

# Family Focus On... Death and Dying

Issue FF12



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## Death as Normative in Family Life

by Susan K. Hoppough, MSN, RN, Instructor; and Barbara Ames, Ph.D., CFLE, Professor,  
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The terrorist attacks of September 11, the graphic representation in the media, and the ensuing military response has put death in the center of daily life in a way never experienced by post-World War II generations. These events have assaulted us with the issue of our own mortality, a topic we, as a culture, tend to avoid. In order to more effectively help families in dealing with death at every stage of the life course, we as family professionals must begin to see death as an important and appropriate subject matter for family life education. In this article we reflect on attitudes toward death and suggest strategies for dealing with death as a normative component of family life across the life course.



institutionalized death, leaving the home a sanitized and protected refuge. At the same time, physicians and family members avoided discussions of death with dying individuals, seeking to "spare" them knowledge of their grave condition. While physicians and nurses no longer engage in this evasive behavior, the advancement of technology and increasing health-care options encourage families to discuss ways of prolonging life rather than death itself.

In the 1960s, the hospice movement reintroduced the notion of death in home settings, making it more common for individuals with terminal disease and their families to choose home as an appropriate location for death. Within hospice, death is openly discussed, family members of all ages are encouraged to participate in providing comfort care prior to death, and bereavement services are provided for family members.

Death discussions related to terminal disease or aging frequently focus on end-of-life decision-making. Current family health policy related to end-of-life decision-making includes support for the use of advanced directives, which are legal instruments outlining choices for medical and life-prolonging treatments. However, we have observed that it is uncharacteristic for families to face critical illness armed

### DISCUSSIONS OF DEATH

Historically, death was a common experience within families. Death was linked to childbirth and acute disease, and young children often experienced parental death. Because death typically occurred within the home, all family members interacted with dying individuals, witnessed death, and participated in the funeral process.

As a result of shifts in mortality, death is now expected in old age, but not in youth. The advent of hospitals at the beginning of the 20th century

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Susan K. Hoppough, MSN, RN

with a plan for death. Few have discussed a will, planned a funeral, or completed advanced directives. Patients who have completed advanced directives report feeling comforted in knowing preparations for death are in place, reducing the burden on their families.

Our position is that discussions of death within families must occur at times unrelated to a death event.

Such opportunities may occur as part of a ritual or in relation to violence reported in the media. Ritualistic practices and beliefs related to death vary among cultures and religions, but all provide a framework for discussing death. Children can participate in these practices through the lighting of candles, prayers, and days honoring the dead.

Secular opportunities to discuss death may occur only in relation to the report of violence in the media. Events such as the shootings at Columbine or deaths related to natural disasters leave children feeling frightened and unsure of their safety, and parents unprepared to respond to their questions. Confusing and sometimes frightening euphemisms such as “passing,” “losing,” “gone to heaven,” or simply “gone” result from this uncertainty.

**DEATH AND FAMILY LIFE EDUCATION**

Family life educators are uniquely positioned to provide families with assistance in the discussion of death from a normative perspective. We offer

suggestions for inclusion of death within each of the ten content areas with the goal of validating death as an appropriate topic of discussion within a life-course perspective.

- 1) **Families in Society:** Recognition of cultural variations among families related to death beliefs and practices. The development of culturally relevant curricula will help professionals interact more effectively with families who are dealing with death issues.
- 2) **The Internal Dynamics of Families:** Death is a stressful event within families. Family openness about death will ease disruption of the internal dynamics of the family when death does occur.
- 3) **Human Growth and Development:** Death is part of the life cycle. Using teachable moments across the life course (e.g. the loss of a pet) will help families incorporate death as a normative topic of discussion.
- 4) **Human Sexuality:** Death is related to sexual values and decision-making. Incorporating discussions of death as part of the life course related to sexual choices is essential in achieving healthy sexual adjustment. Family life education should include such topics as sexual relationships in illness and sexually transmitted diseases that result in death.
- 5) **Interpersonal Relationships:** Death is part of all interpersonal relationships. Understanding and freely sharing thoughts, fears, and desires related to death is essential to interpersonal relationships.
- 6) **Family Resource Management:** Decisions related to death and end-of-life issues frequently hinge on resources and the distribution of those resources among family members after death. Helping family members to discuss death prior to the death event will enable families to make informed choices about life-prolonging measures and to reduce

conflict related to disbursement of financial assets after death.

- 7) **Parent Education and Guidance:** Parents feel unprepared to discuss death with their children. Providing developmentally appropriate materials and strategies will assist them in introducing and continuing the dialogue across the life course.
- 8) **Family, Law, and Public Policy:** Families of all ages and at all stages of the life course must plan for death, but few policies or other supports are available to encourage this planning. Family responsibilities that need public-policy support range from routine safeguards such as creating wills to making end-of-life decisions.
- 9) **Ethics:** Death as an appropriate topic of discussion across the life cycle is essential in understanding the formation of social attitudes related to the distribution of limited health-care dollars and the implications of technological change. Recent advances in stem cell research and the killing of embryos force us to examine the ethical dilemmas associated with procreation as well as death.
- 10) **Family Life Education:** Planning, implementing, and evaluating life course death education, with sensitivity to cultural and familial diversity, is a critical role for the family life educator.

When death is a normal topic of discussion across the life course, families are better prepared for this inevitable event.

Talking about mortality is not easy, and the natural response is to protect family members from this difficult subject. However, by acknowledging death as a normal and appropriate topic of discussion across the life course, families can better prepare themselves for this inevitable life event. Family life educators have an important role in facilitating this discussion.

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# A Visible Death

by Susan K. Giboney, M.A., CFLE, Professor of Education, Pepperdine University, Malibu, California

**O**ur culture treats dying as if it were invisible. We try to solve the problem of death by hiding or denying it. We discourage dying people from knowing of their condition, because death seems unmentionable.



Susan K. Giboney, M.A., CFLE

Patients, in turn, try to convince others that they are getting better.

Physicians are expected to prevent dying. Many critically ill persons die in the hospital with only medical staff members attending them.

Mourning is discouraged and death is considered too unpleasant a subject for polite conversation.

In studying lifespan development, people usually want to know what it is like to die. However, since the dead cannot tell us, those who have been with the dying are a good source of information on dying and death. I had the privilege of studying a man named Terry who taught about dying in a visible way. He, along with his wife, taught numerous classes on marriage and parenting and was aware of the implications of death on a whole family. When Terry was first stricken with cancer, he thought he would learn much about illness and share it with others.

During his second round of terminal cancer, while still in his mid-fifties, he decided to teach about how to die. He did it nobly and faithfully and left a lesson for all who shared his dying experience. His death was not invisible, nor was it gruesome, but it was real and inspiring and sad all at the same time. As a family life educator and as Terry's wife, I share his desire to make dying, death, and grief less hidden.

## A TERMINAL DIAGNOSIS

Terry called me at my office on a Tuesday. I knew he had a doctor's

appointment that day, but I thought it was routine. When I heard his voice, I knew I had to get home immediately. The diagnosis of his invasive cancer put us in shock! Here is Terry's first entry in the journal he decided to keep, "It is our son's 25th birthday, but somehow that got lost in the events of this day — a day that begins a journey into the unknown for me, a journey of pain, faith, doubt, tears, prayer, and, hopefully, healing. As I got into the car to drive home from the doctor, I felt discounted in value. I felt like damaged merchandise, like someone had suddenly stamped on my forehead, 50 percent off. I had become a liability rather than an asset to my wife and family."

It was hard for us to fathom that this healthy, lean, happy man could be riddled with disease. We began a journey of dying and death. As I told him, "You do not have cancer alone, we have cancer."

## ACCEPTING DEATH

Elizabeth Kubler-Ross, a foremost author on death and dying, gathered her information primarily by talking with dying patients. She summarized the dying process in five stages. We found our experience to parallel much of what she discovered. According to Kubler-Ross the five stages of dying are denial, anger, bargaining, depression, and acceptance. During his first bout with cancer, Terry summarized them this way in his journal:

**Bright:** Life is great and I am hale and hearty and in control.

**Plight:** I have cancer and I'm going to die — maybe soon.

**Fright:** Life is in a tailspin, I'm scared, my fears know no resolution.

**Flight:** I want to run, but where can I

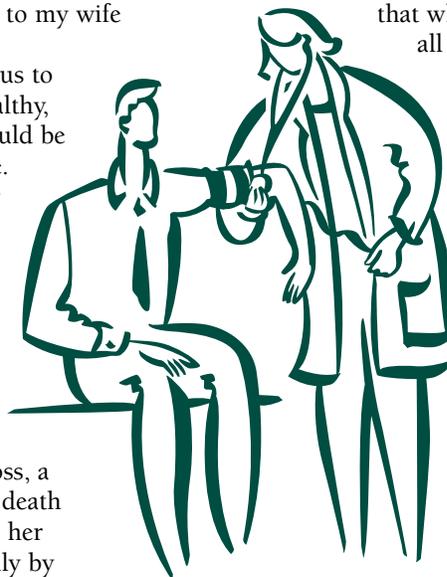
go? The problem is within.

**Night:** Against the prospects of no earthly future, the computer of my mind can only flash, "Does not compute!"

**Light:** Just when the night was darkest, a pinpoint of light became visible. Fanned by hope and help, it became my beckoning beacon and compass.

**Right:** Gradually sight, insight, and delight came into the new and beautiful world unfolding daily in front of one who has been given a reprieve from his sentence of death — even if full pardon is not assured.

**Right:** It is all right. Finally there is a sense of peace and confidence that whatever lies ahead will be all right. The fear of the night is past. The dawn of faith is breaking.



As the caregiver, my two main goals were courage for me and loving care for him, care that would be as painless as possible. The family supported his desire to die at home with dignity, and we enlisted the support of hospice care. With this choice, we felt we had more control of the process and could support each

other in our stage of anticipatory grief. Not everyone has the opportunity to prepare for death, but as painful as it was, we used this time to share our gratitude for the past, gain support for the present, and clarify plans for the future.

Dying people basically need food they can eat, a comfortable physical environment, rest, freedom from pain, and assurance that the family will be cared for. Distribution of possessions, clarifying finances, confirming a will or living trust, and making funeral arrangements are tasks many want to complete. Terry wrote, "My prayer all along has been to exit this life with the same

Visible Death continued on page F7

# Death: A Family Event for Mexican Americans

by Estella A. Martínez, Ph.D., Associate Professor, Family Studies Program, University of New Mexico, Albuquerque

The strong familistic orientation of Mexican Americans and other Latino families serves a support system that is particularly evident when there is a death in the family. Clearly, the presence of immediate and extended family members and the manner in which they respond demonstrate that death is a family event for Mexican Americans. The events surrounding death function to reintegrate the family. Family members reunite despite any geographical or psychological distance between them.

Adaptations to death reflect group tradition and status. Death is often viewed as a tragedy during which emotions are expressed rather than suppressed. Intense release of grief by the bereaved is common. Death may even be accepted as a life event beyond the family's control. The influence of a family's working-class socioeconomic status contributes to a fatalistic acceptance of death.

## THE IMPORTANCE OF FAMILISM

Despite their heterogeneity, Mexican American and other Latino families have an intra-group consistency in their ideology of death. Attitudes toward death vary among the highly educated and more acculturated family members. Nevertheless, "familism," that extraordinary importance placed on the family, serves to maintain consistency within the group when it comes to their attitudes toward death.

The funeral is the most significant family ceremony among Mexican Americans. This is demonstrated by the common opinion that it is more important to attend a funeral than any other family event. The family and the

community rally for the funeral, which functions to reintegrate the family and to reinforce ethnic identity. A sense of historical identity is also revived because family members who have been geographically and psychologically apart are reunited. This reinforcement of ethnic values and demonstration of social support serve to replenish ethnic identity and reinforce a feeling of family cohesiveness.

