



Duet

Partners In Health & Aging

CAREGIVER SUPPORT

Maricopa Association of Governments

2018 Human Services Conference

December 4, 2018



Duet: Partners in Health & Aging

- Non-profit organization serving Maricopa County since 1981
- Interfaith, founded by Reverend Dr. Dosa Carlson and the Church of the Beatitudes
- All services free-of-charge

Duet's Mission

To promote health and well-being through vitally needed services to homebound adults, family caregivers, faith communities, and grandfamilies.



Duet's Vision

A community where every person ages with compassion, dignity and hope.





Duet's services focus on four main areas:

- Volunteer services provided to homebound adults
- Support for family caregivers
- Support for grandparents raising grandchildren
- Support provided to Faith Communities looking to establish/ maintain health and wellness programs



Family Caregivers—America's Silent Army

- 40 million unpaid family caregivers in U.S.
- 37 billion hours of care valued at \$470 billion in unpaid care

- *In Arizona...*
 - Approximately 800,000 family caregivers
 - Providing \$12 billion annually in unpaid care



Who is considered a Caregiver?

- Refers to anyone who provides unpaid care to a family member, friend or loved one
- Care provided can include:
 - Direct, physical care
 - Indirect care managing living arrangements, household chores, respite care, medical needs, etc.
 - Emotional care and support



The “Sandwich Generation”

- The average age of a mother at the birth of her first child is increasing.
- Older birth rates = older parents.
- Effective support will benefit 3 generations.



Family Caregivers

- In Arizona, family caregivers are required to meet the care needs of the more than 130,000 persons with dementia.
- Compared to other caregivers, twice as many family caregivers of people with dementia report substantial financial, emotional and physical challenges.

Caregiver Self-Identification

Once a caregiver self-identifies, they are **over 90%** more likely to look for resources and support.



The Caregiving Journey

- Different for everyone
- Common themes that significantly impact caregivers' quality of life:
 - Social isolation
 - Grief associated with ambiguous loss
 - Lack of self-care



Caregiver Self-Care

- Foregoing self-care is often the first, and most significant sacrifice that caregivers make for their loved one
- Lack of self-care rarely happens intentionally
- Difficult to address when high ambiguity, high caregiver burden





Common Barriers to Seeking Support

- Lack self awareness
- Don't want to hurt their loved one's feelings
- Already overwhelmed, and it's one more responsibility
- Time and shifting priorities
- Hesitant to ask for help
- Unaware that support services exist



Alzheimer's and Related Dementias

- More than 5.7 million Americans have Alzheimer's disease
- In 2017, 16.1 million family caregivers in the U.S. provided an estimated 18.4 billion hours of unpaid care for people with Alzheimer's and other dementias valued at \$232 billion



