Grief: A Companion on an Uncertain Journey

Kenneth J. Doka
College of New Rochelle, kdoka@cnr.edu

Follow this and additional works at: http://digitalcommons.cnr.edu/facpubs

Part of the Gerontology Commons

Recommended Citation

This Book Chapter is brought to you for free and open access by Digital Commons @ CNR. It has been accepted for inclusion in Faculty Publications by an authorized administrator of Digital Commons @ CNR. For more information, please contact lfazzino@cnr.edu.
Grief, the constant yet hidden companion of Alzheimer’s disease and related dementias, can first arise with the realization that recent symptoms are \textit{not} a normal part of aging and that something is wrong, or in the physician’s office when a diagnosis is confirmed. Grief certainly will be experienced by family members as well, continuing as they view the slow deterioration in memory and the being of the person they love gradually slip away. The grief will increase as family members see a stranger emerge; a stranger who needs unceasing care, yet cannot recognize the caregiver. And grief will continue after the death, complicated by feelings that emerged over years, if not a decade, of caregiving. These feelings emanate from the family caregivers’s own sense of losing someone they love who is still alive, guilt about decisions, and, perhaps, troubling feelings of relief and emancipation at the death. The grief may even be shared by professional caregivers who, in moments of intimate care, bonded with the individual with late-stage dementia as family members were already grieving the loss of the person they once knew.

This chapter considers issues of grief that arise in dementia. It begins by exploring ways that individuals with dementia grieve the reality of the advancing illness as well as how they grieve other losses encountered during their journey with dementia. The chapter then considers the grief of family members. The final section addresses clinical implications, noting ways that clinicians can assist grieving individuals, whether the person with dementia, a family caregiver, or a healthcare professional.
KENNETH J. DOKA

GRIEF AND THE PERSON WITH DEMENTIA

Anticipatory mourning in the course of dementia

Therese Rando (1986, 2000) reminds us that the term anticipatory grief, or as she prefers, anticipatory mourning, is paradoxically misunderstood yet useful. The misunderstanding comes when the term is seen simply as a reaction to an anticipated or future loss, where the concept of anticipatory mourning is limited to describing only how an individual reacts to the foreknowledge of an impending loss.

To Rando (2000), the term anticipatory mourning is useful when broadly referring to the reaction and response to all losses encountered in the past, present, or future of a life-threatening illness. These losses, and the grief reactions they evoke, are part of the daily experience of both those living with the disease as well as their family and caregiver.

These losses can be profound. First, there is the very real loss of the past; as one ceases to remember, links to the past are severed. One individual with dementia poignantly expressed this type of loss to his physician by crying out, “I used to remember!” as he struggled to recount an incident from childhood.

The deterioration of memory also affects the present. Memory links a person to another, allowing the ability to recall shared relationships and histories. Those with dementia eventually can no longer remember individuals around them, or are unable to recall or express relationships. For example, one woman with Alzheimer’s disease had long been close with her daughter-in-law. Yet, as the disease progressed, she could only express the relationship as “the woman who married my son.” This term caused a great deal of grief for the younger woman, as it seemingly invalidated what had been a long, positive relationship.

As memory lapses, other losses follow. One may no longer be able to function effectively in other roles; work and cherished activities may have to be relinquished. Couples frequently have to renegotiate their roles as progressive memory losses unfold (Robinson, Clare, & Evans, 2005). In addition, other relationships will change. The person with dementia and the family will need to decide how and to whom they will disclose the diagnosis. Some families begin to withdraw or isolate themselves from others (Robinson, Clare, & Evans, 2005). In the early stages of dementia, both the person with dementia and the family may experience these losses, but as the disease progresses, individuals with dementia often lose the ability to recognize loss and grief. The sense
of specific loss and cognitive deterioration may be replaced by a vague feeling that something is wrong. This generalized sense may manifest in behaviors that evidence inner pain, such as agitation; as cognition declines, feelings and states of emotional stress remain (Rando, 1993).

Eventually, the individual with dementia may experience *psychological death* or the loss of individual consciousness. The person ceases to be aware of self. “Not only does he not know who he is—he does not know that he is” (Kalish, 1966, p. 247). Of course, others can only infer this state.