The traditional family values of demonstrating respect for elders, for tradition, for authority in the family, and for religion pervade the funeral. Out of respect, family members forego personal principles, such as not practicing religion or going to church regularly, by participating in traditional funeral events with the family. If there are any nontraditional variations on the funeral, they are viewed as being imposed on the family by social forces outside the family such as religious dogma or cemetery officials.

## FAMILY ROLES

Traditional values are also evident in the roles assumed by family members during the crisis periods of death. For example, socialization to funerals begins at a young age. Children attend funerals regularly. Controls by the older generations over the younger generation are reasserted by expecting and demanding the participation of children and youth in events such as the wake or rosary, the memorial service or mass, as well as the funeral and subsequent family gatherings.

Women tend to be the focus of support and emotion. This may be a response to their traditional roles of service and affection that function to consolidate the family. Men attempt to maintain an acceptance of death. Often

their antireligious behavior is relinquished out of respect for the dead as well as for the family. They often control the public expression of their feelings, but they admit to greater overt expression of grief than do men in contemporary mainstream society. Religion provides all family members with opportunities for expressing feelings through rituals. Unity and togetherness are, however, most important to the family's morale.

## COPING WITH DEATH

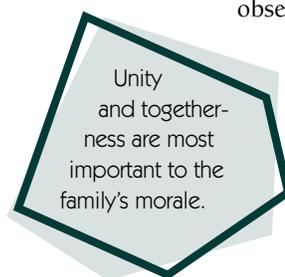
Mexican Americans readily accept death as both an abstract concept and a reality. There is a willingness to admit fear of death. Discussing death may be avoided, but there is a preoccupation with death. When death occurs, the expression of feelings is intense. Mexican Americans cope with death by attempting to master it through ritualistic acts such as a rosary, a mass, a graveside service, and the annual

observance of All Souls' Day on November 2, which is more commonly known as the Day of the Dead or Día de los Difuntos.

They also cope with death by dwelling on it until the anxiety is worked through, and

by integrating it meaningfully into life in various ways such as visits to the cemetery where graves are decorated with flowers, balloons, and other mementos on holidays or special family days. The influence of acculturation to the values of mainstream society, however, modifies many of these death-related behaviors among members of Mexican American families.

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# Using Movies to Teach about Death and Dying

by Cheryl Malone Robinson, Ph.D., CFCS, CFLE, The University of Tennessee at Chattanooga

In light of the recent attack on America, end-of-life issues have become the focus of discussions in many homes, offices, and houses of worship. As a society, however, Americans resist addressing these issues until confronted with the death of a grandparent or parent. Even then, we are sometimes hesitant to explore the information needed to successfully resolve the passing of a family member or friend. Like the majority of Americans, college students have difficulty addressing issues surrounding death. Even though we often hear it said that death is just a natural part of life, most of us continue to be reluctant to explore and discuss these issues.

Fear and anxiety in regard to the process of dying as well as death itself are very common emotions in our culture. Worries about not being able to care for ourselves, being a financial and emotional drain on our loved ones, suffering pain and physical impairment are also very common. We also fear being separated from those we love and losing control of our destiny. Because we generally experience negative emotions when our thoughts turn to death and dying, we usually avoid talking about the subject, much less studying it.

## DEALING DIRECTLY WITH THE ISSUE

Some universities include courses in their curriculum that focus primarily on the aging process and death issues. Others offer courses that briefly address these issues through chapters embedded in texts on more general topics. It's a challenge to design a course that deals directly with the issues surrounding death and that will engage students and encourage critical thinking. One way to do this is to use a movie that illustrates these issues.

Using movies makes it easier for students to think about death.

One such movie is *The Lies Boys Tell*, starring Kirk Douglas and Craig T. Nelson. The movie opens with Kirk Douglas, in the last stages of lung cancer, confined to bed at home. He is being attended by members of his family. His wife of many years, son, daughter, their spouses, and grandchildren are quick to offer opinions and advice. Family members focus on having him follow the doctor's orders and avoiding risks of any kind. They totally ignore *his* wants and *his* emotional needs as he prepares to live his last days.

The attitudes of the movie's protagonist and the characters that surround him give student viewers insight into typical behaviors often displayed by family members in these circumstances. Characters behave as they believe they *should* behave. Their actions are solemn and influenced by rigid tradition. Our culture is just awakening to the importance of listening to dying people in their last days and valuing their wishes. Students watching the movie have the opportunity to examine these issues.

Mourning rituals provide comfort and a feeling of security during the time surrounding the death of a loved one. Of course, mourning rituals vary with religion and ethnicity. The use of movies in the classroom may be the only place that students have the opportunity to be exposed to rituals other than those of their own family.

## COURSE STRUCTURE

Here's how I structured the course when I showed *The Lies Boys Tell*. If the class was long enough, I showed the movie during regular class time. If not, I showed it over two class periods. As a last option, students could check the movie out and watch it.

I prepared a movie guide to lead students to the most salient parts of the film. The guide contained questions that encouraged students to think critically,

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### These articles include:

Last Wishes

by Joyce A. Shriner and Ted G. Futris

Rituals Help Us Cope with Grief

by Patricia H. Zalaznik

Adolescent Grief

by Sueanne Krzyminski

The Expression of Disenfranchised Grief on the Web

by John A. Blando and Katie Graves-Ferric

[www.ncfr.org](http://www.ncfr.org)



Cheryl Malone Robinson, Ph.D., CFCS, CFLE

draw conclusions, and raise additional questions. Discussion flowed easily, even though the topics had previously been difficult to approach. Students seem genuinely interested in learning about the issues highlighted in the movie.

The movie is educational, but it is also humorous. Using this approach makes it easier for students to think about death and dying and to ask the questions they have hesitated to ask before.

*The movie guide is available by request. For more information, contact Cheryl-Robinson@utc.edu.*

# Death and Dying During Pregnancy: Perinatal Hospice

by Joann O' Leary, MPH, MS, Ph.D. Candidate; Work, Community, and Family Education; College of Education & Human Development; University of Minnesota

In a recent column Jane Brody told the poignant story of a family who ended a pregnancy because of multiple fetal abnormalities. Sadly, this phenomenon is more common than most people realize. It is speculated that congenital abnormalities occur in three to five percent of all births. There is currently an increase in families of reproductive age who are at risk for unfavorable pregnancy outcomes. This is partly due to the increase in reproductive technology, as families who were unable to conceive previously are now getting pregnant.

According to the 1992 publication *Health Care Issues in Genetics*, some 200,000 infants are born each year with birth defects. This is the leading cause of infant and childhood mortality. Our health-care system has difficulty dealing with chronic disease and providing family-centered, community-based, multidisciplinary, and coordinated services for children and adults. With rare exceptions, our current managed-care systems do not provide important primary care services for couples who are at risk for unfavorable pregnancy outcomes. Genetic counselors estimate that only about one percent of these families receive the long-term medical and preventive services they need.

When some families receive bad news, they chose to continue a pregnancy. These families have unique issues to face as they prepare for labor, birth, death, and their continued life as "family." The medical community labels these pregnancies "perinatal hospice." In layman's terms, this refers to a mother carrying a baby who will die during pregnancy or shortly after birth. Although the medical community may speak of "perinatal hospice," for these families, this is, first of all, their baby, and only secondarily a baby with a genetic abnormality.

## PARENTING THE BABY

The literature on infant loss points out that infant loss is especially difficult because parents are supposed to die first. In addition, it has been well documented that infant loss is not something parents "get over." An infant who dies continues to have a place in the family. The parents must now incorporate their grief into their family story, and this affects their parenting in profound ways. Many of these families have other children who are also affected. This is potential area for family education professionals to provide support and education.

Professionals should begin by helping families to understand their role as parents to the unborn baby during pregnancy. Learning about fetal development helps parents to build memories of this child and his or her place in the family. We know, for example, that babies hear in utero by 20 weeks gestation. Even sick fetuses are aware of their environment and know the voices of the people in their family.

Parents can be encouraged to keep a journal, including ultrasound pictures of their baby. They can write the "story" of the pregnancy from the beginning, up to finding the bad news, and how they are now "being with the baby." This acknowledges they are still parents and helps them "be with" the baby before he or she dies. It also gives them something concrete to hold and look back on after the baby's death. Grandparents, aunts, uncles, and friends can also participate in this memory-building.

The family can "be with" the baby and create memories of this child.

## TELLING THE SIBLINGS

It's painful for parents to tell their other children that this new baby is going to die. While they initially may not want to do this, clinical practice has demonstrated that children are aware of emotions in the family and need to know what is going on. They, too, will mourn the loss of the baby that was expected to come home. They, too, need to be involved in building the memories. Here are some ways that parents can support their children during this time:

- Tell the children about the baby's death using only as much detail as is necessary. Keep in mind each child's developmental level.
- If the child is in nursery or elementary school, tell the teacher what is going on in the family. The teacher can watch for unusual behavior and give support to the child during a time when parents are grieving and may not be as available to their children.
- Involve the children in the baby's story. Older children can write in the journal or draw pictures of things that are important to them. If children are too young to draw, parents can trace their hand and foot prints so they can remember how old they were when this baby was part of the family.
- If the parents are comfortable and this is allowed, let the children be part of future ultrasounds so they can "see" the baby, too.
- Find someone who will talk with the children about what to expect when the baby is born. Many hospitals have child-life specialists who are very knowledgeable in this area.
- Decide before the birth whether siblings will see the baby after he or she has died. Clinical experience has demonstrated that most children see a "baby," not abnormalities. They are



*Perinatal Hospice continued on page F7*

**PERINATAL HOSPICE** *continued from page F6*

always grateful they were able to see their brother or sister. Some families who chose not to do this have found out later that their children regretted not being able to see their sibling.

**MAKING THE BABY PART OF THE FAMILY**

These memories are helpful for children. Having a booklet that “tells the story” of the pregnancy of their sibling will allow children to review what was going on in the family at that time. As children mature, they will ask more detailed questions when they are ready for more information. The booklet becomes a visible reminder of the baby who is still part of the family but no longer physically present. Its presence lets children know that the baby is a topic that can be openly discussed in the family.

The booklet also becomes a resource for the family if there is a

subsequent child. The “story” of the other baby becomes part of the family. This helps later-born children become their own persons without feeling they have to replace the baby who died. Older siblings will also be able to share the memories with the later-born children. This assures that all children in the family have their own place and role.

Although we think of pregnancy loss, stillbirth, and newborn death as medical problems, they affect the entire family. That’s why families in this situation would benefit from working with a multidisciplinary team that includes not only medical and hospital personnel but family life educators as well.

*Joann O’Leary’s research is supported by a fellowship from the Bush Foundation, St. Paul, Minnesota. For more information, contact jandj@pro-ns.net.*

**VISIBLE DEATH** *continued from page F3*

peace, confidence, courage, and unswerving faith that I have tried to live. I want the last chapter of my life to be the finest, not for me, but that in my death I will help others seek and discover an unfathomable richness in faith and to not lose heart.”

**HELP FOR THE GRIEVING**

The death of a loved one is among life’s most stressful events. The grieving process may occur over a short period of time or it may never be finished. Research shows that generally grief reactions are dealt with on four levels. These levels were real to me. I discovered that some things helped and some did not.

- **Physical:** Help with physical needs such as food, cleaning, transportation, and care is welcome. Second-guessing the choices for physical care or intrusive physical care are not helpful.
- **Intellectual:** Appropriate conversa-

For families, sadness and stress are inevitable, but courage and support in the dying process are achievable.

tions, reading material, solicited advice, and realistic expectations are helpful. Stories of unrelated experiences, denial of grief, and providing trite answers are not helpful.

- **Emotional:** Allowing tears and open conversation about the deceased is helpful. Repeating cryptic platitudes, denying emotions, and acting as if nothing has happened are not helpful.
- **Social:** Social invitations, letters, and listening are helpful. Ignoring or demonstrating discomfort with grief is not helpful.

