

Coping with Anticipatory Grief

Presented by

ALZHEIMER'S
TEXAS[™]

THE STATE OF MIND

Joan Asseff, LCSW-S

Alzheimer's Texas

A privately funded voluntary health organization formed in 1982 to serve Central Texans with Alzheimer's disease and their caregivers.

MISSION

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

VISION

To create and sustain a dementia capable Texas in which persons with Alzheimer's and related disorders, and their families, receive quality care, effective treatments, and meaningful support.



ALZHEIMER'S TEXAS™



Learning Objectives

- Define anticipatory grief in terms of the experience of dementia caregivers and their families.
- Understand how anticipatory grief impacts dementia caregivers and their families.
- Learn strategies for normalizing and effectively coping with anticipatory grief.
- Think about and share ways we are supporting ourselves and/or caregivers who are experiencing anticipatory grief.



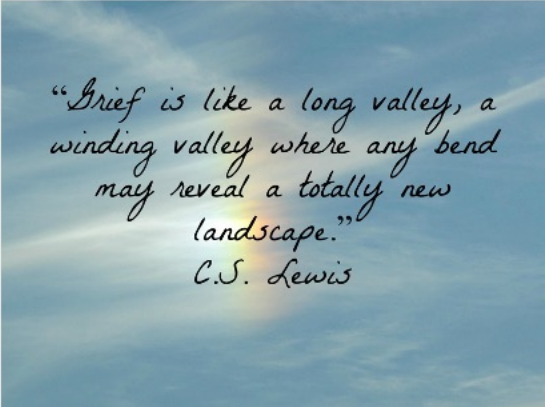
Remember to take care of yourself during this presentation . . .

***Put on your
oxygen mask
before helping
others.***

***Be aware of your own
loss history.***

***Share as you feel
comfortable doing so.***

Take breaks, as needed.



*"Grief is like a long valley, a
winding valley where any bend
may reveal a totally new
landscape."
C.S. Lewis*

What is Anticipatory Grief



- “Anticipatory grief” refers to the complicated emotional process that can take place in people who are expecting the death of a loved one. This type of grief can be just as powerful as grief experienced after the death of a loved one and can be a tremendous weight for a caregiver to carry.
- Caregivers and family members of people with Alzheimer’s or other dementias tend to experience a unique version of anticipatory grief — something many doctors refer to as “dementia grief.”
- The memory loss and personality changes that a person with dementia exhibits often leave caregivers feeling like their loved one is already gone.
- Despite the fact that they are still physically present, psychologically the loved one with dementia is no longer the same person. This type of loss is referred to as “ambiguous loss”. (Pauline Boss, 1999).



Anticipatory Grief Related to Ongoing Decline



Many caregivers and family members experience a wide array of grief related emotional responses:

Elisabeth Kubler-Ross (1969)

On Death and Dying:

- Denial
- Anger
- Bargaining
- Depression
- Acceptance

Other Common Grief Responses

- Bitterness
- Sadness
- Guilt
- Despair
- Loss
- Hope
- Love
- Joy
- Irritability
- Numbness



Losses Related to Anticipatory Grief

- Shared memories/experiences
- Intimacy
- Companionship
- Family Roles/Tasks
- Family History/Knowledge
- Friendship
- Mentorship
- Joyful experiences/routines
- Dignity
- Independence
- Privacy/Comfortable space
- Job/Employment
- Recreation/Hobbies
- Ability to plan for the future
- Sense of self
- Spirituality



Disenfranchised Grief

- Characterized by unacknowledged, minimized, or stigmatized bereavement that may cause extreme isolation for the griever.
- Sometimes the nature of the death itself can cause disenfranchisement, as in the case of homicide, suicide, or other stigmatizing deaths.
- For various reasons, people are disenfranchised because they are not seen as legitimate grievers.
- The paradox of **disenfranchised grief** is that the griever is isolated despite having increased needs for support.

(Doka, 2002)



Symptoms of Grief

Cognitive

- Forgetfulness
- Disorientation
- Difficulty with decision making
- Impaired Judgment
- Difficulty with concentrating

Emotional

- Sadness
- Loneliness
- Anger
- Irritability
- Guilt
- Depression
- Anxiety
- Numbness

Physical

- Sleep changes
- Eating changes
- Fatigue
- Body aches
- Agitation



Impact on Caregivers

Anticipatory grief was shown to be significantly and independently associated with caregiver burden, beyond the effects of known predictors such as background characteristics, behavior problems in the care recipient, and depressive symptoms. (Holley & Mast, 2009).