**Experiencing grief**

Even as individuals struggle with dementia, they may experience additional significant losses apart from the illness. Loved ones, such as spouses or siblings, may become ill, be hospitalized or institutionalized, or die.

The question is whether or not to inform the individual with dementia that a loss has occurred. We sometimes think that such information is an inherent right in relationships. Yet, to a person with dementia, this information may simply add pain or confusion. Individual cognitive functioning and social support need to be taken into account. Will the individual with dementia know that others are sad and grieving? Will the individual with dementia notice the absence of the person? When the loss is due to death, it may be better to spare the individual with dementia any additional grief if the deceased was not part of his or her daily life.

If the individual with dementia is to be informed of the loss, it should occur when the individual is rested and functioning well; generally, in the morning or after a good sleep. The news should be shared by a familiar, supportive person who will remain for whatever time is needed so the individual with dementia can process the information as much as capable without feeling abandoned.

Persons with dementia may be unable to retain the information that an individual has died. They may ask repeatedly what has occurred to that person and seemingly mourn the loss, only to reiterate the question later. In such cases, caregivers should acknowledge their own frustration and be reassured that such behaviors are normal in the disease and not indications of an inadequacy of explanations. One technique that can be useful is to return to a picture or memory each time the person with dementia questions the loss or expresses a sense
of grief. Speaking of the person who has died in the past tense may also be helpful.

Unfortunately, there is little research that considers how an individual with dementia copes with loss. Persons with dementia may confuse the present loss with earlier losses. Herrmann and Grek (1988) documented two cases where bereaved spouses with dementia retained a delusional belief that a parent, rather than a spouse, had died. Rando (1993) emphasizes that the loss of cognition should not be compared with the absence of emotion. Grief in dementia may be evident in changes in behaviors as well as unusual or increased manifestations or even agitation or restlessness.

Expression of grief by an individual with dementia can be affected by a variety of factors, including the extent of disease and loss of awareness, certainty and immediacy of the lost relationship, and the ability to communicate the loss. It is critical to be sensitive to the loss; it has even been hypothesized that significant losses, as well as the inherent changes that occur as a secondary effect of loss, may exacerbate the dementia (Rando, 1993; Kastenbaum, 1969).

In dealing with losses experienced by persons with dementia, consider assuming an experimental ethos, constantly assessing what works best with a given individual at a particular time. Ritual and reminiscing about the person who died may be helpful; Lewis and Trzinski (2006) suggest two techniques that might facilitate processing. In spaced retrieval, new information is shared and then asked to be recalled over increasing intervals. In group buddies, an application of play therapy, the individual is given a stuffed animal to bring to a support group to "watch and learn." Clients then process information with their "buddies" following the group meetings. While both techniques may be helpful, ongoing assessment is essential to see if or how well they assist each person responding to loss.

Given the individuality of persons with dementia and varying cognitive functioning, there is no single approach that is universally applicable. For one person with dementia, keeping a photograph of the deceased to refer to whenever he or she asks about the individual can serve as a gentle reminder of the loss. For another person with dementia, removing the photograph may prevent repetitive questions and ongoing distress.
GRIEF AND FAMILY CAREGIVERS

During the illness

The concept of anticipatory mourning encompasses families of individuals with dementia as well. The losses the family experiences, and the grief engendered by these losses, will become more profound as the individual with dementia deteriorates (Ponder & Pomeroy, 1996; Meuser & Marwit, 2001). Families may perceive this as an ambiguous loss; the person is still alive but now changed (Boss, 2010). Here, families experience a deep sense of psychosocial loss; the persona of the person, or the psychological essence of individual personality, is perceived as lost although the person remains physically alive. The sense of individual identity has so changed that family members experience the death of the person who once was (Doka & Aber, 2002). Spouses may become cryptowidows, married in name but not in fact, and grieve losses associated with that role, such as intimacy, companionship, and sexuality (Doka & Aber, 2002; Teri & Reifler, 1986).

