



# What's Next After My Caregiver Journey Ends?

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# Goals

- ▶ Consider grief's impact on the post caresharing journey
  - ▶ Learn about resilience and self-care
  - ▶ Explore ways to construct identity in a “new normal” time
  - ▶ Work on a personal plan for a “different reality”
- 


*There is no “cookbook”  
or “one size fits all”  
answer in dealing with  
the caregiver journey*





***The journey of  
caresharing and  
beyond is a marathon  
not a sprint.***




# Grief and Loss

- ▶ Grief is normal and painful.
  - ▶ Each person deals with losses and grief in their own way.
  - ▶ People around you may not “get it.”
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- ▶ Grieving is not a linear process. It goes in cycles.
  - ▶ There may be no resolution to a loss.
  - ▶ Culture & family influence how loss and grief is experienced.
  - ▶ Some losses are obvious; some subtle.
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- ▶ Acknowledging and naming losses and grief are beneficial.
  - ▶ Current losses may expose past loss and grief, especially “unresolved grief.”
  - ▶ Not dealing with difficult losses can lead to complicated grief.
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*Name losses you  
have experienced in  
being a care partner  
or that you face in  
not being a carer?*




# Loss Post Caregiving

- ▶ Relationship/companionship
  - ▶ Remembered shared history
  - ▶ Changed hopes and dreams
  - ▶ Altered sense of meaning/  
purpose not doing direct care
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- ▶ Different roles
  - ▶ Changes in structured/  
unstructured time
  - ▶ Challenges in connection to  
others (Covid-19)
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# Grief Overload

- ▶ Adverse effects of many losses building up over time
  - ▶ “Little” & “major” losses
  - ▶ A sense of “too-muchness”
  - ▶ A compounding of losses
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Grief can feel like it is grey  
and stormy all the time....


# Anticipatory Grief

- ▶ Grieving for coming losses
  - ▶ Occurs incrementally
  - ▶ Needs naming
  - ▶ Puts persons in limbo
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# Ambiguous Loss

- ▶ As caring progresses, losses accumulate.
  - ▶ There may not be an opportunity for resolution.
  - ▶ Unresolved grief prevents “moving on.”
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- ▶ Grief can be frozen and “put on hold.”
  - ▶ Is a roller coaster of losing/finding over and over
  - ▶ “Emotional quicksand”
  - ▶ Balancing present reality in face of the future
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- ▶ Uncertainties are difficult.
  - ▶ Need recognition and reflection
  - ▶ Requires “paradoxical” thinking
  - ▶ There is discomfort with unanswered questions.
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# Resilience

- ▶ Bouncing back from setbacks
  - ▶ Returning to sense of balance
  - ▶ A buffering factor in challenges
  - ▶ Having future purpose
  - ▶ Getting stronger in challenges
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# Ways to Build Resilience


- ▶ Make connections.
  - ▶ Avoid seeing crises as insurmountable.
  - ▶ Accept change as a part of living.
  - ▶ Move toward goals.
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- ▶ Find a sense of purpose
  - ▶ Take decisive actions
  - ▶ Look for opportunities for self-discovery
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- ▶ Nurture a positive view of yourself
- ▶ Keep things in perspective
- ▶ Maintain a hopeful outlook


- Adapted from American Psychological Association

# Internal Strengths

- ▶ Faith
  - ▶ Humor
  - ▶ Problem solving skills
  - ▶ Family support
  - ▶ True Grit™
- 



# 7 Guidelines for the Journey


- ▶ Find Meaning
  - ▶ Balance Control with Acceptance
  - ▶ Broaden Your Identity
  - ▶ Manage Your Mixed Emotions
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- ▶ Hold On AND Let Go
- ▶ Imagine New Hopes and Dreams
- ▶ Take the Time to Mind Yourself


Pauline Boss (2011)




# Discover Meaning

- ▶ Ask “who am I now?”
  - ▶ Journal or tell stories.
  - ▶ Stay in the “now” of feelings.
  - ▶ Use positive channels to share.
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- ▶ Understand how you grieve (“feeling” / “doing.”) Blending them can help.
  - ▶ Look to religious / spiritual teachings.
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- ▶ Affirm “both/and” and because/therefore thinking.
  - ▶ It is ok to set boundaries! Don't let others define you.
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# Balancing Control and Acceptance


