

Anticipatory Grief

Whether you are a beginning or a veteran caregiver, experiencing grief will be a part of your caregiving journey. This hand out explores anticipatory grief, a common experience for caregivers, and provides suggestions on how to cope.

What is anticipatory grief?

When we think of grief, we generally think of the process and feelings we experience after someone dies. In reality we begin this process on the day someone we love is diagnosed with a life threatening illness. This process of mourning before someone we love has died is called anticipatory grief. According to noted grief expert, Dr. Therese Rando, anticipatory grief refers to the process in which we begin to mourn past, present and future losses.

Why Alzheimer's caregivers are vulnerable to anticipatory grief

Good-byes are always painful, and Alzheimer's is the ultimate "long good-bye." Anticipatory grief is rampant, and perhaps inevitable, among Alzheimer's caregivers because of the slow, progressive, and incurable nature of the disease. University of Indianapolis researchers asked more than 400 caregivers the open-ended question, "What would you say is the biggest barrier you have faced as a caregiver?" The majority, more than 80 percent, referred to the loss of the person they used to know.

The friends and family of someone with Alzheimer's or dementia are often experiencing two difficult psychological states at once:

- Anticipatory grief, coping with the very real feelings of loss for someone who is still alive
- Ambiguous loss, interacting with someone who's not fully present socially or psychologically

Common losses for Alzheimer's caregivers

During the course of the illness there will be many losses for the care recipient and primary caregiver. These may include: intimacy, sex, privacy, independence, dreams, partnership, dignity, money, control, intellectual stimulation, friendship and family position. These losses will produce accompanying feelings of anger, sadness, depression, and abandonment. It is common for both the care recipient and the caregiver to feel isolated, invisible, and numb.

How to cope with anticipatory grief

- **Know your feelings are normal.** It can help simply to know that anticipatory grief exists. A long term illness leaves a person with a "mixed bag" of feelings. As you watch someone you love in pain, you may wish them to be out of their misery. This

feeling can be followed by feelings of guilt and remorse, that we "wished" this person to die. Discussing these feelings is a survival necessity. Care recipients and caregivers need someone to hear and validate their feelings.

- **Acknowledge the losses that you experience.** An individual who experiences loss is likely to experience a series of secondary losses that spring from the initial loss. As mentioned previously, caregivers may lose intimacy, partnership, and friendship and family position. These losses may occur so rapidly or gradually that the caregiver may not realize how significantly their lives have been altered and stress has been increased. Acknowledging the losses can help caregivers develop strategies for coping with them, or perhaps regaining some of what was lost.
- **Rely on a support network for an emotional outlet.** Long-term studies have found that Alzheimer's caregivers who receive counseling and support, formal or informal, have better health and a lower incidence of depression. You may feel the need to put on a "brave face" in front of the sick person all the time, when expressing your conflicted feelings is what would serve you better. A support network lets you do this. Venting on paper - writing about your feelings - can help during those moments when you can't see someone from your support network face to face. Family members and close friends can be good sources of support, but if they are either physically or emotionally unavailable, support groups and mental health professionals can be a great source of support.

This hand out was compiled from the following articles:

Kay, J. Anticipatory Grief. Retrieved January 3, 2011, from http://www.caregiver.com/articles/print/anticipatory_grief.htm.

Spencer, P. How to Cope With the "Living Death" of Alzheimer's: Anticipatory Grief. Retrieved January 3, 2011, from <http://www.caring.com/articles/anticipatory-grief-alzheimers>.