Death is real, palpable, anguishing, exhausting, inspiring, courageous, and noble. Death is part of life. For families, sadness and stress are inevitable, but courage and support in the dying process are achievable. Death does not have to be a hidden, lonely process. Thank you, Terry, for a mighty lesson!

*For more information, contact Susan.Giboney@pepperdine.edu.*

**RESOURCES**

**Americans for Better Care of the Dying.** Founded in 1997, this Washington, DC based organization has three goals: 1) build momentum for reform, 2) explore new methods and systems for delivering care, and 3) shape public policy through evidence-based understanding. [www.abcd-caring.org](http://www.abcd-caring.org)

**Home Care Guide for Advanced Cancer.** This site, cosponsored by the American College of Physicians and the American Society of Internal Medicine, offers practical advice for caregivers. Of special interest is the section entitled “What to Do Before and After the Moment of Death.” [www.acponline.org/public/h\\_care/index.html](http://www.acponline.org/public/h_care/index.html)

**Hospice Foundation of America (HFA)** offers information on how to locate a hospice as well as an “end-of-life database.” [www.hospicefoundation.org](http://www.hospicefoundation.org)

**Last Acts** is a national coalition of nearly 800 organizations whose mission is to improve care and caring near the end of life. Members include AARP, Catholic Charities USA, American Hospital Association, and National Council on Aging. The site offers articles on medical, legal, and other issues. [www.lastacts.org](http://www.lastacts.org)

**MEDLINE plus: Death and Dying.** The National Institute of Mental Health offers articles about all aspects of the topic and links to other relevant sites. [www.nlm.nih.gov/medlineplus/deathanddying.html](http://www.nlm.nih.gov/medlineplus/deathanddying.html)

**Partnership for Caring** is a national coalition that includes the Academy of Hospice and Palliative Medicine, the National Academy of Elder Law Attorneys, National Council on Aging, AARP, and many other organizations. It offers counseling services (toll-free hotline, 1-800-989-9455) and educational services, tracks and monitors all state and federal legislation and significant court cases related to

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# Recognizing the Humanity of Dying Inmates: Prison Hospice Programs

by Norma A. Winston, Ph.D., Professor of Sociology, University of Tampa; and Svetlana Yampolskaya, Ph.D., Research Assistant Professor, Florida Mental Health Institute (FMHI), University of South Florida

**M**ost families with a relative in prison never think of that person dying there. Yet the chances of doing so have increased in America in recent years. Since 1993, the proportion of deaths among inmates has risen by 550 percent. Factors responsible for this unanticipated increase



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include the rise in the incidence of AIDS among prisoners; the imposition of longer sentences as punishments for crimes committed; the increased likelihood, since the passage of the Sentencing Reform Act, that the prisoner will serve the full time imposed at sentencing; and the fact that it is very difficult to get a medical parole.

The need to provide quality medical care to an increasing number of terminally ill prisoners has strained the capacity of the correctional system. Utilization of external systems, like hospitals and rehabilitation programs, has proved expensive and posed additional security problems. One alternative that has developed is the Prison Hospice Program.

## PALLIATIVE CARE

Hospice is an interdisciplinary, comfort-oriented program of care that allows seriously ill and dying patients to live and die with dignity and as little pain as

possible. *Prison Hospice* promotes palliative care for terminally ill inmates. The goals of the program include providing appropriate care for dying prisoners, assurance of “death with dignity,” and cost-effective care.

Eligibility requirements for entering the Prison Hospice Program include a diagnosis of a terminal illness, a prognosis of six months to one year left to live, and a request from the patient for hospice care.

All Prison Hospice Programs are offered within the prison or the prison hospital. Hospice personnel consist of multidisciplinary teams that include a nurse, a physician, a psychologist, a social worker, a clergy person, and a security official. Hospice staff provides mental, emotional, spiritual, and educational counseling to the dying patient, as requested or deemed necessary.

## INMATE VOLUNTEERS

One special feature of prison hospice is that prison inmates volunteer to help dying individuals. All inmate volunteers receive eight to 36 hours of training in accordance with standards established by the National Hospice Organization. Before receiving their training, all volunteers undergo a thorough security screening.

Once trained, these inmate volunteers provide dying prisoners with companionship and assistance with daily activities, such as eating, personal care, or letter-writing. Volunteers generally give care outside of their regular work hours. But once their patient is diagnosed as actively dying, volunteers may be released from work to spend up to 24 hours a day with the dying inmate. This means that the inmate does not die alone.

## RECONNECTING WITH FAMILY

With the patient's permission, hospice staff work to locate family members with whom the patient has lost contact. Patients are encouraged and assisted with letters and other forms of communication with family members. When possible, family members are advised and appraised of the patient's on-going medical condition.

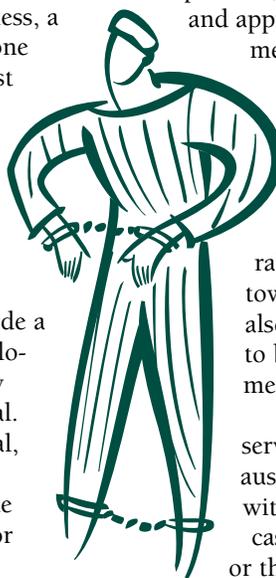
As the patient draws closer to death, visitation rules are relaxed for biological and surrogate family members. Hospice staff provides information or referrals on accommodation to out-of-town family members. The staff also offers bereavement counseling to biological and surrogate family members.

After death, a memorial service is held, either under the auspices of the hospice program or within the prison itself. In some cases burial can also be arranged or the body can be shipped to the funeral home nearest to the family.

Approximately 20 prisons in the United States have or are working toward establishing Prison Hospice Programs. The programs already in operation have proved very effective. Reports indicate that the Prison Hospice Program has served to “humanize” terminally ill patients. Patients have felt the warmth and concern of others and have been spared the indignity of dying alone. In some cases, patients have renewed ties with family members, who have the opportunity to say “good-bye” and to be with the patient at the time of death.

## THE VOLUNTEER'S EXPERIENCE

Perhaps the most surprising outcome of Prison Hospice is the transformation experienced by many of the inmate volunteers. As one inmate volunteer said, “It made a world of difference



*Prison Hospice continued on page F10*

# Medicare Hospice Policy in Nursing Home Settings Hinders End-of-Life Care

by John Machir, CFLE, Director of Social Services, Willow Point Nursing Home, Vestal, NY

Since the beginning of the hospice movement, there have always been naysayers who decried the type of care that hospice organizations give dying individuals. Many medical professionals, accustomed to restorative



John Machir, CFLE

medicine, were unwilling to “give up” on more aggressive treatments, though the inevitable outcome of the disease was certain. With a great deal of teaching and the passage of time,

however, the medical profession has learned to let patients determine the course of their own medical treatment.

These days, most people recognize the benefits of hospice care for both dying individuals and their families. Palliative care treats death as a normal process without hastening or delaying it. Such care considers and integrates the psychosocial and spiritual aspects of the individual, acknowledging that the mind and spirit, in conjunction with the body, constitute the individual. Hospice services include specialized nursing care, medical social services, counseling and bereavement services, friendly visitors, pastoral services, and, of course, appropriate pain management. The goal is to provide a comfortable, dignified death for the individual and to support family members as they deal with anticipatory grief and bereavement.

The emergence of the Medicare hospice benefit has made it possible for many people to take advantage of hospice services. This benefit is a real help for individuals who die in their own home among family and friends. But for the 20 percent of Americans who die in a nursing home, Medicare policies create specific inequities that can complicate the dying process.

## BARRIERS TO ACCESS

Whether an individual is at home or in a nursing facility, Medicare requires that the anticipated life expectancy be determined. Physicians must certify that the anticipated life expectancy of the patient is six months or less. Nursing facilities, which are strictly regulated by the federal government, are often much more conservative in their estimate of life expectancy because Medicare has traditionally frowned upon improved health outcomes for persons enrolled in hospice care. Thus, nursing-home residents enrolled for hospice services are almost certain to die within the specified six-month time frame.

Clearly, individuals with diseases such as ALS (Lou Gehrig’s disease) and some forms of cancer can benefit from palliative care long before the final six months of life. That’s because while they may live longer than six months, curative treatment is no longer the focus, and restorative treatments only create discomfort or pain without changing the outcome. Thus, in some circumstances, the six-month prognosis requirement limits access to hospice services for individuals who prefer palliative care.

## A HOSTILE REGULATORY ENVIRONMENT

Nursing-home patients face additional problems. Medicare policy is strongly oriented toward rehabilitation and restorative goals for these patients. The Omnibus Budget Reconciliation Act of 1987 (OBRA) specifies that the goal of nursing-home care is “...to attain or maintain the highest practicable physical, mental, and psychosocial well-being of each resident.”

To this end, the Centers for Medicare and Medicaid Services (CMS), formerly known as the Health Care Finance Administration (HCFA) have

developed the Resident Assessment Instrument (RAI). The RAI consists of a Minimum Data Set (MDS) and Resident Assessment Protocols, which are considered indicators of poor or inadequate care. The RAI does not have existing protocols geared toward palliation. This means there are no standards that directly apply to individuals who are actively dying from chronic, progressive, incurable illness. Therefore, nursing facilities are at risk in state surveys for declines in resident health if surveyors feel that these declines were medically avoidable.

The hospice agency is responsible for the implementation of the care plan. But the nursing facility retains the responsibility for the quality of care under the survey process. The facility must continue the same level of care the individual has been receiving, with the addition of the hospice services. The

hospice organization, while providing care within the nursing facility, shares none of the regulatory burden. That’s why some nursing facilities, operating under already tight regulatory scrutiny, are reluctant to enter into

contracts with providers of hospice services.

## AN EMPHASIS ON RESTORATIVE THERAPIES

Medicare reimbursement policies encourage nursing homes to focus on restorative therapies. Under the current Prospective Payment System, new residents must be classified in one of 44 Resource Utilization Groups (RUGs). RUGs for restorative therapies are reimbursed at higher rates than RUGs for hospice care. Medicare assumes that rehabilitative therapies are more costly to provide and that restoration of function is always the most desired health outcome. But in the case of dying

Medicare policy supports rehabilitation and restorative care for nursing-home patients, rather than palliative care.

Medicare continued on page F10

**MEDICARE** *continued from page F9*

individuals, skilled pain and symptom management, personal care, and emotional support are more desirable. The current payment structure does not acknowledge the benefit of these services, and offers no financial incentives for nursing homes to provide them.

**FINANCIAL INEQUITIES**

Payment sources and ability to pay create financial inequities that limit access to hospice care. Individuals who are eligible for both Medicaid and Medicare have the most financially neutral option for hospice care.

But reimbursement is complicated. Medicare hospice benefits pay for the cost of hospice services but do not pay for room and board. Medicaid, however, pays hospice providers at least 95 percent of the normal rate for room and board. Hospice providers then “pass through” the room-and-board payment to the nursing home. Room-and-board charges typically include the cost of personal care services, medication administration, cleaning, use of durable medical equipment, and assistance with activities of daily living (there are some variations from state to state).

Individuals covered by Medicare alone must, after a hospital stay, choose between the skilled nursing benefit which covers room and board or the hospice benefit which does not. Families who do not qualify for Medicaid coverage but who do not have the

resources to pay for room and board, face a dilemma. Many families choose skilled nursing benefits to avoid the high costs of room and board, even though they prefer palliative care. This choice also favors nursing homes since reimbursement rates for restorative care are higher. In this situation, dying individuals must worry about current finances as well as the long-term financial impact on family members.

