

# Finding Hope in Alzheimer’s Disease:

## Helping Caregivers Understand Ambiguous Loss and Increasing Resilience

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MN/ND Chapter of Alzheimer’s Association

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# The Inspiration

Bridget Brown-Leonard, MSW, LICSW  
Jess Steinbrenner, MSW, LICSW  
Pauline Boss, MSW, PhD  
Ted Bowman, MSW, PhD

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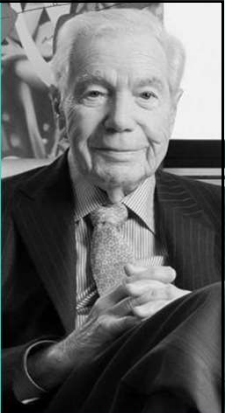
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*“Do things here and now, not after you’re gone. If you have some money, share it. And if you have some time, do something worthwhile.”*

-Jerome Stone



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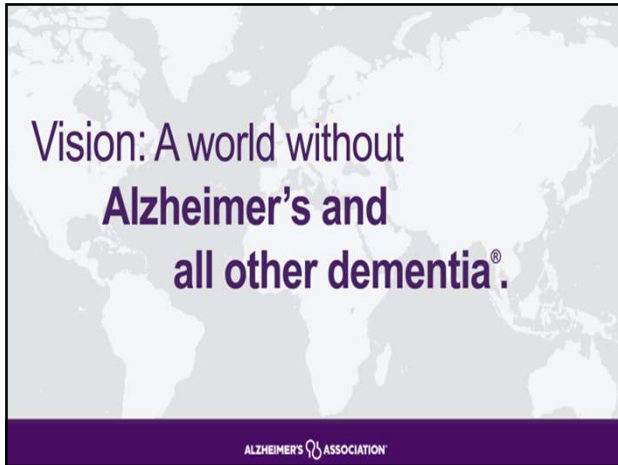
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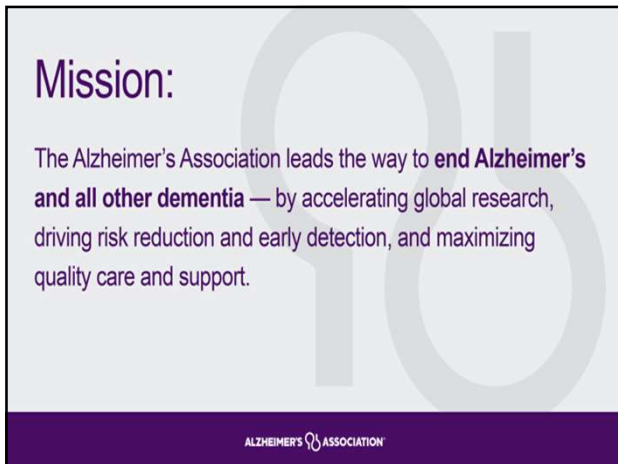
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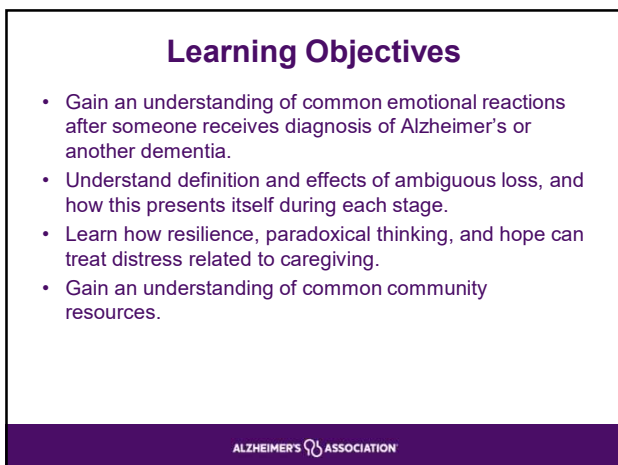
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## Disclaimer

There are many thoughts and feelings after receiving a diagnosis. There is no "right or wrong way" to process the diagnosis.