Alzheimer's and Related Dementias

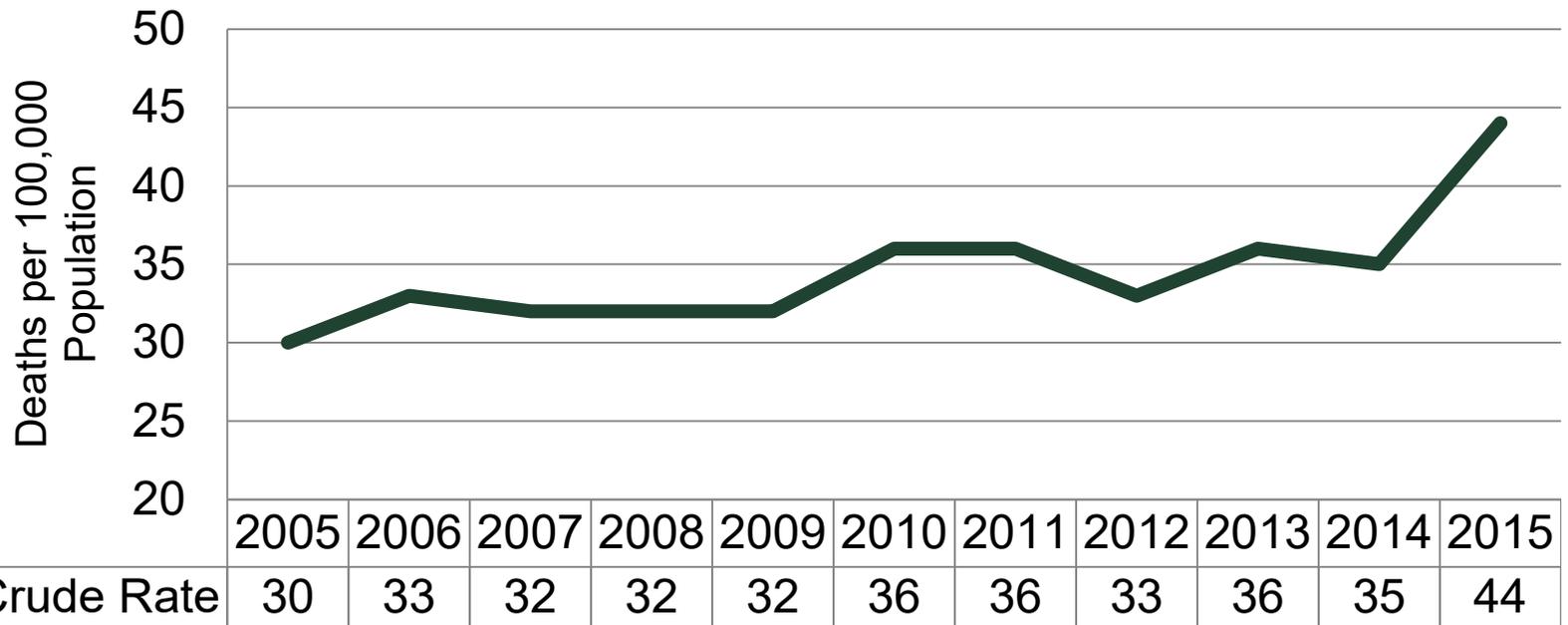
- Number expected to triple by 2050
- By 2050, cost of care could rise to \$1.1 trillion
- By 2030 nearly half of Americans living with Alzheimer's will be Latino or African American



Alzheimer's Disease accounts for 60-80% of Dementia Cases

- “Alzheimer’s is the most under-recognized threat to public health in the 21st Century.”~
Dr. David Satcher, former U.S. Surgeon General and former CDC Director

Mortality Crude Rate for Alzheimer Disease, 2005-2015





Leading Cause of Death

- ❑ United States Deaths, 2016: Alzheimer's was the 6th leading cause of death; some believe with full reporting it would be the 3rd. Without full reporting, it is expected to reach the 4th leading cause of death in 2050.
- ❑ Arizona Deaths, 2015: Alzheimer's was the 5th Leading Cause of Death, a 182% increase since 2000



Arizona, Looking Ahead

- In Arizona, the number of people aged 65 and older with Alzheimer's is expected to increase by 42.9% by 2025.

2018: 140,000

2025: 200,000



Not only a Higher Mortality Rate

- Arizona, 2017: The higher health care costs for Caregivers who were caring for someone with Alzheimer's were estimated at \$187,000,000.

Alzheimer's disease: Family Caregivers

- Caregivers who experience stress while caring for loved ones with dementia die at a rate 63% higher than people the same age who are not caring for someone with dementia

