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## Grieving and the Experience of Long-Term Caregiving *Support Systems, Early Decision Making Are Key in Coping with Loss*

by Katherine Beck-Ei, BSSW, MSW, Family Services Coordinator

Noted speaker Elie Wiesel has been quoted as saying — watching a person you care about move through the stages of Alzheimer's disease is like watching pages being torn from a favorite book, one by one. In the end, all you have left is the cover. I have often thought this to be a particularly eloquent, accurate, and dramatically heart-wrenching description.



It is estimated that people with Alzheimer's disease live two - 20 years from the time symptoms first appear. As the illness progresses, affected persons slowly lose their memory. And, despite their best efforts at making life meaningful, comfortable, and fulfilling for the person, caregivers watch helplessly as the individual slowly disappears.

"Every time you lose a part of them, you grieve," explains former caregiver Katherine McPike of Ludington. "They leave you in bits and pieces."

Much has been written about the caregiving experience and the challenges of providing care for people with Alzheimer's disease. Terms such as "caregiver burden" and "caregiver stress" are commonly used to describe what it is like to give such care. However, the grief associated with long-term caregiving is frequently unrecognized and seldom discussed. Family and friends —and even caregivers themselves — often

fail to recognize the compounding grief which occurs gradually, over many months and years.

In his book, *"Share My Lonesome Valley: The Slow Grief of Long-Term Care"* Doug Manning talks about the feelings of grief and isolation experienced by someone providing care for a loved one with Alzheimer's disease, or other chronic illness. It is a different kind of grief than that encountered with acute illness; people providing care for someone with an acute illness are commonly able to discuss their feelings of loss. However, for caregivers of a person with Alzheimer's disease, feelings of sadness, loss, and anger may not be attributed to "grief" because the person is still living, although aspects of their being are slowly lost over time.

Many times, the cognitive and behavioral changes experienced by a person with Alzheimer's are not shared with others. Because people with the disease often

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## Chapter Assists Families During Later Stages

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### *Support Services Help Families Cope During Challenging Time*

Even in the very late stages of Alzheimer's disease, the Alzheimer's Association can assist caregivers. Our staff is available to discuss management and planning of long-term, late-stage, and hospice care. We can assist you over the telephone or in person.

The Chapter can also provide information on and registration for brain autopsy through the Michigan Dementia Postmortem Network (MDPN). MDPN was established to assist families in obtaining brain autopsy in order to receive a definitive diagnosis of Alzheimer's or related disorders. Referral liaisons in our chapter office can provide you with information about this program and assist in the registration process. Because preregistration is required,

it is best to have this completed prior to the person entering the later stages of the disease. Registration, however, does not obligate families at the time of death to have the autopsy performed. Contact the chapter office nearest you at (800) 337-3827 to obtain more information.

Finally, support groups and educational programs can provide caregivers with an opportunity to share their grief with others who understand. This can be especially important during the later stages of the disease. We encourage caregivers and their families and friends to take advantage of the information and supportive services we offer.

### How to Determine When Hospice Care is Appropriate

Determining when hospice care is appropriate for an individual with end-stage dementia can be challenging; even severely ill individuals may have a prognosis of up to two years. Survival time depends on comprehensiveness of care and the presence of any coexisting medical conditions. The following medical guidelines can assist in determining whether an individual is appropriate for hospice care and/or eligible for the Medicare/Medicaid Hospice benefit.

I. Does the individual show all of the following characteristics:

- |   |  |
|---|--|
| <input type="checkbox"/> Unable to walk without personal assistance | <input type="checkbox"/> Incontinence of urine and stool             |
| <input type="checkbox"/> Unable to dress without assistance         | <input type="checkbox"/> Unable to speak or communicate meaningfully |
| <input type="checkbox"/> Unable to bathe properly                   |  |

II. Has the individual experienced one or more of the following medical complications related to dementia during the past year:

- |  |   |
|--|---|
| <input type="checkbox"/> Aspiration pneumonia                  | <input type="checkbox"/> Inability or unwillingness to take food or fluids sufficient to sustain life; not a candidate for feeding tube or parenteral nutrition |
| <input type="checkbox"/> Upper urinary tract infection         |   |
| <input type="checkbox"/> Septicemia                            |   |
| <input type="checkbox"/> Decubitus ulcers, multiple, stage 3-4 |   |
| <input type="checkbox"/> Fever recurrent after antibiotics     |   |

These are guidelines only; clinical judgement is required in each case. If your loved one or patient seems to meet these criteria, consider contacting a hospice provider in your area for an evaluation.