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## Dementia:

An 'umbrella' term used to describe a range of symptoms associated with cognitive impairment

### Types of Dementia

- Alzheimer's
- Vascular
- Lewy body
- Frontotemporal
- Other, including Huntington's
- Mixed dementia: dementia from more than one cause

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Let's begin by discussing common feelings associated with receiving a diagnosis...



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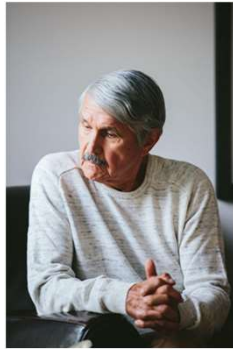
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## Common Feelings

- Relief
- Depression
- Anxiety
- Sadness
- Anger
- Hopelessness
- Confusion about identity  
("Who am I now?")



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## With Dementia....

- Losses can be subtle and slow.
- Still looking at the same person.
- Hard to know when to hang on and when to let go.
- There are many secondary losses associated with Alzheimer's.

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*We do not live an equal life, but one of contrasts and patchwork; now a little joy, then a sorrow, now a sin, then a generous or brave action.*

Ralph Waldo Emerson

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### A Few Words about Guilt...

- Regret over relationship pre-diagnosis.
- Having unrealistic expectations.
- "I should have....I would have....I could have...."
- Feeling badly for wanting to take a break.
- "I have failed."



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### And... Anxiety

- Financial worries.
- Uncertainty about relationships with others.
- Concerns about stigma and telling others.
- Isolation.
- Not aware of community resources or support.
- What to do when disease progresses?
- How will I manage?

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yourbeautifulife.org

"Feelings are  
just visitors,  
let them come  
and go."

-Mooji

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## Why does an Alzheimer's Diagnosis Cause These Reactions?



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## Ambiguous Loss

Definition: **Loss** that occurs without closure or understanding. This kind of **loss** leaves a person searching for answers, and thus complicates and delays the process of grieving, and often results in unresolved grief.

Pauline Boss

Who Has Dementia"

"Loving Someone

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## Ambiguous Loss (as it applies to Alzheimer's)

Physical absence with physical presence (and/or psychological absence with psychological presence) :

The person living with Alzheimer's is physically present AND the person living with Alzheimer's can have a variety of physical/psychological impairments-depending on the stage.

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### Early Stage Alzheimer's

- May appear physically 'normal,'  
-AND-  
person may have functional decline in IADL's such as:
  - paying bills, keeping track/organizing appointments, losing items, and/or word-finding difficulties.
- Loss may not be readily apparent to people not close to the individual.

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### Middle Stage Alzheimer's

- Appears physically normal  
-AND-  
person may begin to display more observable changes to the general public.
- Mood/personality/behavior changes
- Increased confusion
- Impairment with ADL's
- Wandering
- Forgetful of personal events/past

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### Late Stage Alzheimer's

- May be physically present  
-AND-  
display symptoms that is consistent with an medical condition.
- May need round-the-clock physical care, display changes in physical abilities-walking, sitting, and eventually swallowing.
- May have a great deal of difficulty with communicating preferences.

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### Underlying Secondary Losses

- Driving
- Traveling
- Wage earner
- Title/role
- Disease trajectory
- Relationship you once had
- Traditions
- Stigma
- Independence
- Isolation
- Freedom
- Change of finances
- Home
- Shared history
- Intimacy
- Others?

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### Resilience

Defined as a psychological capacity to bounce back from adversity, uncertainty, conflict.

"With ambiguous loss, resilience means having a high tolerance for ambiguity." (Boss, 2006, 2022).

Many paths to resilience through family, cultural and spiritual beliefs, and community.

**\*\*Caution:** this assumes agency and power. In some communities-'resilience' can have different meaning.

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### Tools to Promote Healthy Coping

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## Clients are Experts!

### A few things we have learned through our work:

- Grief process must be acknowledged and normalized.
- It's not easy to ask for help.
- Wish they would have set up help sooner.
- Relationships can get sticky!
- Able to manage better when what they can and can't control are identified.



