



Dementia Grief Why is it Unique?

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The Grief Journey

- The issue of loss and grief is one of the most significant issues when supporting someone with dementia.
- Losses and grieving occur in different ways at all stages in the dementia journey.

Family caregivers can
experience and grieve the
loss of:



GRIEF

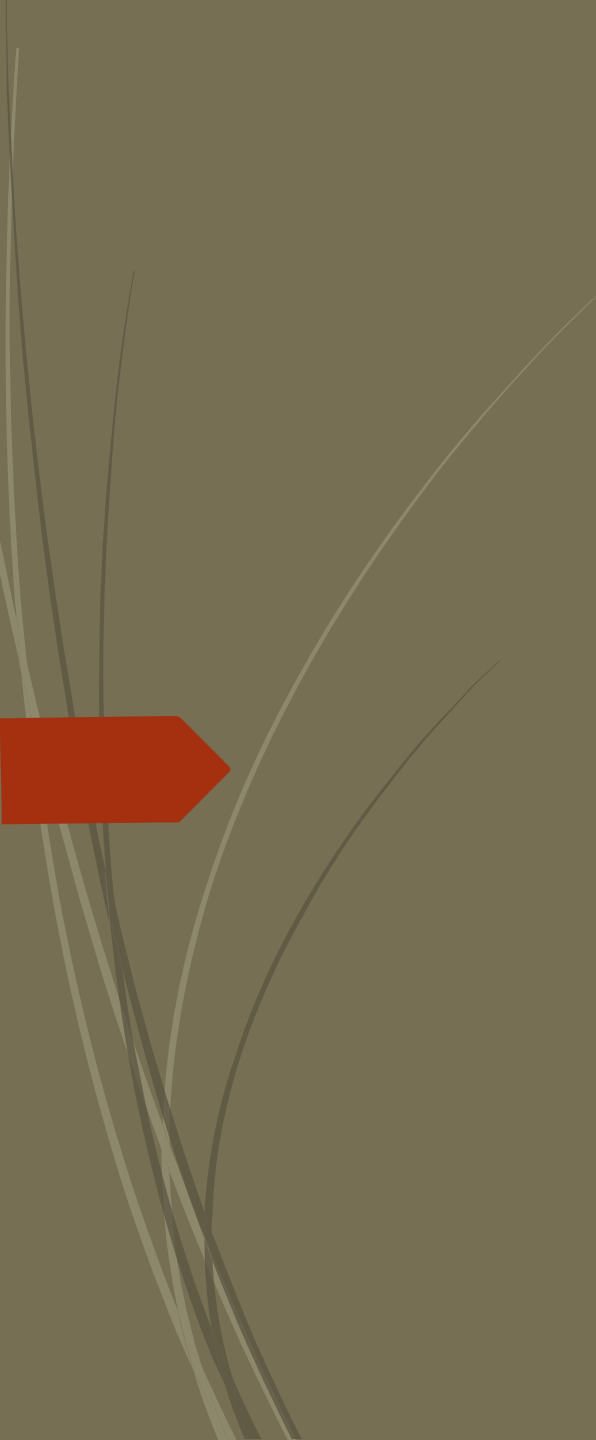
- Their dreams and expected plans for the future
- A confidant and a partner
- Shared roles and responsibilities
- The progressive losses in the life of the person with dementia

Different types of Grief

- ▶ **Compounded Loss** happens due to loss of memories, loss of their abilities to drive, cook or make important decisions or losing the companionship and missing their personality.
- ▶ **Anticipatory Grief** is when you feel grief in anticipation of the loved one's eventual death. Much of the anguish is due to losses that have already occurred and anticipation of more significant losses before physical death.
- ▶ **Disenfranchised Grief** refers to grief that is not publicly acknowledged or validated. This can occur when there is significant loss of some sort but not the opportunity to talk about it openly because of stigma or lack of understanding and sympathy from others.
- ▶ **Ambiguous Loss** refers to a significant loss that is lacking in finality and does not have a normal sense of closure. The individual remains physically present but is psychologically absent. It is very difficult to grieve someone who may no longer be mentally present as a spouse, parent or companion but who remains a physical presence with ever-increasing needs for care that must be met.

