

BAI BEACON

*The Newsletter from Family and Community Services
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Finding Myself beyond My Role as Caregiver

Who am I as a caregiver? I am a person who cares for my partner - spouse, parent, sibling or friend who has Alzheimer's disease (AD) or a related dementia. This is an unpaid position with a lot of responsibilities. And although there are times it is rewarding, there are equal times when I feel stressed, frustrated, resentful, and just downright confused. So what is the matter with me?

For years caregiver stress and burden have been studied and measured as actual outcomes resulting from caregiving. But as it turns out, the real culprit of these complex and sometimes uncomfortable emotions may actually be a unique type of loss experienced by caregivers of persons with dementia.

Ambiguous Loss is a theory developed by Pauline Boss, Ph.D., that describes loss that is unique to the caregiver experience. Ambiguous loss is a loss that is unclear; it has no resolution, and it has no closure. In dementia caregiving, ambiguous loss occurs *when the physical body is present but psychologically the person is absent or different than how they once were*. Dementia causes ambiguous loss. It is unclear, confusing, and unpredictable. It can't be cured or "fixed", and it has no closure. Dr. Boss notes the loss can be physical or psychological, but status as absent or present remains unclear. A family member is here but also gone; or gone but not for sure."⁽¹⁾

As the person with dementia changes in such significant ways, the ambiguity, coupled with loss, creates a powerful barrier to both coping and grieving for caregivers. Our culture has no familiar rituals for guiding behavior and bringing people together in support of your loss. And, there is real and deep sadness experienced by caregivers⁽²⁾. It is somewhat beyond our comprehension to imagine grieving



someone who is in front of us. That confusion as well as the lack of support for ambiguous loss often results in what Dr. Boss calls "frozen grief". It leads to inability to get things done, and can keep us feeling stuck. Dr. Boss writes, "What looks like depression is often sadness; what looks like anxiety is often the immense stress and confusion that comes from not being able to fix the situation. Family conflict often results. Isolation increases."⁽²⁾

Ambiguous loss differs from the loss we experience when someone dies. It creates complicated and chronic grief because it goes on too long. However, Dr. Boss says "the complication is due to the EXTERNAL context of ambiguity and not caregiver weakness."⁽¹⁾ This is important for caregivers to know. Complicated grief is to be expected with dementia, but it is not YOUR fault. Rather, it is the fault of the disease that causes the ambiguity. You are not sick, the situation is sick!

As a caregiver it is important to reflect on the losses you have experienced, and to honor and recognize continued losses as the disease progresses. Some losses shared by

Our Mission

To end Alzheimer's disease without losing a generation, to set a new standard of care for patients and their families, and to forge a model of collaboration in biomedical research.



Ask The Expert

Susy Favaro, LCSW, MSW
Social Worker, Stead Family Memory Center

Dear Susy,

My mom has been diagnosed with Alzheimer's disease. Some days she recognizes that she is forgetting and needs help, but other times she fiercely denies that anything is wrong. Her mood is changeable, unpredictable, and she is often angry and resentful if I try to help. I am an only child. Her friends are often critical of me. I feel confused, overwhelmed and guilty. Nothing I do seems to be right. What can I do?

Signed,
Barbara

Dear Barbara,

Dementia can be erratic, and change from moment to moment, leaving caregivers to question themselves. Your feelings of guilt, overwhelm (and probably even anger) are normal. You are experiencing grief and loss as you witness these changes in your mom's illness that you can't control. We have learned that dementia causes a unique type of loss in caregivers known as ambiguous loss. That is, your mom is physically present but psychologically absent/or different from how she once was. Subsequently, this has changed your relationship with your mom and it will continue to become more one sided as the illness progresses.

Since you can't control your mom's illness or the situations that arise, you have to make a decision to control what you can and let go of those things for which you have no control. There will need to be a shift in your thinking that now allows you to be both her daughter and her caregiver (which may at times seem more like her parent). This may include a conscious choice to live with a less than perfect relationship than what you've known in the past.

While you care for your mom it is important for you to develop new and secure connections with others to balance what is changing. Allow yourself to grieve what has changed or been lost, but celebrate what is left in your mom and your relationship. Consider exploring caregiver support groups and talking with supportive friends and family who allow you to express your feelings. And, don't forget to care for yourself. You know your mom would want that for you!



Have a Question?