The very experience of caregiving may complicate grief. As caregivers, individuals may experience secondary losses such as social and recreational roles, work roles, and relationships with others. The increased demands of caring for someone with a progressive illness, and the experience of psychosocial loss and possibly secondary losses, may generate an unceasing state of grief, sometimes identified as chronic sorrow (Roos, 2002; Mayer, 2001; Burke, Hainsworth, Eakes & Lindgren, 1992; Loos & Bowd, 1997) and reactive depression (Walker & Pomeroy, 1996).

For many family caregivers, the decision to place their loved one with dementia in a facility can complicate grieving. Reactions to the loss generated by institutionalization can include responses such as relief, guilt, and failure. Professional caregivers can assist early in the process by encouraging families to “draw a line in the sand” by defining in advance when taking care of the person at home will become too difficult. Such a question plants a seed that future institutionalization may be unavoidable as their loved one’s condition continues to deteriorate. Most families generally go beyond what they initially believed was possible; this “delayed” institutionalization is seen as a success rather than failure. Professional caregivers can also help families redefine their caregiving role after institutionalization; they are still caregivers, but their role changes from provider of direct
care to that of advocate. There may be other decisions, too, that will generate guilt and complicate grief. Moreover, the long-term effects of caregiving can diminish coping abilities, and the constant demands of care may limit social support (Bodnar & Kiecolt-Glaser, 1994).

Dementia also affects caregiver grief in another way. As individuals with dementia deteriorate, their ability to monitor and regulate their behavior diminishes. Some exhibit a range of unusual behaviors such as using foul language or indecent and inappropriate actions. They may relive earlier traumas. For example, some Holocaust survivors experiencing the symptoms of Alzheimer’s disease began to hoard food, experience troubling flashbacks, or have a heightened sense of anxiety (McCann, 2003). People with dementia may express attitudes that were once self-censored, such as engaging in racial or personal diatribes. These behaviors can humiliate, embarrass, and isolate caregivers, increasing ambivalence and discomfort that subsequently complicates grief.

**Grief at the time of death**

When the person with dementia dies, grief changes focus. Some people experience a *liberating loss* (Jones & Martinson, 1992; Elison & McGonigle, 2003), characterized by feelings of relief and emancipation that caregiving responsibilities and suffering by both the patient and family have ended.

Some may actually grieve the loss of the caregiving role, and feel a lack of focus and meaninglessness in their activities. For some, these feelings are accompanied by guilt and sadness. Survivors may reminisce about the caregiving experience, reflecting on times that they might have shown more patience or empathy. They might believe that there was more that they could have done, or regret hurtful things that were said. Such memories, while common and understandable, are related to greater depression, stress, and social isolation (Bodnar & Kiecolt-Glaser, 1994).

This grief may not only be manifested in affect, but in cognition, behavior, and spirituality. It may be experienced physically; health consequences do not end with the change in the caregiving role. In fact, increased medical symptoms in caregivers are associated with transitions from this role, such as nursing home placement or death of the person with Alzheimer’s disease (Grant, Adler, Patterson, Dimsdale, Ziegler, & Irwin, 2002).
Others may disenfranchise the grief that caregivers and people with dementia experience. *Disenfranchised grief* refers to losses that are not appreciated by others. The individual has no perceived “right” to mourn; the loss is not openly acknowledged or socially sanctioned and publicly shared. Others simply do not understand why this loss is mourned and may fail to validate and support grief (Doka, 1989, 2002).

Grief resulting from the death of a person with dementia can be disenfranchised for a number of reasons. Often, the person with Alzheimer’s disease or another dementia is devalued; he or she is seen as old, confused, or burdensome. Death may be seen as a release for both the caregiver and the person who died, or survivors may be expected to have grieved already in the course of the illness. Even customary statements of sympathy and support may be tinged with ambivalent sentiments like, “This is a blessing,” or “It must be a great relief,” without understanding the impact of the loss and the depth of survivors’ grief. A wide range of factors, including the circumstances surrounding the loss, past coping capacities and grieving styles, as well as other social and psychological variables, will affect the nature and extent of grief (Worden, 2009; Rando, 1993; Martin & Doka, 2000). Ethnicity and culture certainly play a role. For example, Owen, Goode, and Haley (2001) found that African-American caregivers, when compared to white caregivers, were more likely to experience higher levels of grief.