The anticipatory grief experience is characterized by traumatic distress from being exposed to life-threatening conditions and the separation distress induced by loss anticipation and current relational losses.

(Coelho, et al., 2020)



Spouses and Partners

Spousal caregivers caring for relatives in a later stages of dementia experienced the highest level of anticipatory grief and caregiving burden, as compared with spousal caregivers caring for relatives in an earlier stages of dementia and adult children caregivers.

Spousal caregivers of relatives in a later stage of dementia had significantly higher levels of anticipatory grief.

(Cheung et al., 2018)



Coping, Healing, and Fostering Resilience

- Access/or provide others with information regarding anticipatory grief
- Identify and normaliz the experience for yourself or others
- Utilize attendant care, volunteer, hospice, or palliative care support for coping and decreasing care burden
- Make time for grieving, when possible.
- Don't go it alone. Connect with your social support.
- Access respite or breaks, when possible, to cultivate joyful experiences
- Focus on joyful experiences with the person living with dementia
- Journal/Mindful Meditation
- Nurture your spirituality/Spend time in your faith community
- Attend a support group
- Practice self compassion



Anticipatory Grief Support Resources

AGE of Central Texas – List of local support groups

<http://ageofcentraltx.org/index.php/caregivers/>

Alzheimer's Texas

<https://www.txalz.org/how-we-can-help-programs-services/>

Austin Area Agency on Aging

<https://www.aaanwar.org/family-caregiver-support-program>

ALZHEIMER'S TEXAS™



ALZHEIMER'S TEXAS™



Questions?

What do you want us to know?

References

- Alzheimer's Texas (2021). Anticipatory Loss, Grief, and Dementia. Retrieved on January 29, 2022 from <https://www.txalz.org/caregiver-connection/anticipatory-loss-grief-dementia/>
- Coelho, A.; de Brito, M.; Teixeira, P.; Frade, P.; Barros, L.; & Barbosa, A. (2020). Family caregivers' anticipatory grief: A conceptual framework for understanding its multiple challenges. *Qualitative Health Research*, Vol.30 (5), p.693-703.
- Cheung, D. S. K.; Ho, K. H. M. ; Cheung, T. F. ; Lam, S. C. ; Tse, M. M. Y. (2018). Anticipatory grief of spousal and adult children caregivers of people with dementia. *BMC Palliative Care*, 2018-11-20, Vol.17 (1), p.124-124.
- Eldridge, Lynne. (2022, January 7). *VerywellHealth*. Coping with Anticipatory Grief. Retrieved on January 29, 2022 from: <https://www.verywellhealth.com/coping-with-anticipatory-grief-2248856>
- GoodTherapy (2019, June 17). Self Compassion. Retrieved on January 29, 2022 from: <https://www.goodtherapy.org/learn-about-therapy/issues/self-compassion>
- Holley, C. & Mast, B. (2009, June). The Impact of Anticipatory Grief on Caregiver Burden in Dementia Caregivers *The Gerontologist*, Vol. 49, (3), 388–396, <https://doi.org/10.1093/geront/gnp061>
- Mendoza, M. (2017, September 15). *Psychology Today*. Retrieved on January 29, 2022 from: <https://www.psychologytoday.com/us/blog/understanding-grief/201709/ambiguous-loss>



Pathways Home Health and Hospice (2022). Anticipatory Grief When Caring For a Loved One With Dementia. Retrieved on January 29, 2022 from:

<https://pathwayshealth.org/grief-support/anticipatory-grief-when-caring-for-a-loved-one-with-dementia/>

Perez-Gonzalez, A., Vilajoana-Delaya, J., & Guardia-Olmas, J. (2021). Alzheimer's Disease Caregiver Characteristics and Their Relationship with Anticipatory Grief. *International Journal of Environmental Research and Public Health*, 18(16), 8838; <https://doi.org/10.3390/ijerph18168838>

Shore, J. C; Gelber, M.; Koch, L., Sower, E. (2016, February). Anticipatory Grief: An Evidence-Based Approach. *Journal of Hospice & Palliative Nursing*, 18 (1), p 15–19.