

Grieving the Living!

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Although the word “grief” is seldom used in the stories of families affected by Alzheimer’s Disease (AD), it surely is woven into the entire fabric of the experience. Grief related to on-going AD is grief for the living, and it is often a disenfranchised grief. Our culture tends to devalue persons who grow to be nonproductive and dependent as is the case in AD; they are often stigmatized socially and marginalized relationally. The person who feels the pain of that devaluation and limbo status is the caregiver. In addition, the person with AD sometimes manifests unpredictable, inappropriate, and even indecent behaviors. These can be embarrassing to family members and intensify their pain and loss. Moreover, as long as the person with AD is alive, caregiver grief, though appropriate, is generally not recognized or sanctioned. The community is more likely to associate grief with a physical death. Yet, grieving the living is real; it is constant and complex; and it is important that caregivers receive help in managing it.

When grief is acknowledged in AD, the concept most often used is *anticipatory grief*. Although this term has value, the losses incurred with AD are not just future; they are actual and profound in the present. Each pre-death loss in this progressive disease is compounded by all previous losses and introduces new tangible losses, as well as potential losses in the future.

In *Treatment of Complicated Grief* (1993), Therese Rando describes six grief processes that must be accomplished when loss occurs in order to integrate the loss successfully.¹ These processes are not linear, but are necessary tasks for the person in grief, and they can be useful to caregivers who experience pre-death losses. Being informed about these processes can assist healthcare providers in their care for family caregivers.

Acknowledging the Reality of the Loss

The goals of this process are to comprehend that the loss is permanent and irreversible and to understand the implications of that reality. For persons with AD, changes are often gradual, variable, and intermittent with good days and even lucid

moments throughout, enabling caregivers to deny that loss is really happening. As the disorder progresses, it is natural for caregivers to want to believe that the deterioration is temporary and reversible, and it is complicated by the fact that the person is very present physically and frequently otherwise healthy. The

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death is psychological and is one which society does not tend to validate. Caregivers lose not only the person as they were prior to the disease, but also lose who they were with them. These secondary and symbolic losses, in addition to the physical ones, fluctuate and are re-experienced over and over again. Professionals can help by encouraging caregivers to identify the layers of loss, by confirming their grief, and by providing information that will help the caregiver assimilate the fact that the changes are real and permanent.

Experiencing the Pain

Healing can be accomplished only by contending with the emotional pain of a loss. Often caregivers of a person with AD are so consumed with the ever-growing list of caregiving tasks that they suppress their pain or do not take time to attend to it. Feelings such as anger, anxiety, and fatigue often go unexpressed when caregivers feel that they must maintain an atmosphere that is cheerful, calm, and optimistic. Unfortunately, our culture confuses care of self with selfishness, a position detrimental both to the caregiver and the person with AD.

Healthcare providers often try to rescue caregivers by trying to take away their pain instead of authenticating the gamut of strong and sometimes contradictory emotions. Providers will do well to remember that all emotions are energy in motion

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and can work for caregivers instead of against them. In addition, prescribing regular self-care for caregivers needs to be considered part of every treatment plan in AD. Most caregivers find family support programs reduce their isolation while enhancing their personal self-care strategies.

Reviewing and Remembering the Person and the Relationship Realistically

The goals of this process are to identify unfinished business, enable a good goodbye, and alter the bonds of the relationship. AD makes this, at best, a challenge, especially in the moderate and severe stages of the disease when the mental faculties needed for resolution are often missing. Yet, caregivers can accomplish the process independently of the person with AD, because it is about caregivers doing their own work—making their peace, finding forgiveness, and marking the significance of the relationship. It is important that caregivers be encouraged to tell the stories of the person and of the relationship—positive and negative. And it is important to recognize that conflicted relationships are nonetheless significant. Allan Gurganas, a North Carolina author, once told me, “Always remember that the story knows more than the storyteller.” To tell the stories of the relationship can restore wholeness in the midst of brokenness. To tell the stories of the past informs the present and the future. In telling the stories, caregivers can find ways to alter the bonds of the relationship in ways that simultaneously allow them to stay connected and to let go.

Adjusting to the Environment Where the Person Is Missing

The usual goal of this process is to learn how to be in the world without a person who has died. However, the caregiver of a person with AD has to adjust to a new environment while the person is physically present and in need of emotional and physical care. Persons with AD never will be their “old selves” again; neither will the family unit. Caregivers are forced into additional roles and stresses that they did not choose and do not want. They have to revise their own identity, find different ways to define self-worth and pleasure, and learn new ways of thinking and relating to the person with AD. Adjusting to a new reality and relearning the world can be stressful; providers can patiently instill confidence in caregivers as they take these most difficult steps.

