

Ambiguous Loss: Living with Uncertainty



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Agenda

- Learn about the concept of ambiguous loss and why it is important
- Explore how it differs from traditional loss and grief
- Acquire new strategies toward increasing tolerance for ambiguity and change



Ambiguous Loss

- Loss that is unclear, has no resolution and no closure
- Coined by Pauline Boss Ph.D.
- Dementia creates ambiguous loss
 - For caregiver
 - For person with memory loss
- The person is physically present, but psychologically or emotionally absent

The Missing Link

Caregivers often report stress
and burden

What is at the core?

A unique form of grief
identified by Pauline Boss PhD

Losses related to absence and
presence

Ambiguous Loss

- The physical body is absent or changed, but psychologically the person is still present to family and loved ones
 - Lost soldier
 - Malaysian Air flight
- The body is present, but psychologically the person is changed or absent from how they had been previously
 - Dementia
- Non-traditional
 - Others may not recognize the loss
- Changes can be confusing and unpredictable
 - Moments of lucidity in dementia that become confusing
 - Cannot be cured or fixed

Ambiguous Loss

Basic premise:

- Absence and presence coexist
- When a person is lost only partially the ambiguity coupled with the loss creates a powerful barrier to both coping and grieving.

Differs
from
Other
Losses

Complicates loss/grief

Continued losses
throughout the course

Confuses relationships

Important to grieve as
you go

Losses Due to Dementia

- Relationship
- Intimacy
- Companionship, support, understanding
- Communication
- Shared hobbies
- Freedom to take part in activities or work
- Lifestyle
- Future plans
- Implementing care

Adapted from Alzheimer's Society: Grief, Loss & Bereavement 2017

Why is it Important?

- Understanding ambiguous loss provides a pathway for caregiver to accept and live with a new reality
 - Changing perceptions
- Allow us to appreciate our person for who they are now instead of longing for the person they once were
 - More effective use of energy
 - Redefines our relationship

Why is it Important?

- Changing our perception
 - **Cannot** control the disease, we **can** control or change our perceptions
 - Helps us find hope
 - Pathway to accept and live with it
 - Helps us connect to the person as they are now with the disease
 - Conscious choice to change how we see things
 - Enables us to appreciate the positive moments

Why is it Important?

- Provides guidelines to help develop our own plan to care for the person we love while caring for ourselves simultaneously
- Provides a model to increase resiliency
- “With a little help people can learn to balance their grief over what was lost with a recognition of what is still possible.” Dr. Boss, NY Times 1998

Why is it Important?

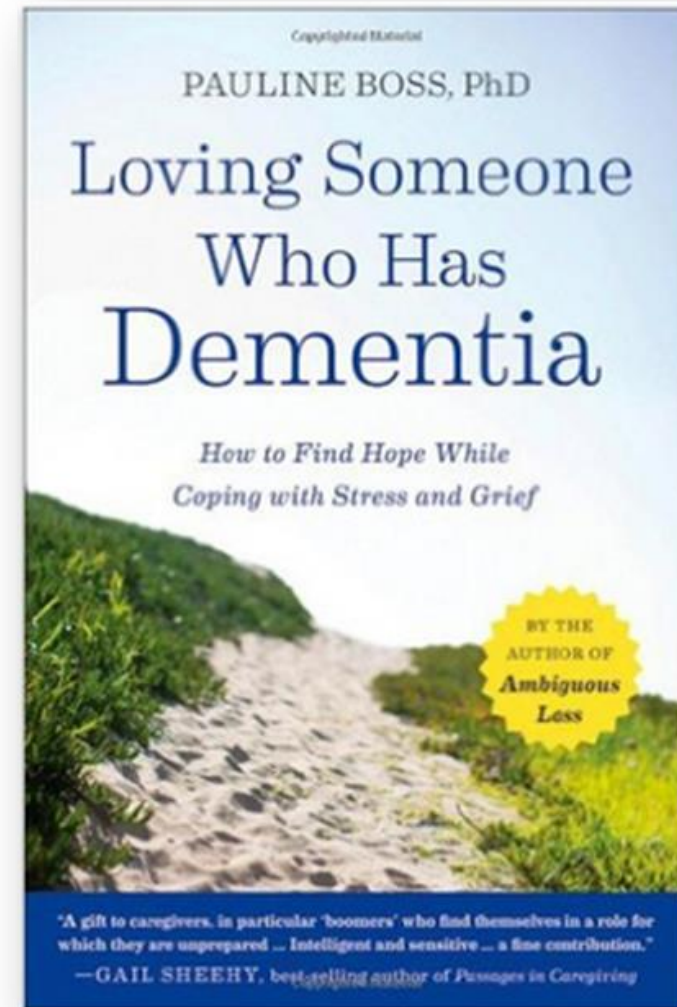
- Offers fluid considerations toward development of our own plan
- Allows us to provide care **AND** take care of ourselves as care partner
- Increases our comfort with ambiguity of this situation and future situations
- Become more comfortable not knowing the ending


Why is it Important?

- Resiliency Reflections
 - Caregiving can make you stronger
 - Flexibility can increase strength
 - Adaption requires of seeing the upside of situation
 - not only the losses/changes
 - Learning to tolerate and feel comfortable with the uncertainty of life
 - Increase our maturity
 - Cease resisting the challenges and begin to go with the flow

How to Begin

- Name the problem: Ambiguous Loss
 - Can help us name the experience
 - Partial loss creates ambiguity
 - Barrier to coping and grieving
- Paradoxical thinking: Both/And
 - Hold two opposing/contradictory ideas at the same time
 - No right answer
 - Trust things will work out





As a result of
caregiving:
I have lost _____
and I have gained _____

Chat

How to Begin

- Less than perfect solutions/finding the middle ground
- CANNOT change the course of dementia
- CAN change our perceptions by accepting less than perfect solutions

Guidelines to Cope

- Find Meaning
- Balance Control with Acceptance
- Broaden Your Identity
- Manage Your Mixed Emotions

Guidelines to Cope

- Hold On And Let Go
 - Revising attachment: letting go while remembering loved one is both here and not here
 - Grieve what you lost, celebrate what you still have
 - Find new human connections
 - Alleviate expectation of closure
- Attachment defined
 - Attachment may remain but the relationship is changed/different
 - Less reciprocal

Guidelines to Cope

- Imagine New Hopes and Dreams
- Take the Time to Mind Yourself
- Caring for yourself is not selfish, instead **self preservation**
- Take time to catch your breath, ask for & accept help
- Avoid trying to be perfect

Increase your Comfort with Ambiguity

- Let go of your need for certainty and embrace ambiguity
- Change your perceptions of a situation/diagnosis that cannot be changed
- Goal is greater acceptance not closure
- Becoming stronger from adversity, more mature with a greater depth of understanding

Increase Comfort in Ambiguity

- Find hope in ambiguity
- Find meaning in the relationship that has changed
- Life brings a great deal of ambiguity

“

When you love someone with dementia the goal is not perfection. The new standard for your relationship is simply for it to be good enough. Life with dementia can be less than ideal and still be pretty good. That perceptual shift is under your control.”

”

Pauline Boss, PhD

Educator and Researcher

Review

- Ambiguous loss is a chronic ongoing loss resulting from the ambiguity of absence and presence
- It is irresolvable loss with symptoms similar to complicated grief
- It is a relational condition
- It can cause care partners to feel immobilized and lead to excessive personal and relational stress
- Ambiguous loss is challenging, but we can learn to live with ambiguity.



Questions?

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