The Person With Dementia Will Grieve

- ▶ **People with dementia are also likely to experience feelings of loss and grief over their diagnosis and throughout the progression of the disease as their abilities change. Some ways to help them are:**
- ▶ By focusing on what the person can do at each stage of the disease, rather than the abilities that have been lost.
- ▶ By acknowledging the grief and sense of loss felt by the person with dementia. The caregiver can listen with empathy & offer comfort & reassurance without denying or discounting the feelings expressed.
- ▶ By looking for way to make meaningful connections with the person each day.
- ▶ By sharing their intimate knowledge of the person with dementia – personality, needs, interest, likes, dislikes, favorite activities, life stories with professional caregivers so they are able to connect and support them.



Some caregivers of a person with dementia find they have grieved the loss for so long they don't have strong feelings of grief when the person dies. Others do experience a range of emotional reactions.

Feeling numb

Denial of the situation

Feeling overwhelmed

Changes in sleep and eating patterns

Fatigue

Feelings of isolation

A sense of lack of purpose

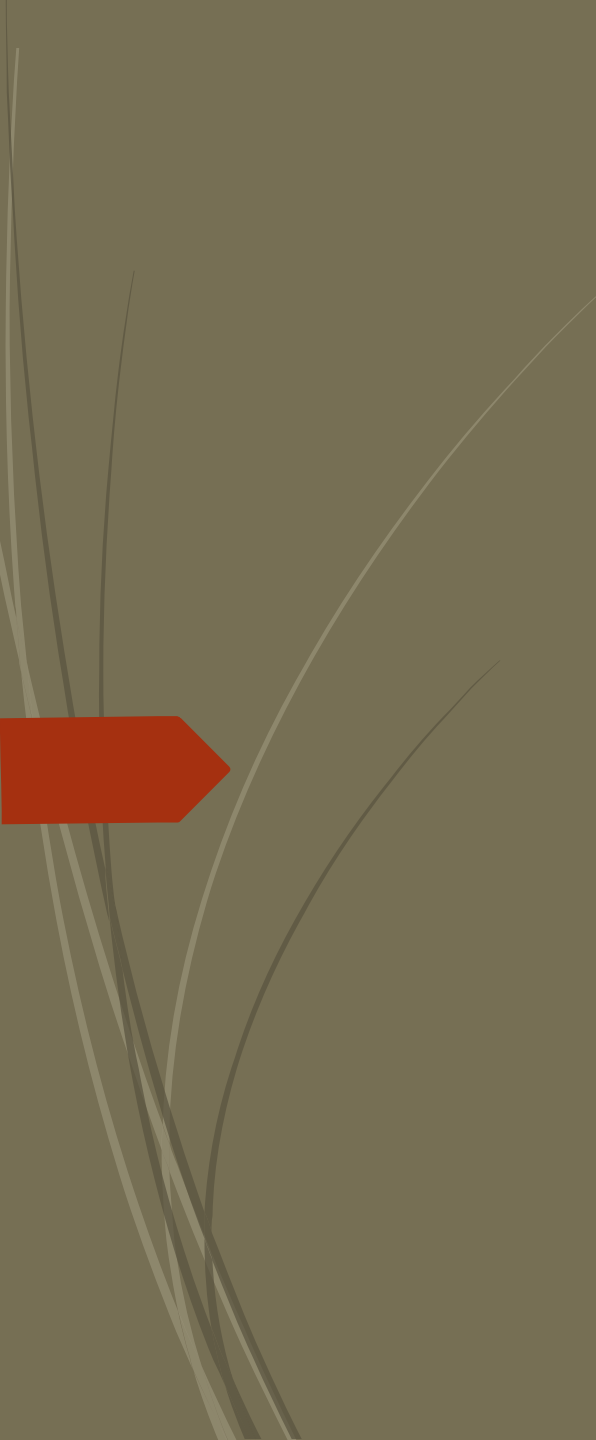
Shock and pain, even when death is expected

Relief both for the person with dementia & for yourself

Guilt

Sadness

Anger



Strategies for Living Positively with Grief

- Reflect on the losses that occur in the life of the person with dementia and your own life as well.
- Stay connected to family and friends and be open to building new relationships with others can be supportive.
- Look after your own needs. Stay physically active, eat well and do what you can to relieve stress. Take breaks from being a caregiver.
- Let family and friends know how they can help instead of assuming they know what you need.
- Seek out support groups and share advice with others in your situation
- Express grief in creative ways: writing, painting or other art forms.