Other research has noted that manifestations of grief were different between those whose partner with dementia was maintained at home compared to those who placed their partner in a nursing home. Those who provided care in the home reported exhaustion, stress, anxiety, and anger; partners of individuals placed in nursing homes indicated higher levels of guilt and sadness (Rudd, Viney, & Presten, 1999; Collins, Liken, King, & Kokinakis, 1993).

While many influences can mediate the experience of grief, one fact remains: grief is a constant companion to Alzheimer’s disease and dementia up to and following death. The goal of support is to acknowledge and validate the loss—to enfranchise grief.

**Grief and professional caregivers**

Grief is not based solely on familial ties; grief is based on attachment. It is not unusual for professional caregivers to become attached to their patients, and thus experience grief. This grief can be particularly
intense among caregivers likely to be more involved in the daily care of the patient, such as home health aides or nursing assistants.

This reality can create a paradoxical situation. As family members grieve the loss of the individual they once knew, aides or other professional caregivers become attached to the person with dementia they see today. This can cause certain ethical quandaries. In one situation, a well-known and respected attorney and judge was institutionalized in the final stage of dementia. Her family deeply grieved the loss of a brilliant woman and devoted mother. Yet, as her dementia progressed, she thought every staff member in the facility was family and treated them as such, kissing and thanking them for every kindness. The staff grew to love her. Her advance directives were written with great clarity, indicating her wish not to be treated for certain conditions as she entered the end-stage of Alzheimer's disease, so when she developed pneumonia, the ethics committee of the facility and her family agreed that the advance directives should be honored, but the staff was demoralized by her death (Doka, 1994).

Enfranchising grief

In validating grief, it is critical to revisit two points: grief is experienced in varying ways by the person with dementia, the family and professional caregivers; grief is encountered throughout the illness as well as after the death. Thus, assistance and support should be offered to all involved both during the illness and following death.

Two considerations are essential in offering support to persons with dementia: validation and control. When an individual is diagnosed with dementia, his or her anxiety, anger, or other manifestations of grief may be discounted and denied. Often, this is done to protect the person by offering glib reassurance that everything is fine, even when the individual with dementia is aware and fearful of manifestations of the disease.

This response is unhelpful. Persons in the early stages of dementia have very clear awareness of the symptoms of decline; even later in the illness, individuals may have vague feelings of loss of certain capabilities. Empathetic listening, expressions of support, reassuring remembrance that reaffirms relationships, and, when appropriate, physical touch, can validate and show support.

Another way to respect an individual with dementia is by helping him or her retain a sense of control. An individual feeling abilities slip away may be determined to maintain as much control of the
environment as possible. In the early stages of dementia, there may be expressions of anticipatory bereavement (Gerber, 1974) or actions clearly indicating the need to plan for impending losses. The individual may want to finish business by contacting associates, give instructions to family, and review or create advance directives. All of this should be supported. However, not every person chooses to confront feelings or plan for the future, which also is a way to cope.

Provide education about the underlying condition

There are many strategies to assist family members as they cope with the inevitable losses associated with dementia (Doka & Aber, 2002). It is important to assess each person’s perception of the affected individual’s underlying condition because often, the family’s understanding of that condition is faulty. Through this exploration, counselors can determine whether each family member’s perspective of the diagnosis and prognosis sustains false hopes or unrealistic beliefs (e.g., that the person can control behavior or will get better).

Exploring each family member’s beliefs gives counselors the opportunity to provide education at each person’s level. Counselors should be prepared to suggest resources, such as organizations, self-help groups, and particularly, books by people who have experienced similar loss. Such education not only provides realistic information about the nature and course of the disease, it can also enhance feelings of coping and control by allowing family members a sense of meaningful activity and by providing them with opportunities to anticipate and plan contingencies.

Offer support for coping with the emotional issues related to the loss

Family members often feel constrained in recognizing and expressing their emotions. Because the person with dementia may live in the same community or the same home, family members may lack opportunity to express negative emotions, or face social sanctions from friends and relatives who consider such expressions disloyal or unfeeling.

