

DUKE DEMENTIA FAMILY SUPPORT PROGRAM

Caregiver Connections

An Educational Webinar Series With The Experts

**The presentation will begin shortly.
Thank you for your patience!**

**dukefamilysupport.org
919-660-7510**



Ambiguous Loss: Unique Experiences of Loss and Grief while Caring for those with Dementia

Speaker: Margaret Albert, LCMHC, NCC

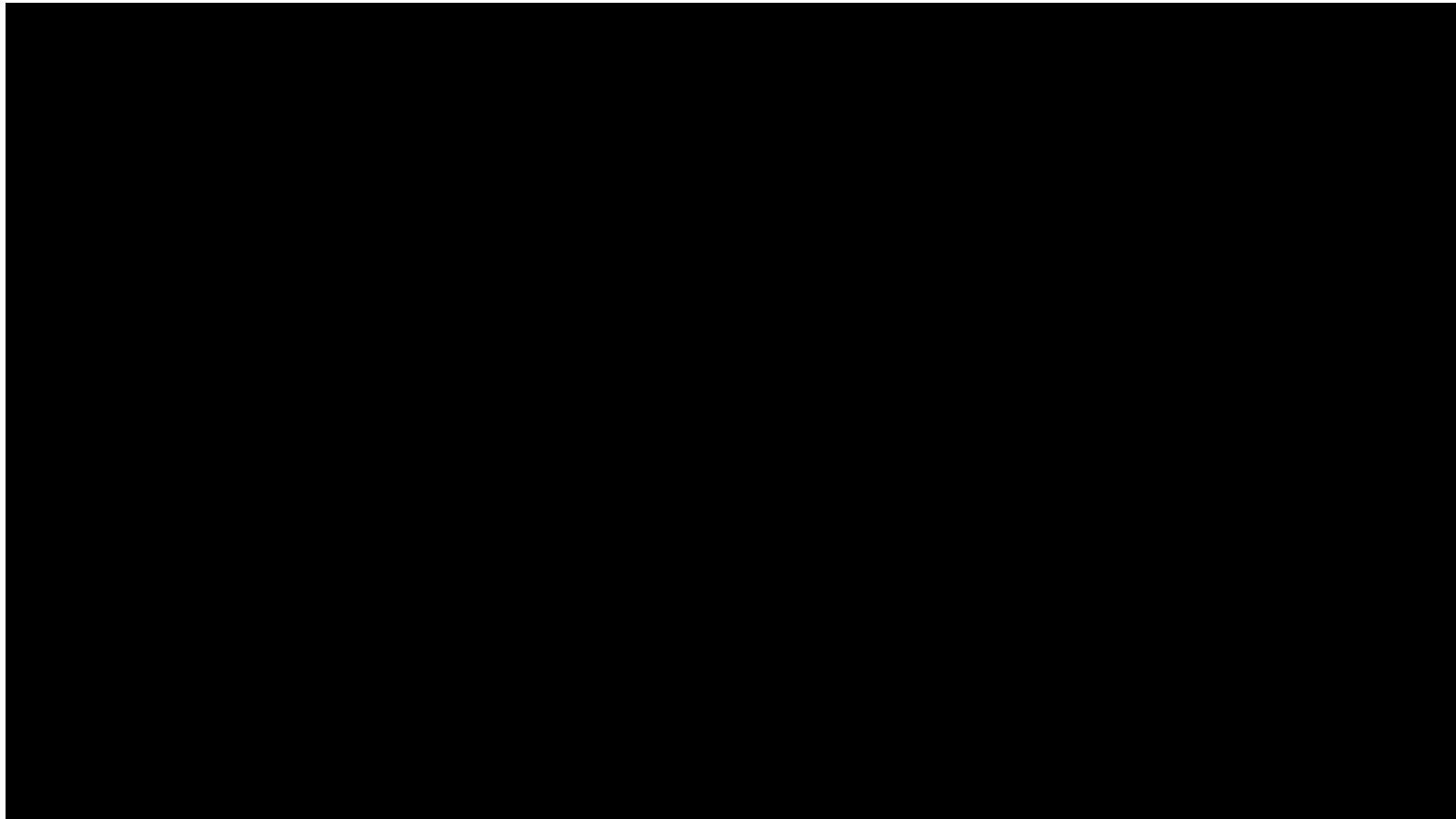
Bereavement Counselor with
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What will we learn?

- Understand the concept of ambiguous loss and how it relates to experiencing changes in an individual with dementia.
- Identify the different stages of dementia and accompanying losses experienced with each stage for caregivers.
- Identify three strategies for support and adaptation as caregivers experience ambiguous loss.





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What is ambiguous loss?