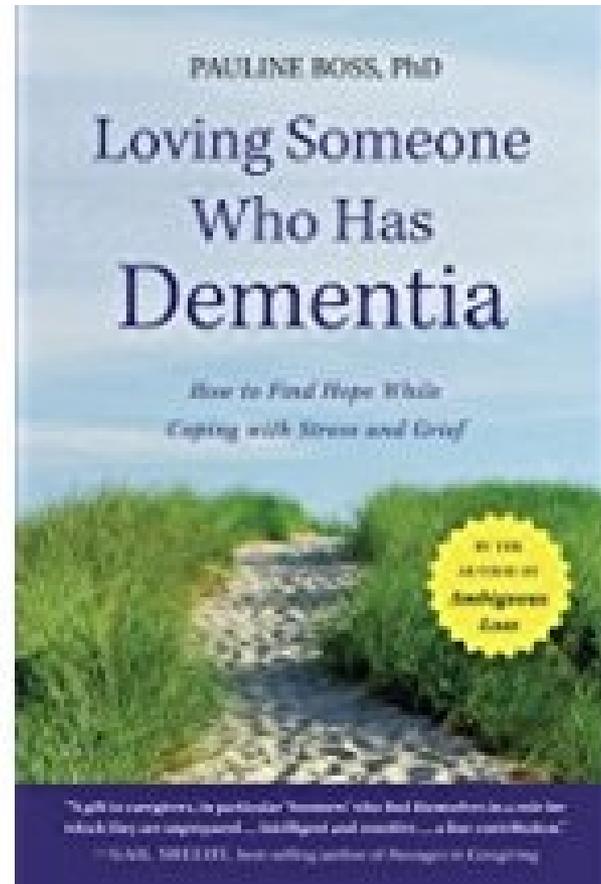


Ambiguous Loss

*Loving Someone
Who Has Dementia:
How to Find Hope
While Coping With
Stress and Grief*
(Jossey-Bass, 2011)

Available at

www.amazon.com





What is Ambiguous Loss?

- Term coined by Dr. Pauline Boss to describe the complicated grief that many caregivers typically experience
- A loss that's unclear, can't be fixed, and has no closure.
- 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.



Causes of Ambiguous Loss

- Loved one is no longer the person they were
- Loss of relationship as it was before
- Loss of control over one's life due to ambiguity
- Role changes, role reversals and loss of previous identity
- Loss of one's future/dreams

Effects of Ambiguous Loss

- Chronic sadness or depression
- Anxiety
- Hopelessness
- Identity confusion
- Helplessness
- “Frozen Grief”





What Professionals and Society Need to Know

Caregiving is dangerous to one's health. Caregivers need the people in their life - work colleagues, health care professionals, faith community members, family and friends - to be more understanding of the sheer complexity of their daily existence. Their journey of trying to do the right thing in an untenable situation is long and hard, and it requires more acknowledgment and community support to come through it with their health and wellbeing intact.

Pauline Boss, PhD



To Summarize . . .

- Ambiguous loss is the most difficult loss. Unlike death, the pain is ongoing and has no closure.
- Ambiguous loss requires caregivers to do both-and thinking, seeing your loved one as BOTH here AND gone.
- Through this new lens, caregivers can find meaning and hope despite their ambiguous losses.



How Does Ambiguity Create Stress?

- Immobilizes caregiver and relationships
- Confuses decision making
- Freezes grief
- Blocks coping



Possible Effects on Caregiver

- Depression; sadness of grief
- Anxiety, guilt, shame
- Ignores self-care
- Stress-related illness
- Substance abuse
- Possible abuse



Sadness vs. Depression

- Sadness: mildly grieving and unhappy, but still functioning; oscillation.
Intervention: human connection, peer groups, social support and activities.
- Depression: sadness so deep one cannot function; cannot care for self or others.
Intervention: professional psychotherapy, family therapy, perhaps medication.

(Adapted from Boss, 2011, pp. 26 & 130.)



The Myth of Closure

Goal: resilience, not closure.



Living Well Without Closure Requires Both-And Thinking

- She is both gone—and still here.
- I take care of both him—and myself.
- I am both a caregiver—and a person with my own needs.
- I have both the anxiety of no closure—and the opportunity to move forward with new relationships and interests.
- I am both sad about my lost hopes and dreams—and happy about some new hopes and dreams.



Resiliency-based Techniques to Cope with Ambiguous Loss

- Grow psychological family
- Identify community support
 - Spiritual
 - Recreation and respite
 - Information and referral sources
- Maintain & modify family rituals, celebrations & gatherings
- Accept the good-enough relationship



Seven Guidelines for Caregiver Resiliency & Hope

1. Find Meaning
2. Balance Control with Acceptance
3. Broaden Your Identity
4. Manage Your Mixed Emotions
5. Hold on *and* Let Go
6. Imagine New Hopes and Dreams
7. Take the Time to Mind Yourself

Additional References

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- Doka, K. (1989). *Disenfranchised grief: Recognizing hidden sorrow*. New York: Lexington Books.
- Faust, D. G. (2008). *The republic of suffering*. New York: Vintage.
- Freud, S. (1957). Mourning and melancholia. In J. Strackey (Ed.), *The standard edition of the complete psychological works of Sigmund Freud* (pp. 237-258). New York: Norton. (Original work published 1917.)
- Kubler-Ross, E. (1969). *On death and dying*. New York: McMillan.
- Lindemann, E. (1944). Symptomatology and management of acute grief. *American Journal of Psychiatry*, 101, 141-148.
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- van der Kolk, B. A., McFarlane, A. C., & Weisaeth, L. (Eds.). (1996/2007-paperback). *Traumatic stress*. New York: Guilford.
- www.ambiguousloss.com

