will significantly improve the way they deliver healthcare services—and in a way that will attract patients, physicians, and managed care carriers. Emphasizing a healing, patient-centered approach helps strengthen the hospital's reputation within the community by strengthening both the patient's and the staff's satisfaction with the care the patient receives."

As Orr puts it, "Hospitals have to see the value of redefining healthcare; we are pioneers who will show people that changes can improve care. At Planetree we don't want to run hospitals; we work in partnership with them. Underneath the demonstration projects that analyze economics, organizational structures, etc., is a human story—that we owe our patients personal care and a sense of ownership in their care. If hospitals don't do this just because it's the right thing to do, they will do it because it's the way that makes sense and it's good business." —*Judy Cassidy*

MARKETING

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ing with ill, aging, homebound, or dying parishioners. Invite them to come on home healthcare visits. Form a clergy advisory board, and send news releases and promotional materials for inclusion in their newsletters and for dissemination to their parishes.

Community Service Employees Allied community service personnel also provide referrals; therefore promote your services to paramedics, firefighters, police officers, and others. Marketing can include such activities as on-site and work-site education and recognition events.

The Broad Community Community marketing can include a speakers bureau and promotional stories on home care in the local media. Radio and television talk shows are also effective ways to reach the community. Send editorials to the local newspaper, participate in health and trade fairs, and invite prominent community leaders to serve on an advisory board. Make sure board members accompany staff on visits so they can promote your program through firsthand experience. Also consider inviting key representatives of your hospital's board, auxiliary, and volunteers to make home visits and present programs on home healthcare to all these target groups.

Comprehensive Approach

To promote home healthcare effectively, marketing professionals need to develop a comprehensive approach. Everyone in the community is a potential user of or referral source for home care services. By identifying these persons, educating home health and hospital employees, and making effective use of the media, providers can increase awareness of the value of home healthcare and draw attention to the services they make available. □

PASTORAL CARE

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is at risk but can be protected by an open, supportive, preventive response by the hospital. □

RESOURCES

1. *A Most Important Picture*, Centering Corporation, PO Box 3367, Omaha, NE 68103.
2. *Permission to Photograph and Deliver—Special Cases*, release form, First Foto, 3616 Mueller Road, St. Charles, MO 63301.
3. Certificate or recognition of life: National SHARE Office, St. Joseph Health Center, 300 First Capitol Dr., St. Charles, MO 63301, Recognition of Life; Association for Recognizing the Life of Stillborns, Frank and Linda Pavlak, 11128 W. Frost Ave., Littleton, CO 80127, Recognition of Life; Perinatal Loss, 2116 NE 18th Ave., Portland, OR 97212, 503-284-7426, Certificate of Life.
4. Jane Marie Lamb, "Naming Ceremonies," in *Bittersweet . . . hellogoodbye: A Resource in Planning Farewell Rituals When a Baby Dies*, National SHARE Office, Belleville, IL, 1988.
5. Lamb, *Bittersweet . . . hellogoodbye*, section 1.
6. Karen Whitlatch, "'I'm Sorry': Sonagraphers Assume Special Role in Cases of Fetal Demise," *RT Advance*, September 17, 1990, pp. 1-3.
7. Lamb, *Bittersweet . . . hellogoodbye*.
8. Lise Carlson, *Caring for Your Own Dead*, Upper Access Publishers, Hinesburg, VT, 1987.
9. Jane Marie Lamb, *Starting Your Own SHARE Group*, 5th ed., National SHARE Office, Belleville, IL, 1991.
10. A list of perinatal loss newsletters is available through the National SHARE Office.
11. Birth and death announcements are available through: PatterMark Prints, 1356 N. Planview Dr., Copley, OH 44321, 216-666-6975; Perinatal Loss, 2116 NE 18th Ave., Portland, OR 97212, 503-284-7426.
12. "How Should Catholic Hospitals Provide for Disposition of Miscarried Fetuses?" *Hospital Progress*, July 1983, pp. 70-71; *Ethical and Religious Directives for Catholic Health Facilities*, U.S. Catholic Conference, Washington, DC, 1975, Directive 43.
13. Lamb, *Starting Your Own SHARE Group*, "Hospital Policies."
14. Miscarriage burial cradles are available from Bay Memorial, Tom Zerbel, 321 South 15th St., Escanaba, MI 49829, 906-786-2609.