To submit your question for future consideration email us at: baiinfo@bannerhealth.com

Did you know, Banner Alzheimer's Institute is a not-for-profit and relies on financial contributions of the community to support programs and services offered to our patients and families? Make a gift and join our community of friends, call 602-747-GIVE (4483) or visit www.banneralz.org/support-our-mission.

caregivers include: the loss of time, the loss of the reciprocal relationship they once had, loss of the hopes and dreams, and at times confusion and loss of their previous role.

When the illness is unpredictable, uncertain, and changeable and there is no cure; the only option to feeling less stressed is to decide to see the situation in a different way. We can change our perceptions which can help us find hope and connect to the person as they are right now - instead of wishing for them to be the way they used to be.

So how do we get started in finding hope and increasing our tolerance of ambiguity?

Dr. Boss provides seven guidelines that she describes as flexible suggestions to assist in increasing one's tolerance in living with ambiguity. She asks that you reflect on these alone and talk with others about them. These are not steps that need to be accomplished in any order. She writes, "Tailor them to your own needs. Your goal is not perfection, but rather doing the best you can to take care of yourself on a journey that is long and stressful."⁽³⁾

Find Meaning:

It can be difficult to find meaning when everything you thought you knew about the person and your relationship with him/her is changed because of dementia. The use of "paradoxical thinking" can be helpful. It is the ability to hold two opposing thoughts in your mind, both of which are true. Paradoxical thinking uses *both/and* instead of *either/or* thinking. It can help you recognize that your relationship as it once was has changed, AND it is still a relationship. Examples of both/and thinking include: I can take care of my mom AND take care of myself. I am sad about our lost hopes and dreams AND I look forward to some things in my future. This type of thinking helps us focus on the here and now; to enjoy the time we have with our person instead of longing for what has been changed or lost. Finding meaning has to do with making sense of the loss. Having a name, ambiguous loss, can help define what is happening and help us find some hope for the future. Some caregivers discover new traits and behaviors within the dementia that are endearing and were not expressed previously; such as an ability of the person with dementia to express appreciation to the person providing care. Other strategies include: use of spirituality, forgiveness of self/others, and adapting family rituals to meet the new needs of the person with dementia.

Balance Control with Acceptance:

Ours is a culture of mastery. We value our ability to solve problems and fix things. But dementia is an illness that we cannot control or fix. When we can't control the disease, we CAN control or change the way we perceive it. When we can't solve the problem of ambiguity, we can and need to create a new goal. That is, to decide to accept a less than perfect situation/solution. We need to decrease our self-blame and instead externalize it by understanding the disease caused the ambiguity. We take control of what we can; such as taking time for self, nurturing one's body and spirit with music, literature, mindfulness, physical exercise, taking time with friends and having fun.

Broaden Your Identity:

Our identity gets confused with dementia as caregivers ask: "Am I still married if my husband doesn't recognize me as his wife?" "Am I still the son if I am taking care of my dad?" Broadening your identity has to do with revising your identity to fit the ambiguity. The answer is "yes," we can have more than one identity. You can use paradoxical thinking to understand you can be a child AND a parent (caregiver) when the situation calls for it. This is the time to reexamine family roles and rules, to adjust if necessary. If family is unable to be as supportive as you need them to be, this is the time to adopt a "psychological family". This is a family of choice to assist with care and can include non-family members such as support group members and other friends who are supportive to you and your person.

Manage Your Mixed Emotions:

Ambivalent feelings create positive and negative feelings toward the person with dementia that are contradictory, cause great angst and guilt within caregivers. Feelings of wishing that the situation was over and then feeling guilty because of what that would mean, are normal emotions and to be expected in the stress of living with ambiguity. It is important to recognize our uncomfortable feelings to prevent acting on them in a negative manner. Dr. Boss notes that ambiguity feeds ambivalence, ambivalence feeds the uncertainty about which action to follow, which decision to make, which role to play, or which task to perform⁽²⁾. It is important to talk with others, and at times with professionals to understand you are not alone.

Hold On and Let Go:

Because the relationship with the person with dementia is fundamentally changed, it is common for a caregiver to question the attachment to that person. The goal now is to revise the attachment as opposed to detaching. Part of revising the attachment is forming new attachments with others. Dr. Boss suggests, "Let go while also honoring and remembering (both-and); recognizing that your loved one is both here and gone (grieve what you lost, celebrate what you still have), finding new human connections with people who are fully present."⁽²⁾ We reframe how we think about the relationship, it is not absent but it has been modified and needs to be adapted to fit the reality of the disease.

