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Grief and the Compounded Losses in Dementia

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Grief is a universal experience and a response to a significant loss. Dementia grief, however, is unique—a person with dementia gradually recedes from his loved ones while still being very much present in their lives. It may seem as if the person with dementia is no longer himself, and it is difficult for family and friends to make sense of the loss of the person they had known. Still physically here, yet different and strangely inaccessible, family and friends strive to remain connected to a loved one with dementia.

Grief is complex. It involves several distinct emotions: denial, anger, sadness and heartbreak, guilt, despair, acceptance and love. Typically, grief occurs from a single or major loss. The loss is clearly defined, is final, and mourning is understood and supported by the community.

The core distinguishing factor of dementia grief is the incremental loss of identity in the person with dementia and changes in the self. The losses occur gradually: loss of memories, loss of the ability to drive, cook, or make important decisions, loss of mobility and the ability to speak.

Compounded losses typically occur in succession, building up over time and creating a sense of overwhelming anxiety. In this difficult situation, one loss cannot be accepted or resolved before the next occurs. Even relatively small events can trigger intense emotional reactions because of the impact of multiple losses occurring in a short time. As a result, dementia grief has unique aspects that can be defined as anticipatory and ambiguous.



Anticipatory grief describes feelings of grief that individuals experience prior to an actual loss. Frequently, this concept is applied to the emotions family members of people who have a terminal medical condition experience. With dementia, the situation is somewhat different. While the family member may, in fact, feel grief in anticipation of the loved one's eventual passing, so much of the anguish is due to losses that have already occurred, paired with anticipation of more significant losses once the loved one is physically gone. From the earliest stages of the disease, family and friends frequently refer to “*missing the person*”. This is not something they anticipate with dread for the future, but something that is *already very much a part of their reality*.

Ambiguous loss refers to a significant loss that is lacking in clarity and finality. While an individual remains *physically present*, but is *cognitively absent*—it can be described as, “*The goodbye without leaving.*” How does one grieve for someone who is still physically present but cognitively absent? The very ambiguity of the relationship makes it challenging for the family member to acknowledge the loss, to grieve, and move forward.



Tips & Tools

Coping with Dementia Grief

The single most important coping mechanism you can take is to find a support group that will understand your loss and your emotions.

Find time to mourn and grieve in your own way; understand that not everyone grieves in the same way. Some people need to cry, some need to revisit happy memories, some need to pray, some express grief creatively, and some need to be active and feel useful. Your expressions of your grief may develop in different ways at different times.

Learning and practicing mindfulness skills or meditation can be powerful tools for managing dementia grief. Learn to be present and to tolerate, and accept your grief. But it is important to understand that dementia grief is simply a process of life. It is surely challenging, but in itself, it demonstrates how much you love someone. There is nothing to resolve, nothing to fix, nothing to do with the grief itself, except to recognize and accept its impact on you. Then, when the grieving is done, just let it go.

A person with dementia experiences three major stages: early, middle, and late. The boundaries between one stage and the next are not well defined, yet what is very clear is that the entire course of dementia is a process of loss, and thus, of grief. Let us consider the stages of grief.

Grief in the early stage of dementia: Profound grief is experienced in the early stage of dementia—perhaps a grief shared with the affected person as well. A sadness in knowing that life as you once knew it will no longer be the same; a dread of the future and the changes it will bring, and quite simply, a profound grief.

In the early stage, a person with dementia still retains a high level of function, such that friends, family, and people outside the home may not understand the depth of emotions that you may feel. Often, well-meaning friends will attempt to reframe your expression of fear or grief, intercepting a natural process of confronting grief and loss.

And then it is common for the family members to be overwhelmed by the entirety of the disease: *What will happen? When, and what do I do?* Dementia education and planning counteracts the *ambiguous loss* of the early stage. Learning about the disease and developing new skills to manage symptoms are practical adaptations to the losses of the early stage.

Grief in the middle stage of dementia: The middle stage is often considered the most difficult in terms of the losses and the increasing care responsibilities. While this stage involves some of the most compounded and profound losses, it offers the least amount of time or room to process one's grief. In the

mid stages of the disease, people with dementia often struggle as the world within them swallows the world around them. The caregiver must cultivate the ability to simply be present without judgment. This powerful adaptive tool can counteract the sense of ambiguous loss, enabling one to connect emotionally with the person with dementia even as he progressively changes in response to their disease.



Grief in the late stage of dementia: It is during the late stage of dementia that family members experience true anticipatory grief. A loved one can be severely limited in the ability to communicate, comprehend, or move. This is a time when families struggle to stay connected with their loved one. It can be very helpful to learn to engage at another level with the person with dementia, beyond language. Pay attention to what is communicated through tone of voice and body language. Provide a calm environment; visual stimulation, music, touch, smells, and affection are very helpful. Focus on your loved one's comfort and accept that the disease has taken its course.

Acknowledging and accepting your grief can bring healing and let you re-emerge into a new reality where memories are cherished.

It is important to remember that dementia grief is an experience with unique properties. While aspects of the grief process are certainly common to most family members, we each express and internalize the experience in particular ways to meet our personal needs and move toward wellbeing.

Cherish the one you love, the time you have with him, nurturing and seeding memories that will soothe you for years to come.