
Loss and Grief on the Dementia Journey

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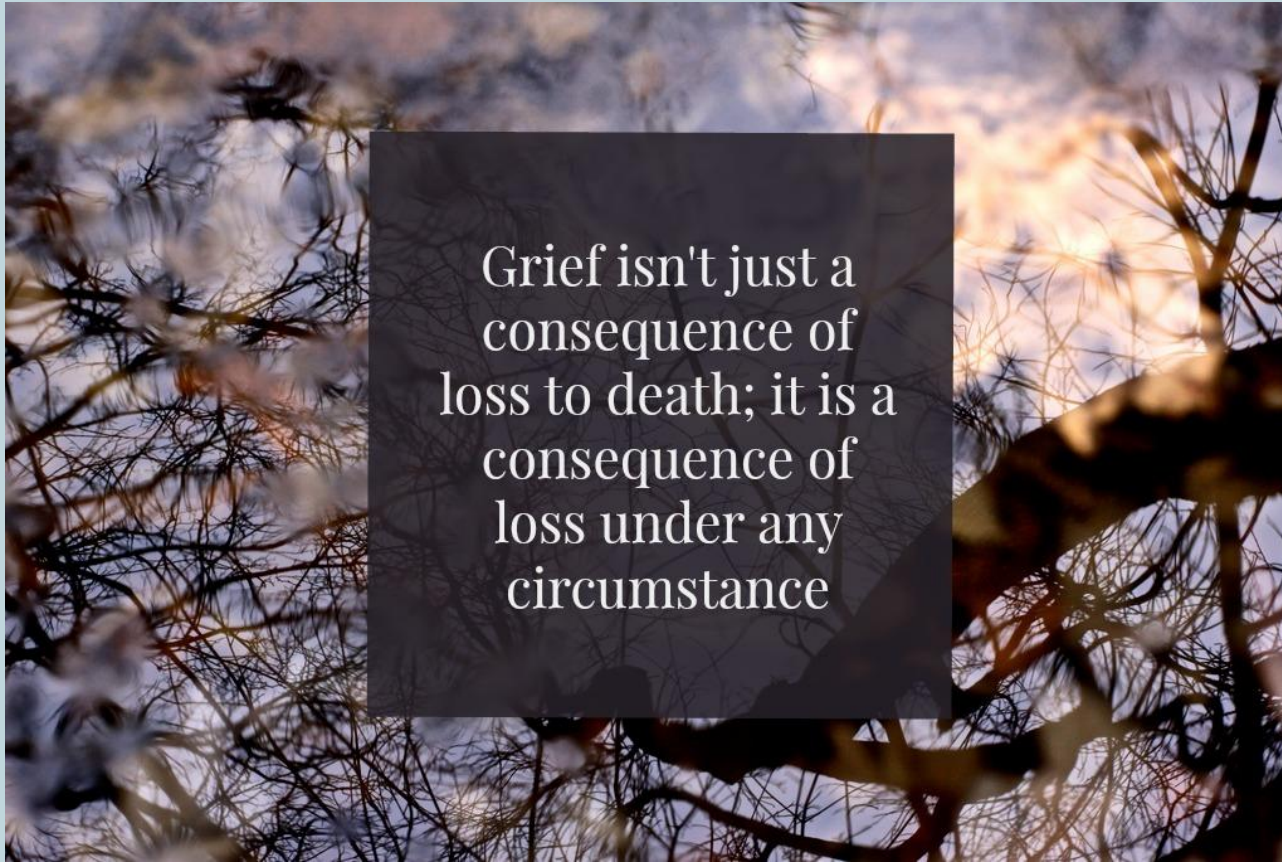


Objectives

- ▶ What is Grief?
- ▶ Grief and Loss Theories
- ▶ Grief Work
- ▶ Building Resiliency
- ▶ Resources



What is grief?