Imagine New Hopes and Dreams:

Dreams of the future can help you to keep going. It is imperative to take care of your person and look for new hopes for your future simultaneously (both/and). Hope comes from making peace with the ambiguity; by learning to allow ourselves to feel comfortable with unanswered questions; to understand that some problems don't have solutions and some things cannot be fixed. Additional strategies that help: use of spirituality, laughing at absurdity, redefining justice; feeling good about yourself even if things don't go your way.⁽¹⁾

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Finding Myself beyond My Role as Caregiver

continued from inside

Caring for yourself and someone else is a balancing act. Dr. Boss writes, "The question of how to be a good caregiver has multiple answers, but taking care of yourself is always one of them."⁽²⁾ Take time for yourself, ask for and accept help, and stop being so hard on yourself. Be aware of your own emotional state and seek out professional help if needed. Find and connect with a supportive community to feed your soul while you continue to care for your person.

To summarize; ambiguous loss is a chronic ongoing loss resulting from the ambiguity of absence and presence. It is an irresolvable loss with symptoms similar to complicated grief. It affects relationships. It can cause caregivers to feel immobilized and can cause significant personal and relational stress.

To increase your comfort living with ambiguity, let go of your need for certainty and embrace ambiguity toward increasing your own resiliency. Recognize your ongoing sadness as it ebbs and flows and talk with others about it. Make a conscious choice to change your perceptions of a situation and diagnosis that cannot be changed. Find hope in ambiguity and meaning in a relationship that

has changed. All of this leads to resilience and maturity as you understand that bad things do happen to good people, the world isn't always fair and "the ego can't always have its way"⁽¹⁾.

"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 you control."⁽²⁾

To learn more about this topic, we invite you to join dementia and caregiving expert Susy Favaro as she leads the Dementia Dialogue webinar/teleconference on Wednesday, November 16 from 12N-1p AZ time. Register online at www.banneralz.org. Click on 'Events and Education' then 'Online Education' or call 623-832-3248.

References:

1. Boss, Pauline. (2016). How to Find Hope While Coping with Stress and Grief, Duet Caregiver Symposium.
2. Boss, Pauline. (2011). Loving Someone Who Has Dementia. San Francisco, CA: Jossey-Bass Publisher.
3. Boss, Pauline. (2006). Loss, Trauma and Resilience: Therapeutic Work with Ambiguous Loss. New York, NY: W.W. Norton & Company, Inc.



CAREGIVER EDUCATION PROGRAM SCHEDULE

December 2016/January 2017

DECEMBER

Transitioning Care

Transitioning from home to a residential care setting can be challenging for caregivers and the person with dementia. This class will discuss the importance of planning and considerations when making the transition from one level of care to another.

Tues., December 6; 4:00 – 6:00 p.m.
BAI, 901 E. Willetta Street, Phoenix
To register, call (602) 839-6850

BSHRI Community Lectures: Holidays and Grief

The Holiday Season is quickly approaching and for many people that signifies joy. For others who may be caregiving for someone with Alzheimer's disease or Parkinson's disease or struggling with the recent loss of a loved one the holiday season may feel stressful. Lori Nisson, LCSW will explore the emotions that may surface, how to better manage them and offer strategies to enhance self-care during this time.

Wed., December 7; 10:00 – 11:30 a.m.
BSHRI, 10515 W. Santa Fe Dr., Sun City
To register, call (623) 832-3248

Dementia Friendly Presents: Emotional Impact of Living with Memory Loss

This class will focus on helping you better grasp the common emotional

changes that may occur in the person with dementia. Learning to better understand emotional changes can help you to increase your level of empathy and reduce caregiver frustration.

Wed., December 14; 1:00 – 2:30 p.m.
Tempe Library
3500 S. Rural Road, Tempe
Free, registration not required

Good News in AD Research

Now is a new era of Alzheimer's disease (AD) treatment and care. As leaders in AD prevention and treatment research, some of the most exciting advances are happening in Arizona. Join one of our researchers to learn how you can make a difference.

