

Dementia Loss and Grief

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What is Dementia?

"Dementia" is an umbrella term that covers a variety of progressive, neurological illnesses including Alzheimer's, Vascular Dementia, Lewy body Dementia, Frontotemporal, Huntington's, that cause abnormal brain changes.

Dementia is progressive, regardless which dementia someone is diagnosed with. Sometimes individuals with a dementia diagnosis live for a long time, others do not. While there are similarities, dementia is a unique experience for the individual and all caregivers.

Dementia impacts more than just memory, however it is the loss of memory that can be most significant to family, friends, and other support people when caretaking for someone with a dementia diagnosis. We grieve the loss of a shared sense of reality.

What makes grief after a dementia loss different?

We are grieving for our person through the course of their disease, from the early signs when we start noticing the changes in our person, to the confirmation of diagnosis, to the daily changes and progression that occur during the process. We are losing our person a little bit every day. And then when the death occurs, we re-grieve for them, for all of our experiences over the course of their disease and their life prior to the disease onset. Ultimately, our person dies two deaths, and we have survived a "long goodbye" - and often the path has been a roller coaster of emotions and experiences, some good and some that have been hard, some even may have felt unbearable.

Caregiver Burnout:

Caregiving is an intense labor of love. It is not uncommon for individuals in the course of caretaking to get burned out. You are taking care of someone who is going through a progressive disease, losing them little bits at a time, trying to hold your grief together and in check while tending to all of their needs and doing your best to care for your own. It is an exhaustive experience. Often feeling short, agitated, and burnt out can also give caregivers a sense of guilt or shame in this chapter of life, and can add to the overall grief experience.

The Guilt of Care Arrangements:

The guilt of caring for our person in-home versus the decision of accessing other help, including but not limited to home-helpers and assisted care facilities, can be enormous, and unique considering the changes in needs and the reality of caretaking and care needs. We may expect things to go a certain way, and dementia can change or alter that expected course dramatically in some cases.

Loss of Role/Identity:

After the death occurs, a secondary loss that can be present is our loss of role/identity as our role as a caregiver changes or leaves with the person who has died. Who are we without this person, and who are we without being a caretaker to them? It is a process of grief and self discovery/re-discovery that can take time and patience.

Types of Grief in Dementia Loss:

- **Anticipatory Grief** - grief that occurs prior to the death-loss, and anticipating the changes that will occur due to dementia.
- **Expected Grief** - a loss that is expected, where people have an opportunity to prepare for it; we know that our person will die, but we don't know when, how long they have, and what their condition with dementia will be by the time the death occurs.
- **Ambiguous Grief** - grief of someone who is still alive; with dementia our person is regularly changing, and we grieve the changes as they come and go, but our person is still physically alive.
- **Secondary Losses** - grief over losses/changes resulting from the primary death/loss. Grief of living situation, grief of our shared reality with our person, grief of our role in their lives pre-dementia vs during dementia vs following their death, grief regarding care decisions and care planning.
- **Complicated Grief** - grief that doesn't follow the "normal" or expected pattern due to complicating factors, which in dementia there are many elements that complicate the lived and post-death experiences for griever.
- **Disenfranchised Grief** - grief occurring when the loss is not or cannot be recognized, validated, openly acknowledged, publicly mourned or socially supported; can occur if dementia is related to "unfavorable" experiences such as substance use/addiction or mental illness.
- **Compounded Loss** - events, changes or losses that occur over time; these losses build up, multiple losses occurring in a short amount of time; can span several different areas of life.

Tips for Coping with Grief from Dementia Loss

As an active caregiver and following the death, it is important to take good and gentle care of yourself.

- **Honor your own unique grief experiences** - acknowledge your emotions, even uncomfortable ones. What do you need right now?
- **Accessing Support** - it can be tremendously helpful to seek support, either through an individual counselor/therapist or a support group, and to connect with others who have a similar shared experience.
- **Engage in self-care that is helpful for you** - whether it's a big self-care activity, or small ones, self-care will help fortify you emotionally, mentally, physically and spiritually.
- **Talk about your person and experiences** - when you're ready. You've been through and are going through a lot.



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