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## Grieving and the Experience of Long-Term Caregiving

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appear physically healthy, it is not readily apparent to others that anything is even wrong. Others often think that the person with Alzheimer's looks so well that the caregiver must be doing fine. Even family members and close friends often do not realize the emotional pain and loss a caregiver is experiencing. In reality, caregivers grieve the loss of a confidante, a romantic partner, a parent's guidance, and a future together. Relationships change and caregivers care for loved ones with Alzheimer's as they are; still they grieve the loss of the people they once were.

"One of the biggest issues for me was the change in the marital relationship," McPike said. "You go from a romantic physical love to a love you would have with a child. The loss of the intimacy of marriage is quite profound — you no longer have anyone to share the issues of everyday life with."

It's difficult for caregivers to think of themselves when someone else is enduring such a catastrophic illness. However, the build-up of emotions and sorrow of the long-term caregiver can become overwhelming. It's important for a caregiver's pain and loss to be acknowledged by, and shared with, others.

"Many people think that because the grief is slow and prolonged, you should recover quickly — but the reality is that it still takes a lot of time," McPike explains. "It takes a phenomenal toll, not only emotionally, but physically as well."

### *Planning for the Future*

The grief experienced by caregivers during the late stages of Alzheimer's can be compounded if difficult end-of-life decisions have not been made in advance.

Advance planning may include preparation of wills and trusts, as well as medical and financial durable powers of attorney. Although it may seem premature, making funeral and burial plans is also advised. Alzheimer's disease prohibits the person from engaging in this kind of planning late in the disease process, due to progressive brain damage. Therefore, these tasks are best accomplished in the very early stages of the disease when the person is able to express his or her wishes.

Also, it's very important to discuss such topics as when and how to decide to stop curative treatments, whether life support methods such as feeding tubes and respirators will be a part of end-stage care, and at what point it is no longer appropriate to treat the person with antibiotics.

Hospice services during the late stages of Alzheimer's should also be explored. All hospices can schedule information visits with families to help them discuss these, and other, late stage issues. It should be noted that contrary to popular belief, hospice patients are not restricted to six months of care. This is particularly important to know when dealing with an illness such as Alzheimer's because of the difficulty in "predicting" how long the person is likely to live. Unfortunately, persons with Alzheimer's are often referred so late in the disease process that they and their caregivers are unable to take advantage of the full benefits of this type of care.

It's never too late to seek help and support from the Alzheimer's Association. Call the chapter office nearest you at (800) 337-3827 to discuss grief and options for support, and to locate a support group in your area.

## Resources

### *Books*

"*Late Stage Dementia Care*," Christine R. Kovach, Ph.D., RN, Taylor & Francis Publishers, 1997

"*Share My Lonesome Valley: The Slow Grief of Long-Term Care*," Doug Manning, In-Sight Books, 2001

### *Manuals/Booklets*

"*Caring for a Loved One with Advanced Dementia*," Hospice of Michigan, 2002

"*Hard Choices for Loving People*," Hank Dunn, 1994

### *Brochures*

"*Steps to Facing Late-Stage Care: Making End-of-Life Decisions*," Alzheimer's Association, 2000

"*Steps to Caring for a Person with Late-Stage Alzheimer's Disease: Responding to the Individual's Increasing Needs*," Alzheimer's Association, 2000

To obtain these and other resources, call the chapter office nearest you at (800) 337-3827 or visit our website at [www.alzmgreatlakes.org](http://www.alzmgreatlakes.org).