The experience of caregiving can engender strong emotions. Caregivers may feel angry or resentful toward the person with dementia, or may be hurt by a perceived lack of support from others. They may feel guilt from their ambivalence about caregiving or any feelings of relief and emancipation after the person with dementia has died. Counselors can help by creating a nonjudgmental atmosphere
where individuals can express and explore these complicated emotions. In addition to reassurance that such feelings are normal, counselors can offer strategies such as journal writing, participation in ritual, or sharing such feelings with an empty chair representing the person who has died. These strategies can help griever cope with a wide range of feelings.

**Help family members respond to change**

Throughout the progression of dementia, people experience many changes as well as losses in their daily lives. Dealing with the constant demands of the illness often means a change in the ability to participate in previously enjoyed activities; loss of pleasurable companionship and loss of contact with friends or relatives; the need to take on new and challenging responsibilities; changes in expectations for the future; and the reality of unmet psychological, social, sexual, and financial needs.

After the death, family caregivers can experience additional losses, including the meaningful role as caregiver. These changes can occur so quickly that persons neither realize just how profoundly their own lives have been altered nor have the time to develop effective coping strategies. The simple question, “In what ways has your life changed?” can release a flood of responses. Counselors can assist individuals in determining which of these secondary losses are most significant; what opportunities exist to regain, to whatever extent, some of what has been lost; and help explore responses and strategies for dealing with such losses.

Counselors can also discuss the nature of the family caregiver’s support systems. Family members should be encouraged to explore how their support system can provide strategies for respite and resumption of missed activity; how to better utilize the supports they have in place, which may allow further discussion of coping styles and problem-solving abilities; and “surprises” in the support system, including both unexpected sources of support as well as support that did not come through as anticipated. This last issue is particularly significant as it provides further opportunity for the counselor to discuss emotional responses such as anger and resentment, as well as focus on personal problem-solving skills and coping strategies.

Upon assessment, individuals may recognize that they did not adequately communicate their needs or feelings to others in their support system, or that they relied on others in inappropriate ways. In one case, a woman angered by her daughter’s seeming inability
to listen to complaints about the caregiving demands resulting from her husband's dementia realized upon reflection that her daughter's strengths were always in "active doing" rather than "passive listening." Once the woman recognized this reality, she was able to modify her expectations and found that her daughter was extremely supportive when asked to help with active tasks, such as providing rides for her father or running errands.

Counselors also assist families by finding additional sources of support, such as self-help groups, day care and respite programs, and, if necessary, institutional care. These additional supports can help reduce stress and allow family members to take direct actions that may diminish guilt and reaffirm control. Support groups have been particularly successful for caregivers as well as for persons who are newly-diagnosed with Alzheimer's disease (Wasow & Coons, 1987; Simank & Strickland, 1986; Yale, 1989). The groups decrease isolation, facilitate grief, and enable exchange of information and resources. But counselors must do more than simply identify needs and sources of support; in some cases, counselors need to explore resistance and ambivalence toward such support. As Quayhagen and Quayhagen (1988) note, some caregivers experience considerable guilt over leaving the care of the person to others, and accepting help from formal agencies may no longer allow the defense of denial.

Counselors can explore role problems, dilemmas, and ambiguities within families. One of the most significant problems of dementia, especially for spouses, is that it creates considerable role strain and generates additional burden. For example, the spouse may be legally married though effectively widowed because the companionship and sexuality that were part of the prior relationship no longer exist. In these situations, it often is helpful for the spouse to explore the tensions, ambiguities, burdens, and difficulties that accompany this state of cryptowidowhood.

Counselors also can encourage such caregivers to explore all possible options. Even if an option is precluded for moral or practical reasons, its very consideration reaffirms a sense of control and reduces the feeling that the future is totally constrained. In one case, a woman whose husband was institutionalized with Alzheimer's disease became involved in a relationship with another man, but decided she would neither divorce her spouse nor live with her new love. However, acknowledging both options allowed her to affirm that she has
some control over events and that decisions she makes now are not necessarily final.

Counselors can be helpful by discussing ways an individual generally copes with change and how the individual is coping with it now; by helping individuals assess which strategies are effective and reaffirming and reinforcing such skills; by providing opportunities to assess, improve or develop better strategies; and by looking at ways the caregiver deals with stress, teaching effective stress-reduction techniques if needed. Counselors also can help caregivers to consider the impact of decisions made around caregiving. For example, an individual's decision to quit work to take care of a spouse with dementia may remove him or her from a support system, eliminate necessary respite, and create financial problems. Counselors should assist individuals periodically in assessing caregiving plans and roles, and in reviewing alternatives. Finally, counselors can legitimize the needs of family members and help them to recognize and balance their own needs with the demands of caregiving.