In some states, Medicaid places liens on the dying person’s home in order to recoup the cost of payments made to skilled-nursing facilities. Living spouses or adult children who are co-owners of the home can retain the use of the home until their own death. But then the home is sold and the medical assistance agency is paid from the proceeds. Some individuals, wishing to leave their home or some other form of inheritance to their families, decline Medicaid coverage entirely and endure restorative therapies for as long as possible under Medicare’s skilled-nursing benefit. The result is often great suffering — not only for the nursing-home resident but also for members of the family who witness the agonizing demise of a spouse or parent.

**RECOMMENDATIONS**

The following changes would greatly improve access to Medicare hospice services for residents of nursing homes:

- Train state surveyors to understand

probable outcomes of palliative care interventions. Accept these interventions as a viable form of treatment for patients at the end of life by establishing palliative care survey standards

- Modify current RUGs to reimburse nursing facilities for intensive personal care services and symptom management at appropriate rates. Modify RAI to reflect a resident’s wishes for treatment through advance directives. Add pain-management protocols for end-of-life care.
- Create uniform standards for services covered by the Medicaid room-and-board payment, and eliminate “pass-through” payment system with direct payments to nursing facilities.
- Establish financially neutral Medicare reimbursement policies for nursing-home hospice that will eliminate the financial penalty to either the nursing home or the individual.

The goal of hospice is to improve the quality of life for individuals who are dying. In order to make this possible, we must remove the barriers to hospice access. Only then can individuals and families find meaning in the final days of life instead of having worry about money and endure restorative care they don’t want.

*For more information, contact john8163@epix.net.*

**PRISON HOSPICE** *continued from page F8*

having someone to care about. I never knew how to care about anyone else but myself before.” As they help the dying patient, the inmate volunteers come to understand their own mortality. They express remorse for their crimes and say how awful it must have been for their victims. Most important of all, they frequently develop a family bond with their patient: hence the patient does not die alone but in the presence of a compassionate “family member.”

Prison hospice programs assure that inmates do not die alone.

“Jim,” who is serving a life sentence at Oregon State Penitentiary, volunteered to care for “Rafael,” a 27-year-old inmate dying of prostate cancer. “I knew that Rafael’s death would be very painful for me if I allowed myself to get close to him,” Jim says. “But keeping my distance, or imposing boundaries on our relationship were never options for me. I wanted and needed to open my heart completely, to be there for him, unconditionally, no matter how painful it might be for me in the end.”

Jim and Rafael spent hours talking about the things that mattered to them: family, love, memories, fears, regrets, spiritual questions, pain, cancer, and death. One day as Jim helped Rafael to the bathroom, Rafael, overcome by the fear that he would soon die, asked, “Are you ready for this?” Jim replied, “What have I been telling you all along?”

Then says Jim, “He gave me a gift I will treasure until the day I die. He said, ‘A month ago I didn’t know you existed, but now you are my family.’”

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## Dying Caregivers

by Judith C. Hays, RN, Ph.D., Associate Research Professor, Department of Psychiatry and Behavioral Sciences, Duke University Medical Center

Odele M. is 54 years old and lives with her two sisters in the home of their mother, who has Parkinson's disease. Although she has her own bedroom, Odele says, "I only get to use it on weekends, because I have to spend the night with my mother in her room through the week. We need somebody to be there with her, to get up with her to go to the bathroom. It's working out okay." Odele, like one of her sisters, has survived a mastectomy and two rounds of chemotherapy. She now has advanced metastatic breast cancer.

Despite the extensive literature on death, dying, and caregiving, virtually nothing is known about the experiences of terminally ill caregivers. In theory, dying well involves continuing to contribute to the well-being of others and planning for dependents following death. Yet caregiving while dying is often neither acknowledged nor supported.

Who among us are caregivers? In one sense, we are all caregivers. In normal everyday activities we take care of family members and ourselves. We prepare meals. We put children to bed. We telephone Mother on Sunday.

There is also the special caregiving for persons with chronic illness. An estimated 7 million caregivers have some responsibility for chronically ill persons in the United States. They are primarily women, middle-aged, and married. Their tasks include carrying out prescribed regimens, preventing and managing medical crises, and controlling symptoms. They try to make life as normal as possible for all concerned.

These women wanted to make a lasting contribution to the emotional and physical needs of those left behind.

Caregivers of the chronically ill describe many problems, including the growing dependency of care recipients, lack of leisure and privacy for themselves, and disrupted routines and relationships.

When a caregiver herself is chronically — even fatally — ill, she must manage her own disease and the chronic illness of her family member. Not all chronic illnesses are so debilitating as to make this dual role impossible. In the case of metastatic breast cancer, for example, patients may be able to function virtually independently while suffering from a fatal illness.

### CARING FOR ONESELF AND OTHERS

I became interested in terminally ill caregivers while conducting interviews with 25 patients with Stage IV breast cancer. They ranged in age from 35 to 94 years. They included both African American and white women. About half were married.

One quarter had responsibility for the care of a frail or chronically ill adult — sometimes more than one. For example, Dorothy J. had recently returned to North Carolina to care for her widowed mother who was an amputee.

Her husband, an alcoholic, accompanied her in the move. She said,

"My husband took care of me and my mother when I was so sick. But as soon as I start to feel a little better, he'll go on a binge. It just turns him into a horrible person! Running in and out — staying out all night. I had to take out a special insurance policy in case he hurts somebody, and they put us both out on the street. He just gets so scared, you know, because he is so dependent on

me. Everybody tells him, 'You've leaned on her too much. And now, you don't know how to do it because you're afraid you might lose her.' "

Another 20 percent of the subjects had primary care of minor children, the youngest of whom was nine years old. Some of these women were married, but others were single parents. Barbara D., for example, was widowed 16 years ago with a three-month-old son. She said, "I just hate for my illness to interfere with (my son's) schoolwork, but I'm afraid it has. His junior year grades are poor, and they are so important to

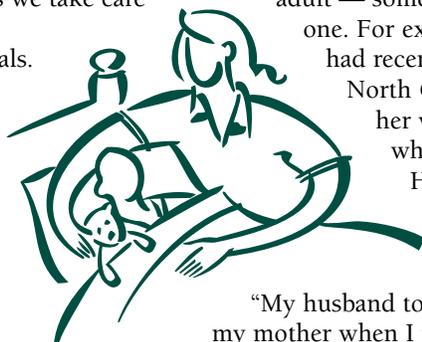
colleges. We have talked about boarding school, but he doesn't want to go, or to go live with my sister in Wilmington. He wants to stay here and graduate with his friends. That's why I kid with my oncologist. He just has to keep me alive two more years, at least!"

Of the remainder of the subjects in the study, one in five was faced with the challenge of providing for her own care without ongoing help from family or friends. Janine R. was one such patient. She was 63 years old, divorced, recently retired, and had no living children. She lived alone. "Who would take care of me is an issue. Because I don't have anyone that I could go live with, that would take me. I don't know what I'll do when I get to (the point of dependence), and I know I will. But I probably need to be thinking about it, making some arrangements. But I don't know what I'd do. I feel very insecure about the future because I don't know where I am going to go. I've always had a terrible fear of having to go into a nursing home. I'd rather just go ahead and die."

### A LASTING CONTRIBUTION

These breast-cancer patients not only took responsibility for their own self-care, the management of their own chronic illness, and care of dependent family members. They also reported

*Dying Caregivers continued on page F12*



## DYING CAREGIVERS

continued from page F11



Judith C. Hays, RN,  
Ph.D.

caring for pets and for the daily and crisis-related needs of friends and neighbors. They counseled and encouraged other patients brought to their attention by their doctors, and wrote letters and sent devotional material to

chronically ill celebrities they read about in the media. They contributed in numerous ways to the well-being of their physicians and nurses. They undertook projects to improve their environments, both interior spaces and the natural world.

The women were also particularly careful for their legacy, for making a lasting contribution to the emotional and physical needs of those left behind. Odele M. hoped her dying wouldn't be "a long, drawn-out painful process. And if it was, I just pray that I would have the grace to go through it, in a way that would not hurt anybody, you know? That's the thing that bothers me about this, is knowing that it will cause my mother and my daughter and my sons and my grandchildren to suffer. And I don't want to leave any bad feelings with anybody."

As I continue my work on caregiving and terminal illness, I am finding a number of urgent research questions. For example, we need to know, in more representative samples of caregivers, how many are terminally ill. We also need to find out how many caregivers there are in samples of patients dying of terminal illnesses other than breast cancer. Most importantly, we need to learn about the unique clinical needs of dying caregivers. Currently, we do not routinely address the extent of caregiving responsibilities or the emotional toll they take on terminally ill patients, but this is something we need to start doing.

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## Ambiguous Loss: Frozen Grief in the Wake of the WTC Catastrophe

by Pauline Boss, Ph.D., Professor of Family Social Science, University of Minnesota

On September 12, the day after the World Trade Center Towers collapsed, I received an anxious phone call from Lorraine Bellieu Fishman, a former student who had taken my seminar on family stress and ambiguous loss some two decades ago. She was calling from New York City. Her husband, Mike Fishman, president of the 70,000-member Local 32-BJ of the Service Employees International Union, had asked her to find help for his members and their families.

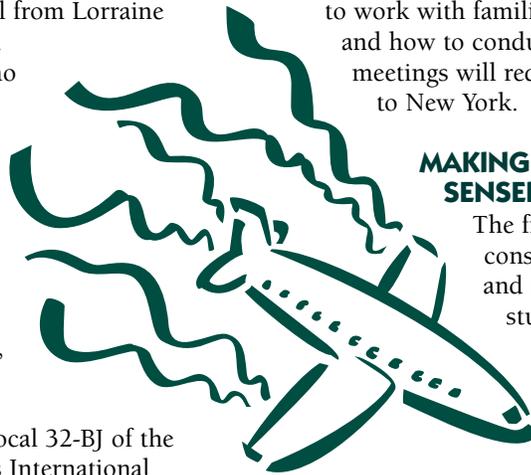
Members of the local include office and window cleaners, maintenance and security workers. Some 350 were working at the World Trade Center on the morning of September 11. Twenty-seven were still missing, and many were eyewitnesses to the attack.

I was not eager to get on a plane and head for New York, but I couldn't refuse. If years of academic work suddenly become useful to people who are trying to recover from an overwhelming crisis, then one has to respond.

I called Charles Figley, professor of social work at Florida State University and founder of the Green Cross Projects, to ask if he could arrange to send a group of certified traumatologists to New York. The Green Cross volunteers worked in the 32-BJ building for a month and were very helpful with the initial trauma work.

At the University of Minnesota, with funding obtained by the Dean of the College of Human Ecology, we organized teams of faculty and family-therapy interns who would fly to New York bi-weekly to do in-building and in-office counseling as well as family

meetings and training workshops on ambiguous loss for therapists. Our new emphasis on training therapists on how to work with families of the missing and how to conduct multiple family meetings will require further trips to New York.



### MAKING SENSE OF THE SENSELESS

The first team consisting of myself and two graduate students, Christine McGeorge and Tai Mendenhall, served from September 16 through 18.

Christine McGeorge and I returned to New York from September 26 through 29 with Dr. Elizabeth Wieling and two other graduate students, Beverly Wallace and John Beaton. A third team, led by Dr. William Turner and myself with graduate students Tai Mendenhall, Kristen Holm, and Jerica Berge, served from October 10 through 14.

The scene we encountered at ground zero was indescribable. The wreckage, the smell, the smoke — it was like entering an entirely different country. I could only think of the World War II movies I had seen as a teenager: utter destruction.

On our first trip, we mostly listened. When something senseless happens, people try to make sense of the event. They do this by telling their story. So we listened: in meetings, out in the hallway, on the run. We heard stories of guilt: some people were outside having a cigarette when it happened. Their friends inside didn't make it out of the building. We also heard many horror stories too terrible to repeat.

Over the course of our three visits, we organized and conducted "family meetings" with those in the union who have missing family members. In addition, we conducted a session of

*Ambiguous Loss continued on page F13*

**AMBIGUOUS LOSS** *continued from page F12*

“multiple family meetings” to connect families of missing persons with other families in the same situation — as well as with a therapist who speaks their language, since many families are Spanish-speaking.