Merriam-Webster Definition of *ambiguity*

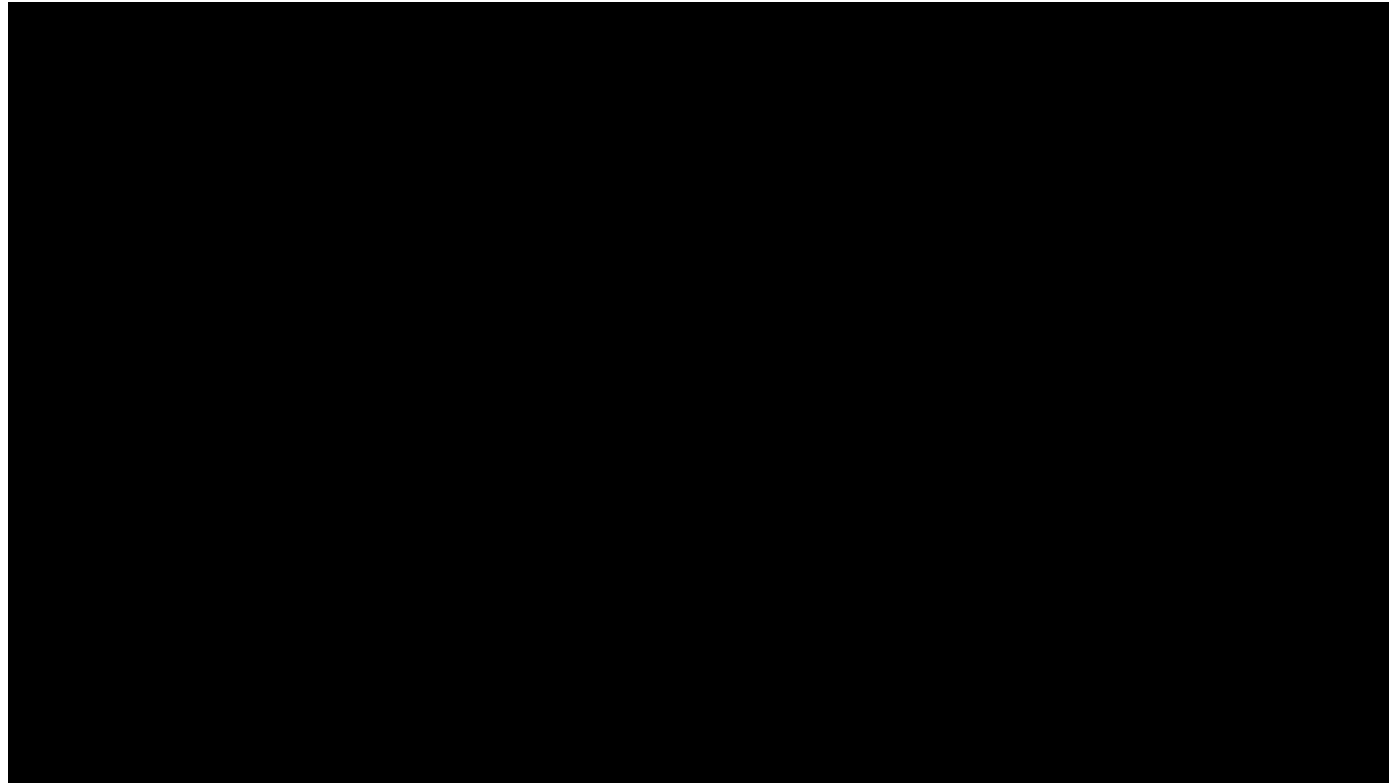
1a: the quality or state of being ambiguous especially in meaning.

The *ambiguity* of the poem allows several interpretations.

b: a word or expression that can be understood in two or more possible ways : an ambiguous word or expression

2: UNCERTAINTY





Pauline Boss, professor emeritus at the University of Minnesota, first coined the term *ambiguous loss* in the 1970s and has been researching and publishing on this theory since then.



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Defining ambiguous loss

Ambiguous loss is a unique type of loss with two basic configurations:

- Someone is perceived as *physically absent but psychologically present* because they have either died or are alive but separated
- Someone is perceived as *physically present but psychologically absent*, in that they are bodily present, but their mind and memory are gone





Why does it matter?