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## Acceptance

"Acceptance stops you from feeding more energy into the negative experiences, thus disempowering the attention black holes that might be lodged in your memory."

Dr. Amit Sood, Mayo Clinic

"Attention & Interpretation Therapy (AIT): A Personal Workbook"

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## Accepting the Diagnosis

- Blame the disease, not the person.
- Teach caregivers to be gentle and non-judgmental with themselves, their family and friends.
- TALK about the disease.
- Normalize the natural shifts in responsibilities and roles.

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## Developing a “New Normal”

"When there's no cure to an illness or condition, the only window for hope is to become more comfortable with ambiguity and a less than perfect relationship."

-Pauline Boss, author of "Loving a Person with Dementia"



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## Dualistic View

- Caregivers can be BOTH sad about lost hopes and dreams AND happy about some new hopes and dreams.
- They can be both a caregiver, and a person with their own needs.
- They can be both relieved there is a diagnosis and sad about what the diagnosis means.

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## Interventions to take with you...

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## Helping to Find Meaning & Purpose

"What makes you feel connected to others?"

"What makes you get out of bed in the morning?"

"What are you good at?"

"What are you passionate about?"

"What activities energize you? What drains you?"

"What brings you gratitude, hope, and joy?"

Gently nudge caregivers to live in the here and now. Eliminate should'ing, would'ing, could'ing.

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## Finding the Hopeful Side of Change

### Activity:

Think about one or two of the most difficult times in your entire life.

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## Activity

- What gave you the strength to keep going?
- Who was there for you?
- How did you cope?
- What lessons did you learn about life and about yourself?
- How did your life change as a result?

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### The Hopeful Side of Change: Lessons Learned

How we've dealt with change, loss, death, fear  
in our past,  
is how we will deal with it now,  
unless we work on cultivating tools on how we  
cope.

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### The Hopeful Side of Change: Lessons Learned

If caregivers feel like they are "losing it," it's probably  
because they are feeling ALONE/ISOLATED.

It's the signal to help them GET CONNECTED.

TEACH them to FOCUS ON THE PRESENT, AND  
WHAT HAS TO BE DONE TODAY.

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### Change Requires Awareness

Teach caregivers to stop, look, and listen to what  
they are saying in their head, to others, to  
themselves, and ask....

"IS THIS TRUE?"

"DO I WANT THIS TO BE TRUE?"

IF NOT, EJECT IT FROM THEIR THOUGHTS.

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## My Advice

Promote and use tools that work best for individual caregivers. There is no one-size-fits-all approach.

Support groups, home care, asking for help, online education/support, individual counseling, family counseling may all have merit, but it's the caregiver who decides what will work best.

*When in doubt, encourage the next small step.*

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## THE "NITTY GRITTY"

- Keep learning!
- Ask for help and be specific.
- Connect and stay connected.
- Embrace the paradox. Life is a series of Both/And's! Stay in the moment and build meaning.
- Caregiving does not define who the person is-it is one role.



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## Alzheimer's Association

- 24/7 Helpline: 1-800-272-3900
- Website: [www.alz.org/mind/](http://www.alz.org/mind/)
- Care Consultation
- Support Groups
- Education
- Advocacy
- Research

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### Additional Community Resources

- MN Senior LinkAge Line 1-800-333-2433
- MN Help ([www.mnhelp.info](http://www.mnhelp.info))
- ND Aging and Disability Resource Link 1-855-462-5465
- Medicare
- Senior Housing/Placement Services
- Insurance Counseling
- Transportation
- Respite programs

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### Veteran Health Administrative Resources

Diagnosis and evaluation  
Home Care  
VA Caregiver Support (1-855-260-3274)  
Respite  
Firearm Safety  
Driver Evaluation  
Home Modifications  
Adult Day  
OT/PT  
Home-Based Primary Care  
Research Studies

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Be content with what you have;  
rejoice in the way things are.  
When you realize there is  
nothing lacking, the whole  
world belongs to you.  
- Lao Tzu

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THANK YOU!



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