**FACING AMBIGUOUS LOSS**

We also conducted a training workshop on ambiguous loss for 100 therapists from the Roberto Clemente Center, the Ackerman Institute of Family Therapy, the Institute of Contemporary Psychotherapy, and social workers from the New York City Central Union Council (AFL-CIO). They told us that this was a new and helpful way of working with families — especially after the events of September 11.

Just what is “ambiguous loss?” It’s a common reaction that occurs when loved ones are physically missing, but there is no verification that they are dead or alive. But it is also felt by many who fear that they have lost a terror-free way of life.

For most of the more than 4,000 missing, there will probably never be any tangible evidence of death. Even as Mayor Giuliani told New Yorkers that “all hope is not lost,” he cautioned them to “prepare for the worst.” The families of the missing are now struggling with “the worst.”

It is hard for the mind and heart to accept death without a body to touch. The absence of a body means that many of the usual ceremonies such as a funeral mass or sitting shiva will not be possible. The situation is very much like that faced by families of soldiers missing in action. They can’t start grieving because they don’t want to be disloyal — there’s always the possibility that the missing person may be wandering around somewhere in a daze. But many now choose to wait for a clear declaration of death through DNA verification.



**FROZEN GRIEF**

Sometimes ambiguity erodes the cognitive and emotional process that allows us to grieve fully and eventually begin coping. The result is “frozen grief.” Without a chance to participate in the rituals that normally bring comfort to bereaved individuals and families, people get emotionally stuck in

sadness and find it impossible to go on with their lives. They may become depressed or unable to make decisions, go to work, or perform daily tasks. This can happen even to strong and competent people.

They may begin to distrust their sanity because they feel so helpless. But in reality, it’s the situation that’s crazy, not the person.

Ultimately, the best way to live with ambiguous loss is to accept the situation, not to deny or avoid it. Immediately after the attack, it was reasonable for families to hope that their loved ones might be found, either living or dead. Years from now, this will no longer be reasonable. But if we are patient with these families now and support them in visible ways, they may more easily move to a resolution of their everlasting ambiguous loss, which will allow them to move on, even as they remember.

We therapists may have the most difficulty with ambiguous loss. Intolerance for ambiguity may be our problem, not the family’s.

**TAKING TIME**

But it is still too early to insist that such families “get over it” and come to “closure,” a word I have come to dislike. We have told families in New York to take the time they need to decide what to do and how to think of the missing person. It’s a message that seems to give them the greatest relief for right now.

At some point, most survivors will have to lean toward the decision that their loved ones are dead. For example,

when the city began issuing certificates of presumed death, Mayor Giuliani made sure that survivors received a small urn of ashes with each certificate. One family member was quoted as saying that he had chosen to believe his brother’s ashes were in that urn. This perception allowed him to move forward and begin coping with his loss. But thousands of death certificates still remain unclaimed because families are not yet ready to make that difficult decision.

Survivors can help themselves by asking whether the missing person would have wanted them to remain so sad or be unable to meet the everyday demands of life. In fact, it’s unlikely their loved one would have wanted them to cancel celebrations or close their eyes to the beauty of the world. Often when people are able to reframe the situation this way, they are able to move forward.

Family members deal with ambiguous loss each in their own way and according to their own personal timeline. This can create conflict when some members of the family are ready to accept the finality of the loss while others continue to hope. Family members need to be patient with each other. They need to realize that there

is no “uniform time” to decide that a loved one is truly dead and gone.

What I learned in New York is that we therapists often have the most problem tolerating ambiguity. It may be that we are the first who must learn this lesson: people take their own time in resolving an ambiguous loss. If we are uncomfortable with ambiguous loss — both our own and that of others — and if we push too soon for what is unfortunately believed to be “closure,” we may do more harm than good in our work with the families of the missing.

**NO ONE TO BLAME**

In these situations, there’s a natural tendency to place blame on a supervisor who insisted that men stay behind in the World Trade Center, on a coworker

*Ambiguous Loss continued on page F14*

**RESOURCES...  
continued from page 7**

end-of-life care, and provides easy to complete Advance Directives tailored to each state's legal requirements.

[www.partnershipforcaring.org](http://www.partnershipforcaring.org)

**Supportive Care for the Dying.**

This coalition representing health-care and Catholic organizations was founded in 1994 as a response to demand for legalized physician-assisted suicide. The site includes "tools for change," including a series of organizational assessment tools and questionnaires; back issues of Supportive Voice, a quarterly newsletter; and useful links and other resources.

[www.CareOfDying.org](http://www.CareOfDying.org)

**Who Gets Grandma's Yellow Pie Plate: A Guide to Passing on Personal Possessions.**

This site hosted by the University of Minnesota Extension Service provides practical information about the inheritance of personal property.

[www.yellowpieplate.umn.edu](http://www.yellowpieplate.umn.edu)

**AMBIGUOUS LOSS** *continued from page F13*

who asked for the morning off, or on a neighbor who is of the "wrong" ethnicity or religion.

Spouses may reproach themselves for encouraging their husband to take a job at a company in the World Trade Center or wish they had insisted their wife had taken a later train to work that morning. We talk with them about letting go of this kind of cause-and-effect thinking or self-blame. Sometimes bad things simply happen even to good people, and there's nothing we did to cause such tragedies.

**WHERE DO WE GO FROM HERE?**

My goal, from the moment I got that anxious phone call, was to connect New York City union members with family centers and therapists in the city who use a family systemic and contextual approach. Therapists also needed to be Spanish-speaking and culturally knowledgeable and to know how to work with families who have missing loved ones.

This has been done.

Where do we go from here? What is clear to me is that those of us who work in family therapy training programs have much to offer during this time of crisis and uncertainty. And I am more

convinced than ever from the feedback and the evaluations that the concept of ambiguous loss is useful to people from different classes, races, cultures, and religions as they struggle to recover and make meaning out of this terrible disaster and the continuing threat of terrorism with our borders.

Learning how to live with ambiguity may be one of the greatest challenges for Americans who are accustomed to quick fixes and the assurance of safety in everyday life. Yet there are some positive lessons to be learned from ambiguous loss. Such a loss can make us less dependent on stability and more comfortable with spontaneity and change. We can learn to let go and take the risk of moving forward, even when we don't know exactly where we're going. In a world of increasing uncertainty, this view may serve to decrease stress levels for many people.

*Pauline Boss is the author of Ambiguous Loss: Learning to Live with Unresolved Grief (Harvard University Press, 2000; also available in Spanish); and Family Stress Management: 2nd edition (Sage Publications, 2001). For more information, contact [pboss@che.umn.edu](mailto:pboss@che.umn.edu).*

**Coping with Ambiguous Loss**

Here are some suggestions we made to people with missing family members and to the therapists who will work with them:

- Gather as much information as possible. The posters lining the sidewalks of New York are a testimony to this search for information. Families also need information from FEMA as well as financial and insurance information. We need to help families find the right people to answer their questions.
- Talk to others about how you feel. To help people do this, we've organized family meetings, multiple family meetings, individual counseling, and religious meetings and counseling.
- Keep hoping, but at the same time, think about what to do if the missing person is never found. Dual thinking is encouraged because it allows for a glimmer of hope while at the same time reinforcing the thinking that leads toward a memorial service and resolution of some kind.
- While it's difficult to find meaning in this tragedy, keep talking with others about the stress of not knowing. Therapists can help families and couples if such conversations cause conflict. Family members will disagree with how they see the missing persons. Try to be tolerant of each other's views.

It's important for families — and the therapists who work with them — to understand that moving forward to a resolution doesn't mean closure. For most people there's never any real closure. Even with a "clear-cut" death, the door remains ajar. With an ambiguous loss, the door may stay wide open for a very long time.



—Pauline Boss

# Grief: Intimacy's Reflection

by Brian de Vries, Ph.D., Professor of Gerontology, San Francisco State University

Each year, over 8 million Americans experience the death of an immediate family member and many millions more experience the death of a member of their extended family, a lover, a friend, a companion animal, or another intimate. Individuals respond to these losses in ways reflecting the *nature* and *meaning* of their relationships as well as characteristics of both the grieving and bereaved individuals themselves. These responses reveal the intense emotional and cognitive efforts expended by the bereft as they cope with and try to make sense of their loss. As one researcher observed, grief “is the study of people and their most intimate relationships.”

Intimacy has both affective and cognitive dimensions that include giving and receiving assistance, physical contact, behavioral interactions, nurturance, and reassurances of worth. The intersection of grief and intimacy offers a unique opportunity to highlight the intimate components of grief in its broadest sense.

## THE DEATH OF A PARTNER

To be sure, the loss of companionship and romantic intimacy is an important aspect of loss and grief. But the loss of a spouse also means daily strains, such as doing the laundry or paying bills. The bereaved husband or wife must face daily tasks without the assistance of the deceased — repetitions that serve over long periods of time as reminders of what has been lost and what is missing. Expressions of stress, distress, and depression are the manifestations of these reminders.

Many individuals report ongoing communication with the deceased. This is not the stuff of séances or extra-sensory experiences; it is a sort of “checking in” and wondering what the deceased would think or do at a particular occasion. It is dreaming of the deceased and believing that they are

watching over the activities of the bereft.

Many caregivers say they miss providing care for their deceased loved one and feeling needed. Some researchers have described “role engulfment” in which the “selves” of bereaved caregivers become eclipsed by their caregiving role; after the death of their spouse or partner, they feel they no longer matter in someone’s life.

As one might expect, gender differences are evident. The kinkeeping role played by wives, combined with men’s greater likelihood of identifying their spouses as confidants

mean that bereaved husbands are often socially and emotionally vulnerable.

The effect of losing a husband appears more complex. Although some women, freed of the constraints of married life, blossom in their widowhood, many bereaved women express loneliness. They are “pining for lost lives”: their husband’s life and their own. Some widows, especially those of lower socio-economic status, “sanctify” their deceased husbands both to keep their connections to them and to bolster their own self-esteem. If a woman was married to a saint, she must have been worthy.

## THE DEATH OF A PARENT

It is estimated that each year, five percent of Americans lose a parent to death. The death of a parent in mid- or later life is an “on-time” loss, part of the natural order in which the old die before the young. The normative nature of this loss, however, does not diminish its impact.

The tie between parents and children spans the total life course and assumes multidimensional forms throughout. Death does not sever this tie. Some claim that the essential

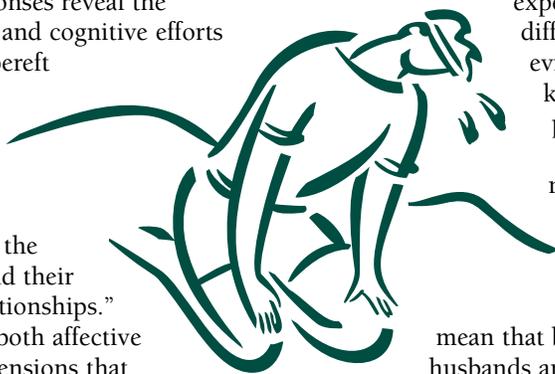
qualities of the relationship continue as children continue to look to the parent for direction and affirmation that they are fulfilling the parent’s expectations.

The pattern of grieving differs with the death of the first or the second parent. At the death of the first parent, condolences are expressed primarily to the remaining spouse. The adult children may feel left out. An adult child may then assume more of a caregiving role in relation to the surviving parent. At the death of the second parent, there may be a vivid re-experiencing of the impact of the first death. When both parents have died, adult children experience changes in self-perception and the meaning of time. The now orphaned children become the oldest living generation of the family, a role replete with new roles and responsibilities. There is no generational buffer between the surviving individual and death.