While counseling a husband whose wife had AD, I encouraged him to adjust to her new reality rather than trying to force her back into his reality—being with her mentally wherever she was. As he began to adjust to the new reality, he was able to sell their home of 40 years and move to a retirement facility where she had 24-hour care and he could still be near her while also having additional support for himself.

Revising the Assumptive World

Each of us has expectations of how things should be and should happen. When we adamantly declare that life is not fair, there is an assumption of what constitutes fairness, i.e., good things happen to good people. However, the goal of this process is to make sense of things NOW, not as we think they should be. When caregivers watch a vibrant personality disappear before their eyes, be unable to recall a rich life, and no longer recognize the familiar, they experience moments that do try their souls. Reeve Lindbergh, daughter of Ann Morrow Lindbergh, recounts a time when she shouted to her mother, who had AD, “Stop it. Don’t abandon your principles... Don’t be strange. Don’t be weak...”²

This process of grief propels caregivers to re-define the values and core beliefs on which they can still base their lives. If they are religious, their faith can be a source of comfort and guidance as they encounter the mysteries of life and death. The essential movement is from “Why me?” to “What now?” Providers, without imposing their own values, can be instrumental in this transition. Again, Reeve Lindbergh’s words are appropriate, “What we have is a day...We cannot make plans. We must live a border life and make concessions to both sides—a little life here, a little death there.”³

Integrating the Loss and Reinvesting in a Meaningful Future

Throughout life, we are always integrating our losses—small and large. How we integrate these losses determines whether we move through life in despair or with gratitude. In the instance of AD, reinvestment means integrating not only what is lost, but also exploring what is still possible in the relationship. One woman with AD had played the piano for the children’s department in her church for many years. When I entered her room one day she was singing a hymn so I joined her. She never changed her blank stare, but began singing in perfect alto harmony all the words of the hymn. I told her four adult daughters about this experience, and when they next visited, they spent almost an hour singing with their mother. In that brief time, they had part of their mother back and meaningful memories to recall in later years.

Additional Recommendations for Caregivers

Although the grief process in AD is complex, there are additional things that healthcare professionals can do to support caregivers of persons with AD and nurture their own emotional health and wellbeing.

One is *utilizing the health perspective*. It can be tempting to treat caregivers much like the person with AD—to foster dependency and to try to rescue them from pain. However, the health perspective recognizes that most people have the internal and external resources needed to integrate their losses into a meaningful future. Inherent health principles in framing this experience are: (1) pain and loss are normal, and grieving is a

healthy way of taking care of ourselves; (2) each person has a unique style of doing grief work, and people have the right to interpret their loss and make choices that are right for them; (3) grief is a long process where small steps and partial accomplishments are enormous and should be affirmed; (4) grief is a healing process, not a disease. People have tremendous inner strengths to heal themselves if they are provided good information, a safe place to grieve, support for their journey, and reinforcement for their self-reliance.

Secondly, *creating a ritual* can be therapeutic. Society has not created rituals for pre-death grief, yet throughout history, rituals have helped families and nations mark numerous special events and sacred time. Rituals need not be equated with funerals and do not mean that the family is abandoning the person with AD. Instead, a family ceremony can be an intentional time designated for sharing present grief, remembering past joys, and strategizing future plans. Such an occasion can help family members address all of the six processes of grief discussed earlier and provide the momentum to reinvest in a new reality. Healthcare professionals can institute this practice as a standard of care and assist caregivers in designing an event that fits their needs. Families have an amazing capacity for creativity if given

permission, assistance, and encouragement.

Finally, family caregivers can benefit from healthcare professionals directing them to *post-death bereavement services*. When physical death does occur in AD, often the grief reactions of survivors are again discounted because the disease has been so measured and the demands of caregiving have been considerable. Although death is frequently accompanied by a sense of relief, healthcare professionals tend to assume that the grief of AD is completed when the person dies; hence post-death grief is inadvertently disenfranchised. Not only is there the physical death of the person with AD to be dealt with, but there also can be the cumulative effects of a long-term and strenuous illness. Being knowledgeable about and supplying the family with information about specialized bereavement resources such as Duke Community Bereavement Services will be important in legitimizing post-death grief. In most communities, local hospices offer bereavement support to survivors whether or not they have been served by hospice.

Families are incredible. Ordinary people can face extraordinary hardships, and resilience is a more common outcome than defeat. Caregivers of persons with AD can be and have been examples of such invincible courage. **NCMJ**

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- 2 Lindbergh, R. No More Words: A Journal of My Mother, Anne Morrow Lindbergh. 2001. Simon & Schuster: New York, p.67
- 3 Ibid., p. 57.