Loss and Grief on the Dementia Journey

Karen Clay LICSW
Memory and Brain Wellness Center
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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/](http://depts.washington.edu/mbwc/)
- Alzheimer’s Association 24hr Helpline: 1 (800) 272-3900
- Crisis Line: 1-800-273-8255
- *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
References


- 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 Zebedia 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