Sons and daughters respond to a parent’s death in ways anticipated by traditional gender roles: sons are somewhat more stoic and less expressive and daughters more connected to the deceased and more likely to report depressive symptoms. The research also suggests that the relationship between daughters and their fathers may be uniquely manifested in the bereavement process.

## THE DEATH OF A CHILD

Researchers and clinicians have frequently failed to acknowledge an adult as someone’s child and that the death of an adult child is a parent’s loss. Parents identify with their children; children represent extensions of parents, their hopes and dreams, and the selves the parents could not or did not achieve. A child’s death has been described by parents as an “amputation.” This amputation creates “an empty historical track” for many bereaved parents. For example, parents report that their now deceased child would have been married and have children of his or her own by now. The deceased child continues to occupy a part of the parents’ inner world.



# Working with Grieving Families from a Meaning-Making Perspective

by Janice Winchester Nadeau, Ph.D., Marriage and Family Therapist, Psychologist and Nurse in private practice at Minnesota Human Development Consultants, Minneapolis

**G**rief is a family affair. Most of what we know about grief is from an individual perspective. Much can be seen that is useful in understanding and helping those who grieve when grief is viewed through a family lens. My 25 years of working in the death and dying field have convinced me that the meanings families attach to the death of a family member significantly affect their grief.

Of particular interest to me is the process by which members interactively construct meaning. I call this process, “family meaning-making.” The family that construes a member’s death as a relief from pain will grieve differently from the family that construes the death as premature and preventable. Furthermore, when helpers pay attention to family meaning-making, they can determine if help is needed and, if so, how to tailor-make interventions. In order to make sense of the death of a family member, families use interactive strategies to construct meanings.

## STRATEGIES OF GRIEVING FAMILIES

The most common strategy families use to make sense of their loss is *telling the story* of how the death occurred. In our haste to move people toward a less painful place in their grieving, we may deny them one of the most powerful ways of making sense of their experience.

One elderly widow told the story of how her husband had died on the couch while she was in the kitchen making dinner. She noticed that he was quiet and ran to his side. Unable to find his pulse, she called 911. When the paramedics came, she stopped them from “ripping off his shirt and cutting him open.” She said the night before he had dreamed of his mother in heaven. The meanings in the widow’s story were that she had protected her husband from harm and that he had been ready to die. Some of her children, who did not talk

to others in the family, believed she had not called 911 or had called too late. Their disconnection hampered their family meaning-making.

Another strategy that families use is *coincidancing*, my term for the dance-like ways in which members use coincidental events to imbue the death with meaning. Most families *coincidence* and many family stories are built around coincidences. From the helpers’ perspective, the meanings assigned to the so-called coincidences are like family ink blots, revealing the intricate design of family meaning systems.

One family who lost an elderly member was concerned that it was raining as they drove to the gravesite. At the grave, the sun came out just long enough for them to complete their ritual. Once back in their cars, it began to rain again, and they began “coincidancing.” Why had the sun come out just then? Some said it was God. Others said it was Grandmother, herself. One son-in-law said, “It was a coincidence, and nothing more.” Family meanings were constructed as they talked over lunch.

Another common strategy is the *use of dreams*. Family members talk to each other about their dreams, and this fuels the family meaning-making machinery. Through recounting dreams, unpopular or secret meanings come out. Dream-sharing can provide ways of staying connected to the one who died and help resolve unfinished business.

Sally, a member of a family who lost a middle-aged member named Ann, shared a dream that included many of Ann’s eight siblings. Sally, who had never expected Ann to die, had been having trouble sleeping since Ann’s death. Sally told of how Ann had come to her in a dream. She let Sally know that she had found peace. After sharing the dream, Sally was able to sleep soundly. Asking about dreams is a meaning-making catalyst.

Families also *compare* the current



Janice Winchester Nadeau, Ph.D.

death with other deaths, as another strategy for making sense of their loss. Comparisons seem to help families establish themselves along a continuum of greater or lesser loss. Families who lose older members often

refer to losses of younger members of the family or of violent deaths of young people outside the family. They then construct the meaning that their loss could have been greater. Asking families how the loss of a particular family member compares to the loss of others can stimulate the family meaning-making process.

Finally, families make meaning by using *family-speak*. This includes asking each other questions, referring to each other’s meanings, agreeing, disagreeing, interrupting each other, and finishing each other’s sentences. Family-speak reveals meaning as the product of a family interactive process. When families use family-speak, the meanings are shared by all family members and do not originate with any one of them.

## MEANINGS OF DEATH

Many types of family meanings emerge after a death occurs. These may involve religious beliefs, fate, and reunions in the afterlife. Often meaning statements are about what the death does *not* mean. In one family a young father died in a private plane crash. Family members said his death did *not* mean that he had wanted to die. This allowed them to rule out suicide or having a secret death wish, as they put it. Many families say that the death was *not* God’s will. Listening carefully to *not* statements can help us track a family’s meaning-making journey.

*Grieving Families continued on page F17*

## GRIEVING FAMILIES *continued from page F16*

Another interesting group of meanings is *what the deceased would say his or her death meant*. These meanings are often guessed at and recited within the family. They may or may not bring comfort. One family's husband and father died suddenly in his sleep. His survivors found comfort from papers in his bureau giving direction to his family in case of his death, including scripture that indicated his belief in heaven. Meaning? He had anticipated his death even if they had not.

### HELPING FAMILIES

How can we help grieving families make sense of the death of a family member? First, listening is an intervention. Eliciting dreams, making comparisons among deaths, asking about coincidences, promoting family-speak, and validating meanings all go a long way toward helping families tell their story. It is important that helpers respect the family's own meaning-making process, rather than imposing his or her meanings upon the family. Working with

family meaning-making in this way allows helpers to enter the world of grieving families, to stand by them in moments of great pain, and to walk with them in their quest for meanings that help them go on living.

*Janice Nadeau is the author of Families Making Sense of Death, Sage, 1998. For more grief resources, visit her web site at [www.DrJaniceNadeau.com](http://www.DrJaniceNadeau.com) or contact her at [nadea007@gold.tc.umn.edu](mailto:nadea007@gold.tc.umn.edu).*

## INTIMACY'S REFLECTION *continued from page F15*

Society in general often does not appreciate the enormity of this loss. Well-intentioned friends and others may encourage the parents to "move on with their lives," avoid them altogether as if they were contagious in some way, or avoid mentioning the deceased child's name for fear of upsetting parents. The bereaved themselves may avoid new situations and interactions; they wonder how to answer the question, "How many children do you have?" without denying many years of an important relationship or exposing unsuspecting others to their tragedy.

Older mothers say their experience differentiates them from their husbands who could father other children if they chose; older fathers have reported on the futility of their hobbies, crafts, and skills because they can't pass them on. These gender differences, although smaller than those reported by younger parents, may complicate interactions between elderly partners. The symbolic presence of the deceased child and the intimate role the child has played in the lives of the bereft parents structures the social relationships and self-concepts of the parents and is the essence of their grief.

### THE DEATH OF A FRIEND

Older parents have been described as the forgotten grievers; friends of all ages may be described as the neglected or abandoned grievers. This inattention stands in dramatic contrast to the frequency with which this loss is

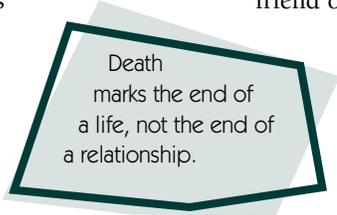
experienced. Each year from one-third to one-half of adults over 55 lose a close friend to death.

Friends assume their position in our lives by choice — theirs and ours — and friendships arise out of these shared values, interests, activities, and experiences. Because friends tend to be similar in gender, age, and socioeconomic standing, the death of a close friend may serve to confront individuals with their own mortality, evoking the fear that "it could have been me" and the relief that "it wasn't." The death of a friend means not only the loss of the relationship, one's role in it, and mattering to someone chosen as an intimate, but it also means the loss of an important basis of comparison and an important self-referent.

For the oldest old, the death of a friend is placed in the context of their history of loss and in the context of their life course. Many reported a profound sense of sorrow because they had outlived all that was important to them. One woman said she missed "not being necessary to anyone." Others made frequent reference to activities that they could no longer participate in. These included conversations, reminiscing, and attending church or social events.

The "role of bereaved" tends to be confined to family members. Friends are left to fend for themselves. Health-care

facilities, employers, and other social institutions often exclude friends during the dying process and grieving rituals. Understanding the ways in which individuals respond to the death of a friend offers a vehicle for understanding friendships in general, an individual's role in this context, and the intimacy that is a part of this experience and is continued in solitude by the bereft.



Death marks the end of a life, not the end of a relationship.

### RELATIONSHIPS CONTINUE

Death marks the end of a life, not the end of a relationship. The finality and unchanging nature of death must be seen in the context of the *ongoing* nature and the fluidity of *connections* with the deceased. In this perspective, grief is not only the response to what once was, it is also evidence of what persists. For those whose professional and personal practice brings them into contact with the bereaved — which by some accounts would be all of us all of the time — it is important to recognize these continuing bonds.

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# Traumatic Loss and the Family

by Kathleen R. Gilbert, Ph.D., CFLE, Associate Professor, Department of Applied Health Science, Indiana University

**O**n September 11, the United States experienced traumatic loss at a level that was, until then, unimaginable. The aftermath of traumatic loss is uniquely intense, putting incredible strain on the family. Yet, it is possible for families to experience such a loss and survive it intact.

## WHAT IS A TRAUMATIC LOSS?

A traumatic loss is one that is sudden, unanticipated, and outside the normal range of experience. These losses profoundly overwhelm the resources of the bereaved, leaving them feeling helpless. Grief that results from traumatic loss differs from “normal” grief in several ways: there is no time to anticipate the death; a generalized sense of horror, helplessness, and loss of control is ever-present for the bereaved; their lives feel disordered and disjointed, and they now see the world as a dangerous place. The process of resolving traumatic grief is almost guaranteed to be complicated and drawn-out. Resources available to the bereaved before the death may not be available: their social network may now be gone or reduced, and supporters may feel overwhelmed and inadequate to the task of helping. Tangible resources may be depleted. Their health may suffer as the stress of their grief impairs their immune system and causes other stress-related health problems to develop.

## FAMILY RELATIONSHIPS AND TRAUMATIC LOSS

When a crisis like a death occurs, the family is thrown into disorder. The family is disrupted and, in order to continue to function, must somehow regain some sort of stability while shifting the various responsibilities among the remaining family members. With a traumatic loss, family members need to answer questions as they attempt to make sense of the death. They may ask questions like: Why did it

happen? Why my loved one? How did it happen? What can I do to prevent it from happening again?

In less intense times, the family serves as a primary source of confirmation of the reality of the experience of its members. With a traumatic loss, family members may find themselves particularly in need of this form of family social support. Unfortunately, family members may be the people *least* capable of providing that support.

Families can experience traumatic loss and survive it intact.

## COMPLICATING FACTORS

Certain factors can confound the ability of family members to be available to each other. For example, the deaths that resulted from the terrorist attacks were violent and mutilating; most were out-of-sequence in the life cycle; they were ambiguous because few bodies were recovered; and the initiating agent was human-made and intentional.

In addition to contributing factors related to the death, other factors can complicate the grief resolution process within the family. These include:

- the relationship of family members with the deceased and any unresolved issues remaining after the death;
- the relationship between bereaved family members and the legacies of their past;
- the personal resources of the individual family members;
- resonating grief, that is, the tendency of one's expression of grief to “set off” other family members;
- competition in grieving;

- gender-based differences in grieving styles, and the expectation that everyone will grieve in an emotive and social way; and
- developmental differences in grief style, coupled with a lack of knowledge about what grief typically resembles at different developmental stages.

## DIFFERENTIAL GRIEF

The factors listed above contribute to a phenomenon I have identified as differential grief, in which family members are grieving in unique ways, at a unique pace, dealing with ideographic issues. Although family members may feel a sense of common purpose at the outset of the crisis, as they each struggle with their own loss, they find it increasingly difficult to “hang together” as they work through their grief. The interaction of these differences and related conflicts may come together to place tremendous strain on the family.