Grief isn't just a
consequence of
loss to death; it is a
consequence of
loss under any
circumstance



Losses on the Dementia Journey

- ▶ “Losing my driving privileges was hardest part. More difficult than being told I have Alzheimer’s.”
- ▶ “I haven’t been able to see my mother for 3 months. I miss her terribly”
- ▶ “People didn’t know how to talk to me even though I was the same person I was five minutes before I told them I had it...They didn’t look at me as the same person...” (Reed, 2017)
- ▶ “We’ve spent almost our whole lives together, but it’s harder now. I miss that easy partnership we always had.”
- ▶ “We have been looking forward to retirement for years. We planned to travel, now I’m not sure if it’s possible.”



Loss and Grief



Acknowledging and Grieving Losses

- ▶ Cultural Challenges
- ▶ Ambiguous Losses
- ▶ Compounded Loss
- ▶ Experiencing the Emotions



Adapting to New Reality and Reinvesting Emotional Energy

- ▶ Eat, sleep, keep house hold running
- ▶ Telling others about a dementia diagnosis
- ▶ Finding new ways to stay connecting
- ▶ Meeting changing care needs
- ▶ Become an advocate
- ▶ Try a new activity



Styles of Grieving

▶ Feeling (“intuitive”):



Vs.

▶ Doing (“instrumental”):



Building Resilience

- ▶ Be patient with yourself
- ▶ Getting enough sleep, eating well
- ▶ Making space for yourself (and grief)
- ▶ Connecting with your circle of support
- ▶ Setting boundaries
- ▶ Identify your coping strengths
- ▶ Read, journal, walk in nature, exercise, cocoon, or do whatever is nurturing for you
- ▶ Living in the moment/mindfulness





Resources

- ▶ **UW Memory and Brain Wellness Center** <http://depts.washington.edu/mbwc/>
- ▶ **Alzheimer's Association 24hr Helpline: 1 (800) 272-3900**
- ▶ **Crisis Line: 1-800-273-8255**
- ▶ ***The Grief Recovery Handbook: The Action Program for Moving Beyond Death, Divorce, and Other Losses including Health, Career, and Faith* by John W. James and Russell Friedman**
- ▶ ***Dementia Reimagined: Building a Life of Joy and Dignity from Beginning to End* by Tia Powell**
- ▶ ***A Loving Approach to Dementia Care: Making Meaningful Connections with the Person Who Has Alzheimer's Disease or Other Dementia or Memory Loss* by Laura Wayman**
- ▶ ***It's OK That You're Not OK: Meeting Grief and Loss in a Culture That Doesn't Understand* by Megan Devine**
- ▶ ***Loving Someone that has Dementia: How to Find Hope While Coping with Stress and Grief* by Pauline Boss, PhD**
- ▶ ***Walking with Grief: Loss and the FTD Journey* www.theaftd.org/wp-content/uploads/2020/02/AFTDGriefBookletForWeb.pdf**

References

- ▶ Dementia (London). 2017 January ; 16(1): 67–78. doi:10.1177/1471301215581081 **Dementia Grief: A Theoretical Model of a Unique Grief Experience**; Kesstan Blandin and Renee Pepin; The Dartmouth Centers for Health and Aging and Geisel School of Medicine at Dartmouth Lebanon, NH, USA (.)
- ▶ AMA Journal of Ethics® July 2017, Volume 19, Number 7: 693-703 MEDICINE AND SOCIETY **Transcending the Tragedy Discourse of Dementia: An Ethical Imperative for Promoting Selfhood, Meaningful Relationships, and Well-Being** Peter Reed, PhD, MPH, Jennifer Carson, PhD, and Zebbedia Gibb, PhD
- ▶ **AMBIGUOUS LOSS AND GRIEF IN DEMENTIA** A resource for individuals and families https://alzheimer.ca/sites/default/files/files/national/core-lit-brochures/ambiguous_loss_family_e.pdf
- ▶ **Walking with Grief: Loss and the FTD Journey** <https://www.theaftd.org/wp-content/uploads/2020/02/AFTDGriefBookletForWeb.pdf>

