

Grieving While Caring

Rev. Jeff Billerbeck, Chaplain, Meriter Retirement Services

In this issue...

Grieving while caring. Page 1

A caregiver speaks out.
Page 2

Especially for you. Page 2

Thought for this issue.
Page 2

Lifeline responds. Page 3

Realizing that one is grieving is important to meeting the challenges of caregiving. . .

Change in any dimension of life carries with it the potential for loss and initiates a process of grieving.

Many caregivers already are aware of the dangers associated with packing more responsibilities into less time and adding more roles to a multiple-role lifestyle. Despite their awareness of the stress associated with caregiving, caregivers often do not recognize grief as a source of their powerful feelings of sadness, helplessness, resentment, anger, and guilt. Realizing that one is grieving is important to meeting the challenges of caregiving with energy, compassion, and resilience. Older adults experience many losses, including diminished health, reduced mobility, decreased social contacts and reduced energy. Each of these losses involves a measure of grief.

Much of the sadness and grief caregivers experience is related to the changes they witness in their aging parent, spouse or significant other. The care receiver is less energetic, less involved, and less independent, becoming more and more dependent. These increased demands conflict with the caregiver's

other roles. Less time and energy are available for the caregivers to participate in their previously assumed roles and responsibilities. They must make changes in how they parent their own children, relate to their partner or spouse, work for their employer, or maintain friendships.

The following are suggestions, adapted from H. Clinebell, for caregivers as they grieve the changes in their loved ones and in their own lives.

- Begin to acknowledge and accept the reality of your losses. A decline in the well-being of an aging parent or spouse is a painful process for both the caregiver and the care receiver. A valuable first step toward self-care is acknowledging and accepting these losses
- Talk about the painful feelings caused by these losses with someone who can be a "loving listener" - a friend, a spouse, a minister, or a counselor. Sharing your feelings helps alleviate the pain and sense of isolation that accompanies grieving.
- Make decisions and take actions that constructively allow you to grieve. Take advantage of respite care, adult day care, home health services and willing neighbors to assist in your caregiving responsibilities. Involve other family members.

(continued on page 3)

A caregiver talks . . .

A Female Caregiver from Dane County

I am a weekend caregiver for my mother. My sister takes care of her during the week and I drive up every Friday evening to spend time with Mother and to give my sister some respite from the responsibility she carries. Some weeks I see little change from the previous visit, but lately there seems to be marked differences in Mother's ability to do many of the small personal tasks that she had been doing for herself. She had trouble buttoning her sweater and couldn't do all of the steps in cleaning her eye-glasses. While watching televi-

sion, she became confused by the controls on the remote. During my last visit, she even seemed to have trouble remembering my name when I first arrived.

On my way home Sunday evening, I suddenly was overcome with great sadness. I remembered all of the times my mother had been there for me when I needed her—the good advice she gave me, the support when I was discouraged, the laughter and companionship we had enjoyed. She had always been the person I could rely on. The sudden awareness that she would never again be that person for me was overwhelmingly

painful.

When I got home, I called a member of the support group I had attended when my husband died. We talked about the changes I am experiencing in my relationship with my mother. My friend helped me understand that even though Mother is still here, I am grieving for the many losses that caring for Mother has brought forward. Our conversation gave me perspective on my emotions and helped me prepare for future losses. It also made me determined to make the most of the time that we have to build our new relationship while I gradually let go of the person I have known.

Especially for you . . .

Monica Deignan, M.S.S.W.; Manager, Elderhouse; Meriter Retirement Services

Guilt is an emotion that often affects caregivers. Guilt can be defined as the end result of other uncomfortable feelings. Sometimes guilt is what we feel when we are struggling to deny our true feelings. Once we can admit these negative feelings exist, it is easier to understand and accept them as an appropriate response to our caregiving situation.

Some common feelings caregivers have described include:

- **Resentment.** Caregivers may resent having to shoulder the additional burden of caregiving. Though they try to do their best, they may be ashamed that they cannot do more and may resent the loved one. Recognizing this feeling may make it easier to accept help, to tap into available

services, and to set more realistic expectations for oneself.

- **Anger.** The caregiver may feel anger toward the parent or spouse who has become frail and is no longer able to provide care for them. Anger is a very natural reaction to this reversal in roles, and once it is recognized, the caregiver can look elsewhere for needed support.

- **Grief.** It is normal to experience grief when a loved one undergoes the gradual loss of physical and/or mental capabilities. Caregivers can better deal with the profound sadness of loss if they allow themselves to name the loss and to grieve for it.

- **Fear.** If caregivers fear their own aging, the physical decline of a parent or spouse can be very threatening. If caregivers

cannot face their own mortality, how can they accept their loved ones' aging and impending deaths?