- Caregivers experience confusion
- It can prevent resolution of the loss
- Ambiguous loss can cause feelings of being stuck in grief





Differences and Commonalities in Loss Experience

- Losses for caregivers will vary depending on the relationship with the individual with dementia
- Research has shown that spouses tend to have a higher sense of duty or obligation than children of caregivers
- One commonality is that it is an emotionally distressing experience, at least some of the time
- Caring for a family member with dementia has been referred to as a 'career' in itself because of the impact that it can have on the family and daily life, lasting for many years

(Vella, 2014)



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Unique Characteristics of Grief

- Grief is a uniquely individual experience and will vary with each person
- Degenerative nature of dementia brings ongoing and ambiguous losses
- The losses are uncertain and incomplete
- Disenfranchised grief is grief that is not acknowledged or recognized by others or society, which means that support for coping may be unavailable to caregivers (Rentz et al., 2005)





Stages of Dementia and Ambiguous Loss

- Studies show that grief shifts as the disease progresses (Vella, 2014)
- Phases of ambiguous loss also shift as changes are experienced during disease progression (Dupuis, 2002)





Dementia and ambiguous loss: early/mild stage

- **Anticipatory loss** - psychologically present and involved in the family unit but ambiguity exists regarding the future (Dupuis, 2002)
- For spouses and partners – losses experienced by partner may include loss of companionship, predictability and feelings of fear and sadness
- For adult children – loss of freedom and support from siblings or others, may experience denial or lack of understanding

(Vella, 2014)





Dementia and ambiguous loss: middle/moderate stage

- **Progressive Loss** - involves living through and dealing with the gradual loss of a loved one and associated confusion (Dupuis, 2002)
- Adult children may shift from denial or lack of understanding to feeling emotions such as sadness, anger, frustration, jealousy and guilt
- Grief is highest at this stage for adult child caregivers, with the focus of loss still being inward
- Spouses/partners may experience an increase in sadness, empathy and compassion with a focus of loss on their life partner

(Vella, 2014)





Dementia and ambiguous loss: late/severe stage

- **Acknowledged Loss** – a perception that their loved one no longer psychologically exists (Dupuis, 2002)
- Loved one with dementia needs a higher level of care
- Adult children may experience a sense of relief along with sadness
 - Focus of loss is now on their parent and relationship with them
- Spouse / Partner may experience anger and frustration
 - Focus of loss shifts from their loved one to themselves

(Vella, 2014)





Loss for Spouses and Partners

As their loved one with dementia become psychologically absent while still physically present, spouses/partners often experience:

- Increased time and attention devoted to caring for their spouse / partner
- Challenges of having to think for their spouse during the entire day
- Loss of the essence of their spouse/partner
- Loss of their spouse/partner as their main companion and partner in life

(Vella, 2014)





Loss for Adult Children

As their elderly fathers or mothers with dementia become psychologically absent while still physically present:

- Adult children may be filled with mutually conflicting thoughts and feelings
- Anticipate even more loss, they both cling and push away
- Often feel guilty, because they fluctuate between wanting their parent to live – and die
- Both accept and reject the caregiving role and are confused about family roles and status

(Boss, 2004)





Ambivalence

- *Ambivalence*: those mixed emotions -- some positive some negative -- that exist at the same time
- Questions arise about confusing role changes
- Such questions reflect an ambivalence which can, if intense enough, paralyze family members into a state of helplessness.

(Vella, 2014)





Ambivalence

Swiss psychiatrist Eugen Bleuler stated:
Ambivalence may often be a normal reaction
to a relentlessly ambiguous situation.





Strategies for Adapting to Ambiguous Loss

Strategy 1

Learn more about your experience.

- Educate yourself about the mental, emotional, physical and spiritual aspects of grief felt while caregiving an individual with dementia (*Loving Someone with Dementia* by Pauline Boss)
- Watch YouTube videos, read books and articles and listen to podcasts (*On Being* podcast with Pauline Boss)
- Attend programs designed for caregivers





Strategies for Adapting to Ambiguous Loss

Strategy 2

Use meaning – making to reframe your experience.

- Name and acknowledge what you are feeling
- Accept the disease and your role as caregiver as a new way of life
- Live one day at a time, appreciating what you are grateful for
- Remember those in less fortunate circumstances
- Rebuild structure in a way that is organized and understandable





Strategies for Adapting to Ambiguous Loss

Strategy 3

Obtain support for yourself.

- Attend a support group for caregivers
- Seek individual counseling from a therapist, clergy or social worker in your retirement community
- Talk to trusted friends
- Reach out to ensure that your needs are addressed



A photograph of a person with a backpack standing in a vast, dry, mountainous landscape. The person is in the foreground, looking up at a large, rugged mountain peak in the background. The mountain is covered in patches of snow and has a steep, rocky slope. The foreground is a dry, brownish-yellow field with some small rocks and a winding path. The sky is blue with some white clouds.

“It is not the load that breaks you down.
It’s the way you carry it.”

— Lena Horne, singer



Questions? Comments?



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Thank you for joining us today!

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