## FAMILY HEALING PROCESS

Given the fact that an identical experience of loss is highly unlikely, if not impossible, how then can grief be

resolved in the family? And how can the family remain intact after a traumatic death? Families must complete three essential tasks if they are to resolve their grief. First, they must recognize the loss and acknowledge the grief felt by all family members. Secondly, they must reorganize after the loss so that essential functions can be carried out. Lastly family members must reinvest in this new family, by working together to redefine what “family” now means.

In my work, I have found families use a number of “tools” to achieve these tasks:

*Traumatic Loss continued on page F19*

## TRAUMATIC LOSS

continued from page F18

- **Open and honest communication.** If grief is to be a collective experience, members must be able to communicate clearly with each other.



Kathleen R. Gilbert, Ph.D., CFLE

- Although it is difficult, family members must especially engage in the simple but difficult act of listening to each other. The process may be slow, though, as each family member has limited resources after a loss.
- **Shared rituals.** These facilitate the family healing process and can include funerals and religious rites, but should also include personal family rituals like shared dinners.
- **Shared sense of purpose.** This may consist of such things as family members spending time together or working together to achieve goals.
- **Acceptance of differences.** Rather than striving for a single view of the loss, or promoting a single style of grieving, family members need to recognize similarities in their grieving and to reframe differences as strengths.
- **Sensitivity to each other's needs.** Each member of the family experiences the loss in a unique way. When necessary, family members should be encouraged to seek out outside help through support groups or individual therapy.
- **A positive view.** Striving to see the best in oneself and other family members can help to buffer stress and make family members more receptive to each other's overtures.

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## Parent Grief

by Paul C. Rosenblatt, Ph.D., Professor, Department of Family Social Science, University of Minnesota

**O**n a hot summer day, Bobby, an adventurous three-year-old, kept returning to the most dangerous place on the farm. Mom, Dad, and Grandma repeatedly stopped him and warned him, but late in the afternoon Bobby eluded everybody and rode his trike to that one place where anyone's life would be in danger. Bobby died minutes after the ambulance brought him to the nearest trauma hospital.

### THE ISOLATION OF GRIEF

I interviewed Bobby's parents, Kris and Eric, six years after Bobby died. Kris said that she and Eric had never talked very much about the death and that as a result there was a big wall between them. Eric said he couldn't talk, because it hurt too much. During the first minutes of the interview they seemed to avoid looking at each other. But soon they were talking to each other much more than to me. They poured out their hearts, weeping, speaking of their pain, their self-blame, their loneliness, how much they missed Bobby, how hard everything had been since Bobby's death, and how much they hurt for each other.

I could say it was an easy interview. They had so much to say, they wanted to say it, and they were eloquent and nondefensive. I could also say it was an extraordinarily difficult interview. Their pain was intense, and they both wanted me to help them make this much more than a research interview, to create a place of safety where they could say all that they hadn't been able to say, and by doing so, destroy the wall between them.

Everything they said was unique to who they were and what had happened,

and yet there was much in the interview that echoed what I have heard from other bereaved parents I have interviewed as part of my research. Like many other bereaved parent couples, they felt isolated from one another. Their views differed about important things connected to the death. Their parenting of their other children was entangled in complicated ways with Bobby's death. They struggled to main-

tain a spiritual connection with Bobby, and they differed in how and when they grieved.

### COMMUNITY RESPONSE

Like lots of bereaved parents, Kris and Eric experienced an out-

pouring of community support at first, but soon the support dropped away. Some people avoided them, and some, perhaps not understanding that parent grief is often a lifetime thing, seemed impatient for them to get on with their lives.

At church, some people offered them religious formulas for dealing with grief. These formulas were not helpful, and, as a result, Eric decided to stop attending church. If you had been a

neighbor or someone at their church, I would have advised you to check in on Eric and Kris periodically and not to assume that you would know where they were in their grieving process. It would have

been best not to offer unsolicited advice, but instead to ask them, at a time and place that was appropriate, what was going on with them, and then to listen, really listen.

If you were a teacher or administrator at the junior high school attended by Eric, Jr., Bobby's oldest sibling, you would know that beginning about eight

In the grief following a child's death, parents and community members may take a new look at public services and policies.



# Dealing with the Violent Loss of a Child

by Carol Werlinich, Ph.D., Director, Family Service Center, University of Maryland, College Park

**T**he death of a child is traumatic, but the murder of a child is beyond endurance. The FBI estimates that an unbelievable average of 14 children are killed per day in the United States. Parents of Murdered Children (PMOC), a support group for families who have lost a child to murder, estimates that each homicide affects, at a minimum, seven to 10 people. The trauma of painful loss is exploding into the lives of more and more people. I studied the loss of a child to murder from a mother's perspective. What I learned may be of help to therapists who find themselves struggling with their clients' issues of death and loss.

## THE MOTHERS AND THEIR CHILDREN

I conducted extensive telephone interviews with 40 mothers of murdered children who live all across the United States. The participants also completed a battery of standard instruments that they mailed to me after the interview. The mothers who participated in this study were mature, averaging 53 years of age. Thirty-seven — 95 percent — were Caucasian. The marital status of these women (over two-thirds were married) had not changed since the murder. However, many women did report that the murder had seriously impacted their marriages, and some women expressed uncertainty about how, or if, the difficulties would ultimately be resolved.

Who were the murder victims? Fourteen daughters and 26 sons were the family members lost to violence. These children ranged in age from 14 to 38 years old, averaging 22 years of age. The causes of death were varied and often involved multiple weapons. Fourteen children had been killed by a

gun — this was the most common instrument of death.

The interviews included a description of the murder; experiences with the criminal justice system; questions about the grief process over time; information about family members and how each family member was affected by the murder from the mother's vantage point; the use, value, and timing of resources utilized by the family; and lastly, an exploration of the most and least helpful aspects of therapy for those who utilized this resource. These interviews were scheduled for one hour (and could have been completed in that time), but typically averaged over two hours in length.

What did I learn which might be of value for therapists? Certainly, data from the study support the idea that families of murdered children constitute an "at risk" group who have special needs in therapy. The salient messages these mothers reiterated focused on three general themes: listening, learning, and linking.

## THE IMPORTANCE OF LISTENING

In vehement and varied ways the mothers almost shouted a list of "don'ts":

- Don't try to fix it.
- Don't say you understand.
- Don't expect me to feel better; "it" gets "softer", not better.
- Don't *do* anything, but listen to my pain. Don't be afraid of it and don't rush me.
- Don't remind me that I have other children and family alive. I know that,

but no one can or should fill the spot of the one I have lost.

- Don't be shocked that I think long and seriously about suicide — not so much about doing it, but mostly I simply wish I weren't alive. Sometimes, even often, I am disappointed when I wake up in the morning that I must live another day.
- Don't be surprised that my husband or partner and I grieve differently or even that our marriage may be suffering. Did you know that folks often ask him how his wife is doing and seem to forget that he is suffering also?
- Don't be alarmed that I go to the cemetery often, or conversely, that I never go at all. Grief is expressed in a wide variety of ways.

## WHAT PROFESSIONALS NEED TO LEARN

- I'll size you up and decide if I can tell you any of these tough things — like that I have "visits" from or dreams of my dead child and this comforts me sometimes but also scares me, too.

These mothers expressed their desire to have someone benefit from their pain.

- Spirituality may bring me one of my few comforts, but I may also struggle with how such horrible things can be allowed by a benevolent God.

- I struggle with my anger, my fear of how ugly and painful my child's death was, my overwhelming sadness, my aloneness.
- I need to know I am not crazy. Therapists must understand the grieving process and validate the "normal" feelings of loss. Post-traumatic stress *response* (not *disorder*) is completely normal.

*Violent Loss continued on page F22*

**VIOLENT LOSS** *continued from page F20*

- I do not need the burden of teaching you, the professional. Learn about the important systems that I will have to navigate, such as, the court and parole systems, victims assistance programs, and other federal and state initiatives.
- I need professionals to be familiar with and suggest (but never impose) reading materials or varied resources which might be helpful at different times in the grieving process for different family members.

**THE NEED FOR LINKAGES**

- Link families to self-help groups such

as Parents of Murdered Children and Compassionate Friends. Attend meetings of the varied support groups yourself; therapists who have first-hand experience will have the greatest credibility.

- Take care of yourself: get yourself a support group and talk over your own experiences regularly. If you cry excessively in sessions, I will have to stop my grieving to take care of you.

Intuitively, we all know that the murder of a child is the most horrible of all losses. It has been said that losing a

parent is losing your past, while losing a child is losing your future. The mothers I interviewed expressed their desire to have someone benefit from their pain; that was one of the reasons they agreed to participate in the study. Their message was clear: expect diversity in dealing with loss and know that the process is a never-ending journey. They have taught me a great deal about catastrophic loss and the place of therapy in the struggle.

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**PARENT GRIEF** *continued from page F19*

months after the death, Eric, Jr., got into a lot of trouble. He was truant, fought with other students, and lost interest in schoolwork. Eric, Jr., was lucky to be going to a school where the counselor knew something about grief and was comfortable talking with grieving teenagers. The counselor helped Eric, Jr., to turn things around for himself. The counselor also helped Eric's parents to understand what was going on with their son, and to think about ways to help him.

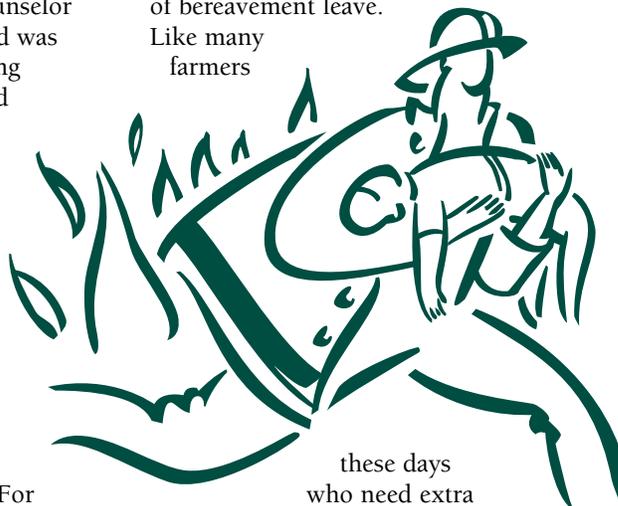
**PUBLIC SERVICE AND POLICIES**

In the grief following a child's death, parents and community members may take a new look at public services and policies. For Billy's father, his son's death said lots about emergency care in rural areas. Perhaps Billy would have died anyhow, but it took close to an hour from the time Billy was injured to the time he was brought to the closest trauma hospital. The doctor on duty was a new resident, relatively new to trauma care and so new to the hospital that he didn't even know what supplies were on hand. Perhaps with different public investments, Billy could have arrived at the hospital more quickly and have been seen by a doctor more experienced at

trauma care and more knowledgeable about the hospital's resources.

The couple's grieving process was also affected by a lack of bereavement leave.

Like many farmers



these days who need extra income to make ends meet, Eric had a full-time off-farm job. Most workers have at least some sick leave, but few employers offer their workers adequate bereavement leave. Eric's employer offered only enough bereavement leave so Eric could attend his son's funeral. The day after Billy was buried, Eric was back at work. His job involved considerable physical danger, and Eric felt that he was a danger to himself and his coworkers for quite a while after he returned to work. Kris felt that she and Eric might have been able

to talk if he had been able to stay close to home in the weeks following Billy's death. But his need to go back to work set up a pattern of not talking that resulted in the wall that separated them.

