

Grieving the Losses of Alzheimer's Disease

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The “long goodbye,” “the vanishing mind,” “slipping away,” “the disappearing mind”: how many ways can we name memory loss? It may seem obvious that Alzheimer's disease and other progressive dementias imply grief and loss, but how many of us truly acknowledge the multiple losses facing each individual and family impacted by these conditions. For individuals diagnosed with Alzheimer's, and those who are caregivers, living in the moment becomes the daily imperative: getting through the daily chores; perhaps managing challenging behaviors, keeping track of medical appointments, prescriptions, and changing health status; maintaining family relationships; looking for humor; living with continuing disbelief that an ability, a word, a name has been lost. In the struggle to handle this multitude of deficits, families often don't allow themselves the space and time to grieve the deep and on-going loss that has occurred in their lives.

Loss is reflected in the mind and heart of the diagnosed partner and the caregiver partner. For the individual with memory loss it means facing the multiple losses of independence, dignity, control and relinquishing decision making to family members. The caregiver faces the loss of a relationship and its mutuality if it is a spouse, or the role-shift if one is caring for a parent. The loss of hopes and aspirations for life “as normal,” the loss of time for friendships, social activities and exercise. And, too, there

are financial losses and worries as one considers the long term consequences of a diagnosis of a progressive dementia.

The traditional models we have for mourning and bereavement, be they religious, cultural or medical, do not hold when we consider Alzheimer's disease. We have no absolute moment in time that acknowledges the loss, as we do at the time of a death, and therefore have no formal marker of when grieving and bereavement can begin. Some have named this ambiguous loss (Mittelman, et al). David Shenk, in his book *The Forgetting*, says "Alzheimer's specializes in...split-level death," by which he means the death of the spirit of the person, or the person we used to know, before the actual death of the body. How can we mourn and then heal when faced with an on-going and constant barrage of loss?

Although the moment of loss may be ambiguous, some lessons may apply from the cultural traditions of bereavement and mourning. Maintaining family and community support is intrinsic to the mourning process. In the instance of Alzheimer's disease, it is important to develop and maintain a support network. This may mean joining a support group (participant and caregiver groups are available – contact the Chapter Helpline for information); many people have begun on-line journaling as a means of finding support networks. Continuing to enjoy family visits and holidays, making friendships and social, educational, travel or work opportunities as much a part of your life as you can; also bring community into one's life.

In traditional models of mourning we know to expect a wide variety of emotions. This is also the case with both diagnosed individuals as well as caregivers. This may mean

that you will feel angry, guilty, hurt and relieved. Adding to the complexity of these emotions for each partner, is that each day can be a different experience given the daily variability of Alzheimer's symptoms. And lastly, we know that loss can be physically and emotionally tiring. Both partners can be advised that caring for oneself, recognizing one's physical limitations, resting when you need it, and accepting help will be enormously helpful in maintaining your own health for the hard daily work.

Our Mission

To eliminate Alzheimer's disease through the advancement of research, and to enhance care and support for individuals, their families, and caregivers.