Help families plan realistically for the future

The nature of dementia often encourages an attitude of living "one day at a time." In many ways, such a perspective is functional; with a progressive disease like dementia, the future can be dismal. Nevertheless, it is important for families to plan, as that allows a sense of control and provides opportunity to rehearse problem-solving skills, anticipate issues, and conduct necessary research and information-gathering. Counselors facilitate the family's planning process when assisting family members through change, as noted earlier; by reaffirming confidence in the individual's abilities, coping skills, and realistic hopes; and by allowing family members to explore the effects of change on their own sense of self, sense of others, and their beliefs.

Alzheimer's disease and dementia can profoundly alter views of self or of others, and fundamental beliefs about faith and meaning. Caregivers may be fearful of their own future; they may question their feelings and beliefs about other family members, perhaps experiencing disappointment in the reaction or support of others.

As caregivers cope with changes wrought by the illness, they may have troubling experiences with the person who has dementia, such as uncovering unusual behaviors or attitudes. In one case, a woman was clearly discomforted by her mother's negative reactions to persons of a different race. Prior to developing dementia, her mother had
been a strong supporter of the civil rights movement and had never expressed such an attitude. Caregivers in similar instances need space and opportunity to confront their emotions and reconstruct meaning. A good beginning would be asking questions such as, "How does this affect your beliefs about yourself and your family or your beliefs about the world?" Assignments in which clients seek out information or enter into discussion with others, including members of their own faith community, can facilitate this process. Tasks such as assembling videos or photo albums can reconnect individuals to earlier, more positive memories.

In addition to family members, it also is important to offer support to professional caregivers. Since many dementias progress over a long period of time, it is not unusual for nursing home aides, home companions, and home health aides to develop strong relationships with family members as well as with the person with dementia. When that person dies, the aide not only ends a relationship with the individual, but often with the family as well. Health aides lose a position and income and may need to develop another relationship almost immediately. In cases of advanced dementia when healthcare decisions have been made, the aide's perspective often is not expressed and would, in some circumstances, be unwelcome. Yet, professional caregivers mourn, too. Their grief needs to be acknowledged and supported by the agencies that employ them. Tangible ways to support such staff include debriefings following an assignment, sharing thank-you notes from the family, and personnel policies that encourage participation in memorials, funerals, or other rituals.

Grief is a constant companion to individuals with dementia and their families. From the first realization that this diagnosis may be a possibility, to the death of the person with the disease, loss is integrally woven in to the experience. Grief impacts the person coping with the disease, even in the later stages of the illness. Grief is also present for the family caregivers and loved ones, who experience losses not only of the person they love, but losses of familiar roles and dreams for the future. Professional caregivers are also touched by grief and may not always have the support they need to integrate those reactions into their daily work.

But grief does not have to be the only companion. As family and friends, counselors, and supportive others travel together, the journey through grief continues, but is perhaps less lonely and not quite as frightening.
Editor's Note: This chapter draws material from Doka, K. J. (2004). Grief in Dementia. In K. J. Doka (Ed.), Living with grief: Alzheimer's disease (pp. 139-154). Washington, DC: Hospice Foundation of America.

Kenneth J. Doka, PhD, MDiv, is a professor of gerontology at the Graduate School of The College of New Rochelle and senior consultant to Hospice Foundation of America. Dr. Doka serves as editor of HFA's Living with Grief book series, its Journeys newsletter, and numerous other books and publications. Dr. Doka has served as a panelist on HFA's Living with Grief video programs for 22 years. He is a past president of the Association for Death Education and Counseling (ADEC) and recently received their Special Contributions Award. He is a member and past chair of the International Work Group on Death, Dying and Bereavement. In 2006, Dr. Doka was grandfathered in as a mental health counselor under New York's first state licensure of counselors. Dr. Doka is an ordained Lutheran minister.

REFERENCES