These are a few of the common feelings that can trigger guilt in caregivers. By recognizing these feelings, caregivers can free themselves from guilt and get on with caring for their loved ones and for themselves.

Thought for this issue . . .

Grief teaches us what is important. It makes the joys more joyous, the sorrows more acute—not only one's own but those of others. And so one grows in empathy, and in compassion.

-Laurie Graham

Caregiver responds . . .**Q**

My sister recently suffered a stroke, which left her unable to speak or walk. While she seems uplifted by my paging through our childhood photo albums with her and telling family stories, I often feel very sad and lonely afterwards. What can I do to feel better?

A

It is good that you realize what action triggers your sadness. Grief often accompanies change. Sharing family memories with your sister may cause you to grieve for what you have lost in terms of the relationship you

enjoyed. Her health changes may signal the end to the life that you shared, and you are mourning that loss. Be honest with your sister as you share your family history by letting her know that you miss those times, but also how much you treasure them. Perhaps one of her health care providers can put you in touch with other caregivers who are experiencing similar losses. Mutual support may ease your pain and help you find positive ways to deal with your loss.

Q

Through my local Alzheimer's chapter, I have been attending a support group for caregivers. At our last meeting, we touched on the grief process that many

caregivers begin while caring for their loved one. Can you tell me more?

A

Grief often occurs in stages, and caregivers of loved ones who have Alzheimer's experience loss of the person that they knew and loved. As the care receiver becomes more dependent, it is no longer possible to maintain the relationship at previous levels. As Alzheimer's progresses, caregivers may mourn this gradual loss of their loved ones as they knew them. Their grief process is very real because their losses are very real. It is good that you have the support of others who understand what you are experiencing and that you, in turn, also can lend your support to others.

Grieving while caring (continued from pg.1)

- Try to put the losses you are experiencing into the wider context of meaning and faith. Unhealed grief can lead to an "infection for the soul" that leads to bitterness, cynicism, and despair. Reinvest in life in healthy and constructive ways through the contest of meaning and faith.
- Seek out others who are facing similar experiences. Some caregivers' support groups provide education and support in coping with the challenges you face as a caregiver.

- Recognize that grief for the changes you are experiencing is not an admission of failure on your part, but a reflection of your love and care for life itself. When someone you love is no longer the person you knew and becomes another person, it is normal to grieve for your loss. Nevertheless, the pain of change can be an opportunity for growth. Who you become in the changes in your life is your choice.

Grief is a constant companion for caregivers as they experience profound losses in their own lives

- The gradual loss of their loved one through physical and/or mental changes, possible loss of their home, loss of a lifestyle or social involvement. As caregivers we are better able to deal with these losses if we acknowledge and grieve them, and move ahead with caring for our loved one and for ourselves.

References

- Greenberg, V. E. (1998). *Respecting your limits when caring for aging parents* (Rev. ed.). San Francisco: Jossey-Bass.
- Koch, T. (1990). *Mirrored lives: Aging children and elderly parents*. New York: Praeger.
- Kouri, M. K. *Keys to survival for caregivers*. (1992). Barrons Educational Series.
- Mace, N. L., & Rabins, P. V. (1999). *The 36-hour day: A family guide to caring for persons with Alzheimer disease, related dementing illnesses, and memory loss in later life* (3rd ed.). Baltimore, MD: Johns Hopkins University Press.
- Parke-Davis (Sponsor). (1994). *Caring for the caregiver: A guide to living with Alzheimer's disease*. Warren-Lambert.
- University of Wisconsin Medical School. (1997). *Caregivers . . . Take care*. Women's Health Initiative Insights, 2(2), 1.
- Zarit, & Boutselis. (1987). *Interventions with caregivers of dementia patients: Comparison of two approaches*. Psychology & Aging 2(3), 225-232.

UWEX Resources

To order publications from the Cooperative Extension call our toll free number at **877-WIS-PUBS (947-7827)** or visit our website at **<http://www1.uwex.edu/ces/pubs>**.

Mailing address:

Cooperative Extension
45 North Charter Street
Madison, WI 53715

Please include the following:
Title & stock number of publications
Quantity
Credit card number & exp. date.

For more information about ordering, email Jim Breitzman breitzman@admin.uwex.edu

UWEX Resources

ElderCare Choices & Decisions

- Caring for the Caregiver (B3603-5)
- Locating Community Resources (B3603-2)
- Understanding Alzheimer's Disease (B3603-6)

Caregiver Lifeline is a newsletter developed by the University of Wisconsin-Extension.

Mary Brintnall-Peterson provided leadership to its development.

If you have questions about the Caregiver Lifeline contact her at mary.brintnall-peterson@ces.uwex.edu

It is being distributed on the Wisconsin Alliance for Family Caregiving at <http://www.uwex.edu/ces/flp/caregiving>