- ▶ Control thinking and acting even as things change.
  - ▶ Clarify what can be controlled and what cannot.
  - ▶ Sometimes “letting go” is the way to stay in charge.
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# Expanding the Idea of “You”

- ▶ “Revise your identity to fit the ambiguity.” (Boss 2011)
  - ▶ Consider needs to forgive or ask forgiveness.
  - ▶ Rethink and reframe roles.
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- ▶ Resist retreating from others
  - ▶ Reach out to and be honest with your supports. Use technology.
  - ▶ Build on resilience and inner strengths. Stay healthy.
  - ▶ Question family rules.
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# Understand Mixed Emotions


- ▶ Fear, anger, guilt, sadness and joy co-exist.
  - ▶ Ambivalence is normal.
  - ▶ Share tough feelings with trusted others.
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Deep sadness  
is a normal part  
of grief in caring...It needs to be  
acknowledged  
and processed in a way that makes  
sense to you...



# “Holding On” / “Letting Go”





- ▶ Be in the “here and now” even while planning the future.
  - ▶ Attend to your own needs.
  - ▶ Improve the space you are in.
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- ▶ Let go of the unchangeable.
  - ▶ Remember that you are doing/or did the best you could with what you knew at the time you were a carer.
  - ▶ Avoid toxic relationships.
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# Imagining New Hopes and Dreams


- ▶ Affirm the “spiritual” and/or religious.
  - ▶ Reflect on meaning and purpose.
  - ▶ Remember that “moving on” with life does not mean “getting over” loss and grief.
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- ▶ Adapt family events to share positive experiences.
  - ▶ Simple rituals can mark changes and offer a way to deal with life transitions (consider ZOOM).
  - ▶ Joy can be shared in celebrations.
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# Self-Care is Key


# Practice Self Care


- ▶ It's a strength to care for yourself!
  - ▶ It's ok to worry but:
    - Don't ruminate
    - Don't catastrophize
    - Harness worry into "what can I do now?"
- 




**Even Superman is Clark  
Kent most of the time!!**

- ▶ Remember to breathe deeply and mindfully.
  - ▶ Monitor the amount of information taken in.
  - ▶ Get enough rest.
  - ▶ Be honest with yourself and others about feelings.
- 


- ▶ Take time to deal with feelings.  
Don't get pressured by others to feel a certain way.
  - ▶ Work on “unfinished business” and forgiveness.
  - ▶ Seek respite, and reach out to caring community.
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- ▶ Find support groups.
  - ▶ At times there is a need to “pull away” from life. Embrace the silence.
  - ▶ Consider professional help.
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- ▶ Put on music, move and feel.
- ▶ Find moments of joy. Embrace the wonder of small things.

- ▶ Use spiritual/religious practices and strengths.
  - ▶ Share your narrative. Write it down.
  - ▶ Use creative outlets, (poetry, visual arts, music).
  - ▶ Show compassion to yourself.
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# Questions


- ▶ Where do I want to be in my journey?
  - ▶ What are my internal strengths in the “new normal”?
  - ▶ Who do I need to ask to assist me in my journey?
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New life can  
spring  
forward  
on the  
journey  
after caring...  
Like a new  
plant shoot



# Resources

- ▶ Boss, Pauline. (2011). *Ambiguous Loss: Learning to Live with Unsolved Grief: Loving Someone Who has Dementia*. San Francisco: Jossey-Bass.
  - ▶ Devine, Megan. (2017). *It's OK that You are NOT OK: Meeting Loss and Grief in a Culture that Does Not Understand*. Boulder, CO: Sounds True.
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- ▶ *Grieving with Your Whole Heart: Spiritual Wisdom and Practice for Finding Comfort, Hope and Healing After Loss.* Woodstock, VT: SkyLight Paths Press.
  - ▶ Richards, Marty. (2009) *Caresharing: A Reciprocal Approach to Caregiving and Care Receiving in the Complexities of Aging, Illness or Disability.* Woodstock, VT: Skylight Paths Press.
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