***Caregivers do not have to go through
this journey alone...***



Connecting Caregivers to Resources & Support



Duet Caregiver Services

○ Caregiver Support Groups

- Source of ongoing support
- Valuable tips, information, and resources
- Build your “psychological family”
- Opportunity to socialize





Duet Caregiver Services

○ **Information & Referral Services**

- Personalized guidance according to caregiving situation
- Help caregivers build “caregiver toolkit”
- Connect to available resources in Maricopa County



Duet Caregiver Services

○ **Caregiver Mentor Program**

- A “support group of one”
- Connect with another caregiver who understands the journey
- Once per week, over the phone
- Mentors are ready to: listen, provide tips, help bounce ideas



Duet Caregiver Services

- ***Finding Meaning and Hope* video discussion series**
 - 10-week series designed to help you reduce stress and build resilience
 - Based on “Loving Someone Who Has Dementia” by Dr. Pauline Boss
 - Helpful for all caregivers (not just Dementia)
 - Various groups throughout the Valley
 - <https://youtu.be/OqhC1g1imuk>

Connecting to Resources & Support





Maricopa County Alzheimer's Caregiver Support Providers

Alzheimer's Association Desert Southwest Chapter
Area Agency on Aging Region One
Arizona Department of Economic Security, Div. of Aging
Banner Alzheimer's Institute
Benevilla
DUET
East Valley Adult Services
Foothill Caring Corps
Foundation For Senior Living
Glencroft Senior Living
Hospice of the Valley
Neighbors Who Care
Verde Cares



The Area Agency on Aging, Region 1

“We advocate, plan, coordinate, develop and deliver services for adults aged 60+, adults aged 18+ with HIV/AIDS, adults aged 18+ with disabilities and long-term care needs, and family caregivers.”

- 24-Hour Senior HELP LINE at 602-264-HELP (4357), Toll Free at 888-783-7500
- For the hard of hearing and deaf, TEXT (520) 775-1899 SMS (Short Message Service).
- The Elder Resource Guide (Maricopa County) published by (available online at aaaphx.org)



AARP and Dementia

“Disrupt Dementia – Sparking bold new solutions for the world’s brain health Crisis”

- Prepare to Care: Anticipate and Plan
- Articles – News, Education, Health and Inspiration
- Support for Caregivers

<https://www.aarp.org/health/dementia/>



The Alzheimer's Association

24/7 Helpline 800.272.3900

Individualized Support, Support Groups, Research, Clinical Trials

- Know the 10 Signs: Early Detection Matters
- Understanding Alzheimer's and Dementia
- Dementia Conversations
- Driving, Doctor Visits, Legal & Financial Planning
- Effective Communication Strategies
- Healthy Living for Your Brain and Body
- Understanding/Responding to Dementia-Related Behavior
- Legal and Financial Planning for Alzheimer's Disease
- Living with Alzheimer's



AARP and The Alzheimer's Association Join Resources

“The Alzheimer's Association & AARP Community Resource Finder allows caregivers to search available resources in their area by simply entering their zip code. The database includes listings for a wide range of services, including:

- Housing options.
- Care at home.
- Medical services.
- Legal services, including elder law attorneys.
- Community services, such as adult day centers and transportation.
- Alzheimer's Association information, programs and services.
- AARP information, programs and services.”

<http://www.communityresourcefinder.org/>



*Arizona Department of Economic Security,
Division of Aging*

- Family Caregiver Support Program (FCSP)
- Training for Professional Caregivers
- Arizona Caregiver Coalition
- Arizona Respite Locator
- AZ Links
- <https://des.az.gov/services/aging-and-adult/division-aging-and-adult-services>

Connecting Caregivers to Resources & Support

- Help yourself to our resource table handouts!
- Q&A



We're Here to Help!

Family Caregiver Services

Duet: Partners In Health & Aging

(602) 274-5022

[www. Duetaz.org](http://www.Duetaz.org)

Thank you!