Tues., December 20; 10:00 – 11:30 a.m.
Mesa Red Mountain Library
635 N. Power Rd., Mesa
To register, call (602) 839-6850

Dementia Dialogue Webinar: Finding Myself Beyond My Role as Care Partner

Caregiving can be an incredibly rewarding role while also creating feelings of overwhelm. This dialogue will focus on strategies to infuse hope and meaning into your life while, balancing necessary care for you and your person.

Wed., December 21; Noon – 1:00 p.m. (AZ Time). Register online at www.banneralz.org under events/education

and then online education. All webinars are recorded and put on our website 24-48 hours after the "live session".

JANUARY

Dementia Dialogue Webinar: Understanding Emotional Changes in People Living with Memory Loss

People with dementia often experience their own feelings of loss or even apathy. This Dialogue will explore how to better understand the person's emotional needs, provide adequate support and increase our own feelings of acceptance.

Wed., January 18; Noon – 1:00 p.m. (AZ Time). Register online at www.banneralz.org under events/education and then online education. All webinars are recorded and put on our website 24-48 hours after the "live session".

As Dementia Progresses: Next Steps for Caregivers

This class outlines the moderate to advanced stages of dementia, how common symptoms can be managed, how to cope with changing function while assisting caregivers to find success in their daily efforts.

Thurs., January 26; 10:00 a.m. – Noon
BAI, 901 E. Willetta St., Phoenix
To register, call (602) 839-6850

Please turn over for more classes →

Communication Tips to Avoiding Arguments

This 2 hour class review changes in communication as dementia progresses and the common mistakes that caregivers make leading to arguments. A variety of alternative strategies are introduced and practiced during class so that caregivers can walk away with new techniques to immediately put into place!

Mon., January 30; 2:00 – 4:00 p.m.
BSHRI, 10515 W. Santa Fe Dr., Sun City
To register, call (602) 230-CARE (2273)

MULTIPLE MONTH CLASSES

Planning Ahead Class for Caregivers

This two-hour class reviews necessary planning for legal, financial and medical decisions for someone with Alzheimer's disease/ related dementia or a movement disorder. Included is an overview of community resources and agencies, how to find help and pay for care in the home, community, and residential care.

Tues., December 13; 10:00 a.m. – Noon
Tues., January 10; 4:00 – 6:00 p.m.
BAI, 901 E. Willetta St., Phoenix
To register, call (602) 839-6850

Banner Brain Health Program

Learn how lifestyle choices can minimize the risk of Alzheimer's disease and then "flex" your cognitive muscles as you determine how to exercise your brain! This class teaches and provides tips for healthy adults how to use certain activities to help improve cognition, memory and recall. **Cognitively Normal Adults.

Wed., December 7; 1:00 – 3:30 p.m.
Wed., January 11; 1:30 – 4:00 p.m.
BSHRI, 10515 W. Santa Fe Dr., Sun City
To register, call (602) 230-CARE (2273)
AND

Wed., December 14; 1:00 – 3:30 p.m.
Tues., January 31; 9:30 – Noon
BAI, 901 E. Willetta St., Phoenix
To register, call (602) 230-CARE (2273)

COMPASS: Directions for Caregivers After the Dementia Diagnosis

Over 90-minutes caregivers are introduced to the basics of disease

progression, treatment and care. In addition, caregivers will learn to implement 8 practical strategies to avoid many of the common problems that arise when caring for the person with dementia.

Wed., December 14; 1:00 – 2:30 p.m.
Tues., January 10; 1:00 – 2:30 p.m.
BSHRI, 10515 W. Santa Fe Dr., Sun City
To register, call (602) 230-CARE (2273)
AND

Thurs., December 15; 4:00 – 5:30 p.m.
Mon., January 9; 12:30 – 2:00 p.m.
BAI, 901 E. Willetta St., Phoenix
To register, call (602) 839-6850
AND

Tues., January 17; 10:00 – 11:30 a.m.
Mesa Red Mountain Library
635 N. Power Road, Mesa
To register, call (602) 839-6850



To learn about upcoming education and support programs dates at:

- Banner Alzheimer's Institute, visit www.banneralz.org and click on "Events Calendar" icon or call Deidra Colvin, Events Coordinator at 602-839-6850
- Banner Sun Health Research Institute, visit www.bannershri.org and click on "Events and Education" or call Veronica Flores, Events Coordinator at 623-832-3248

These programs are made possible by the generous support of the Banner Alzheimer's Foundation.



Banner Alzheimer's Institute
Banner Sun Health Research Institute