Finally, the couple was affected by the limitations of their health insurance coverage. Although Eric and Kris had good medical insurance through Eric's employer, the insurance plan offered no coverage for bereavement counseling. The nearest support group for bereaved parents was 45 minutes away, and it met during a time Eric had to milk the cows. The school counselor had some expertise in dealing with grieving teenagers, but dealing with grieving parents and families wasn't part of his job. The couple's pastor was unhelpful. Practically speaking, the couple had nowhere to turn for bereavement help. For six years they had been terribly distant from each other. The obvious policy question is: When and how will bereavement care be provided — for individuals, for couples, for families?

*Paul Rosenblatt is the author of Help Your Marriage Survive the Death of a Child and Parent Grief: Narratives of Loss and Relationship. For more information contact him at prosenbl@tc.umn.edu.*

# Helping Adolescents Cope with Grief

by Joyce A. Shriner, M.S., CFLE, Family and Consumer Sciences Agent, Hocking County, Ohio State University Extension; and Ted G. Futris, Ph.D., CFLE, Family Life Extension State Specialist and Assistant Professor, Dept. of Human Development and Family Science, The Ohio State University

**B**ecause they are often unexpected and traumatic, adolescent deaths profoundly impact communities.

With the increase in school shootings and youth violence, there is a growing need for communities to develop and implement a response plan when traumatic deaths occur. Yet survivors reports that school

personnel, such as teachers, counselors, and nurses are often not supportive. Here are some ways that schools, community professionals, and youth leaders can ease the trauma during future crises.



Joyce A. Shriner, M.S.,  
CFLE

## DEVELOP A COMMUNITY-BASED RESPONSE PLAN

Community-based response plans can minimize the negative effects of crises and enhance the opportunities for positive growth.

Ted G. Futris, Ph.D.,  
CFLE

Typically, school personnel, community leaders, media contacts, and family representatives work together to create a plan. Most plans involve preparation, team-building, training, and long-term follow-up so that all members of the community-response team understand their specific responsibility during a crisis.

## REASSURE ADOLESCENTS THAT GRIEF IS A UNIQUE EXPERIENCE

Adolescents often believe that their grief is unique and incomprehensible to anyone else. Some may find themselves reacting in new or unusual ways, which frightens them, causing them to think that their reactions are abnormal. Others

may limit their expressions of grief to brief outbursts because they are very concerned about how they are perceived by others, and they worry about losing emotional control. Caring adults can reassure adolescents that grief is a unique experience for everyone and that what they are going through is normal.

## ENCOURAGE RELATIONSHIP TRANSFORMATION

Encourage survivors to maintain an attachment to the deceased. Some of the ways that adolescents preserve the bond between the deceased and themselves include visiting the cemetery, believing in a spiritual realm, praying or talking with the deceased, keeping possessions that the deceased valued, or placing items representing things the deceased valued (such as pictures, notes, sports equipment, favorite hat, or class ring) in the casket. Adults can affirm the value of these behaviors and help adolescents place their relationship with the deceased in a new perspective.

## FACILITATE COMMUNICATION

Adults may suggest creative ways to

facilitate communication about the loss, memorializing the deceased, encouraging expression of grief, and achieving a sense of closure for the adolescents. Suggestions include creating a memory book, cards, or collages; collecting letters or assignments written by or to the teen; displaying a memorial plaque; or planting a memorial tree or garden in the teen's name. At school, teachers can help classmates make decisions about what to do with the empty chair in the classroom. Involvement in activities such as these provides healing for the adolescents, as well as the family.

While most memorial activities are truly beneficial, care should be taken to avoid overdramatization or glorification, especially in the case of suicide. Appropriate activities in this situation include raising funds to support a worthy cause, contributing to a suicide prevention program, or donating to a mental health project.

## PROVIDE APPROPRIATE SUPPORT

Not surprisingly, most adolescents do not want to discuss their feelings of grief with school personnel. They do, however,

*Helping Adolescents continued on page F23*

## Learn How You Can Help

Here's a list of organizations that can provide information and resources for adults who want to help grieving children and teens.

**American Academy of Child & Adolescent Psychiatry** provides resources for parents and teens. [www.aacap.org](http://www.aacap.org)

**Center for Mental Health Services** has a clearinghouse for mental health information in English and Spanish for families, children, and adolescents. [www.mentalhealth.org/child](http://www.mentalhealth.org/child)

**Dougy Center, The National Center for Grieving Children and Families** is a national support center. [www.dougy.org](http://www.dougy.org)

**GriefNet** offers 30 e-mail support groups and two web sites. It includes a moderated chat room for children who are in grief and their parents, lists of books, newsletters, a directory of suicide prevention and survivors' information, and more. [www.griefnet.org](http://www.griefnet.org)

**UCLA School Mental Health Project** provides schools and teachers with resources for helping children. <http://smhp.psych.ucla.edu>



## Elder Grief

by Felix M. Berardo, Ph.D., Professor of Sociology, University of Florida, Gainesville

For most of us, recovering from a significant emotional loss is a difficult task. This is particularly true for those who have entered the later stages of the life-cycle. It is especially



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difficult for older persons who, having spent decades in intimate association with a spouse or significant other, to deal with the loss of that partner.

### WIDOWHOOD

The death of a partner requires the development of alternative patterns of behavior if the surviving spouse and other members of the family are to maintain satisfactory relations within the family, with the kin group, and with

the community. These new patterns of behavior are critical to sustain personal equilibrium. Roles must reassigned, status positions shifted, and values reoriented.

It is important not to underestimate the complexity of loss events and the contexts in which they occur, as well as their historical antecedents. The loss of a spouse may or may not mean the loss of a sexual partner, companion, accountant, or gardener, depending on the roles the spouse fulfilled. If the spouse was the "designated driver," the newly widowed person may have to begin using public transportation or taking a cab. If the deceased husband or wife was a caregiver, the remaining partner may need to sell the house and move to different environment, such as senior housing, assisted living, a nursing home, or the home of an adult child. In some cases, a husband's pension may die with him, forcing the widow to adopt a

far more frugal life-style.

For some widowed persons, the emotional burden of acute sorrow becomes unbearable, and they may feel compelled to resort to escape mechanisms, such as fainting, excessive drinking, or medication. Others may breathe a sigh of relief because a bitter or disharmonious marital relationship has finally been dissolved, or because a loved one has at last been freed from pain and suffering. In many instances, it is only when the deceased is finally buried that disbelief fades and the reality of the circumstances emerges and is gradually accepted.

Death dramatically terminates habitual family relationships, but mental acceptance of its finality usually comes slowly. Habitual responses built up through a long period of intimate interaction and interdependence in family living are not quickly nor easily extinguished.

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appreciate being put in contact with an understanding peer. Adolescents rely on peers for emotional support (for example, being there, listening, or reminiscing) and for clues in how to respond to each other.

To support the bereaved, adults can talk with the bereaved student's peers and stress the fact that their friend needs their help and that he or she would likely appreciate them asking what it is like to lose someone close. Adults can also let peers know that retelling the story often helps the bereaved to begin to make sense out of what has happened to them.

Because such conversations are often painful for the bereaved, they should be initiated only if one is able to deal with the teenager's reaction.

It is also important for adults to be familiar with the deceased's background. Then they can help teach proper funeral home and family visitation etiquette as well as culturally appropriate practices. One researcher notes that "It is helpful to the family and to the students if a few

school personnel are present at family visitations and funerals. Teenagers often attend these services without parental support and may need the support of a familiar adult." Adolescents also appreciate tangible support from adults such as flowers, cards, food, transportation, or funeral home visits.

### DO NO HARM

Researchers have learned that the bereaved are offended and hurt by some support attempts. Behaviors that are considered unhelpful include saying, "I know how you feel," encouraging a speedy recovery, giving advice, minimizing the loss or forcing cheerfulness, and intentionally avoiding the use of the deceased's name. Failing to acknowledge that the death has occurred can also be offensive and hurtful.

*For information or to request a copy of the curriculum "Helping Adolescents Cope with Grief," contact [shriner.3@osu](mailto:shriner.3@osu).*

### Book Helps Grieving Children



Jacqueline Britton has

written a book to help children cope with grief. The main character is Herman, the hermit crab, who travels through time and meets a little boy whose grandmother has died. The book's message is that children have a right to cry, that they will feel lonely, but that someday they will feel better. The book, **Herman and the Boat**, is the second in Britton's Herman the Hermit Crab series. It will be available online this spring through [Synergebooks.com](http://Synergebooks.com).

Britton is a senior a California State University, Sacramento, where she is majoring in history and ethnic studies. She is president of the campus Inter-Tribal Student Alliance. Contact her at [claywoman55@yahoo.com](mailto:claywoman55@yahoo.com).

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The widowed show considerable variation in concluding their grief work, some doing so within months, others sometimes taking years to adapt to life without their mate. A small minority of elders never do get over the trauma of their loss. With help, however, most eventually adapt to their new circumstances, are able to manage their daily lives, and maintain a sense of purpose and personal satisfaction.

**AMBIGUOUS LOSS**

As Pauline Boss has pointed out, unresolved grief — that is, grief that cannot easily be brought to closure — is often associated with ambiguous loss. This results from a wide range of situations in which an incomplete or uncertain loss has the effect of freezing the grief process and thereby preventing its completion. One example of this is the anguish suffered by families of soldiers missing in action. Ambiguous losses in personal relationships can be more stressful or devastating than a clear-cut loss through death.

Many older people experience ambiguous loss when a husband or wife develops Alzheimer's disease or another form of dementia. Although they are still married to a living spouse, that person slowly slips away until he or she no longer exists. In a sense, their spouse is both dead and alive, and they are both widowed and married.

**BEREAVEMENT OVERLOAD**

Extreme grief behavior among some older people may come from having to deal with a succession of bereavements, sometimes in overlapping time frames, which may interfere with the completion of the mourning process. The

successive demise of an older person's friends and loved ones is often accompanied by various personal, physical, mental, social, and economic losses as well. Many older people find themselves overwhelmed.

Researchers have suggested that many negative behaviors we associate with old age are the result of "bereavement overload." Many older people are already experiencing personal, physical losses such as impaired vision or hearing, limited mobility, or stroke-induced problems with speaking or reading. On top of that, they experience multiple bereavements as spouses, friends, neighbors, and sometimes even adult children die in rapid succession.

It becomes increasingly difficult for older persons to respond fully to new deaths while they are still emotionally involved with previous deaths. Individuals living in long-term care may resist making new friends since "they're just going to die anyway."

**CONCENTRATED LOSSES**

Loss in modern society has been increasingly concentrated in the later stages of the life cycle. This means that older survivors, in particular, are left with a limited supply of time, energy, and opportunities to establish new and meaningful emotional attachments. Older caregivers may face isolation and depression because they are always "on duty."

Emotional and behavioral responses reflect each person's idiosyncratic circumstances and contingencies. The

result is often highly individualistic reactions to the actual death of spouses, relatives, and friends, or their "living death" as a result of Alzheimer's disease or dementia. Some variability in grief responses can be attributed to

personal resources or qualities that make coping easier, such as good health, sufficient financial resources, or a sense of optimism and self-efficacy. Grief can be exacerbated if additional loved one die or become incapacitated, thereby requiring simultaneous grieving.

The extent to which others can provide assistance to the bereaved can influence the pattern of recovery. Available confidants and access to self-help groups can help counter loneliness, promote the survivor's reintegration efforts, or help a caregiving spouse cope with the ambiguous loss of a loved one with dementia. Community programs that offer education, counseling, and financial services can also help widowed elders and their families to restructure their lives. Programs that provide respite care for fragile elders or those suffering from dementia can help caregivers experience a few hours of "rest and recreation," including time to see friends, do errands, take a walk, or visit the doctor or dentist.

To be most effective, such services should remain available over long periods of time. As the population ages, services of this kind will become even more important for elders and their families.

*For more information, contact [jberardo@soc.usf.edu](mailto:jberardo@soc.usf.edu).*

Many negative behaviors associated with old age are the result of "bereavement overload."

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