



Navigating Transitions Part III:

*Understanding a Person-Centered Approach
to the Dementia Journey*

Adapting relationships and grief during transitions

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Transition

Understanding common types of grief

Grief & Related Concepts

- **Grief:** *Denial, Pleading, Bargaining, Anger, Acceptance - Anxiety, Depression*
- **Mourning:** Outward expression of grief
- **Anticipatory Grief:** Grieving current losses and anticipating more grief/loss in future
- **Ambiguous Loss:** Having someone physically present, but relationally absent (from the way they were previously known – husband no longer recognizes wife and she must take on primary responsibilities). Losses feel *ambiguous* because there is no typical 'closure'
- Other losses: Personal, Relational, Intimacy, Financial, Planned Future, Social

Typical grief

- Period of sadness and depressive symptoms
- Decrease within a month
- Normalize within a year



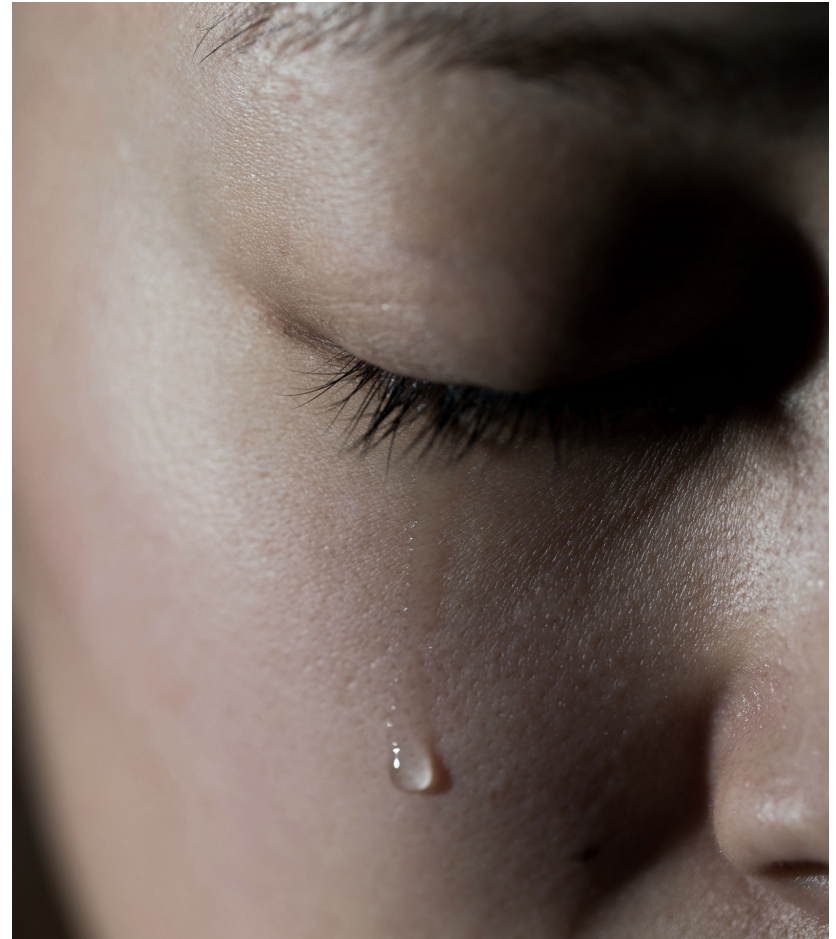
Anticipatory Grief



- Experiencing bereavement in advance of loss
- Involves mourning, coping, planning
- Psychological and social adaptation

Complicated Grief

- Persistent and disruptive
- Key symptoms
 - Trouble accepting death
 - Inability in trusting others
 - Excessive bitterness
 - Uneasy about moving on
 - Detachment
 - Sense that life is meaningless
 - No hope for future
 - Feeling agitated



Ambiguous Loss or Disenfranchised Grief



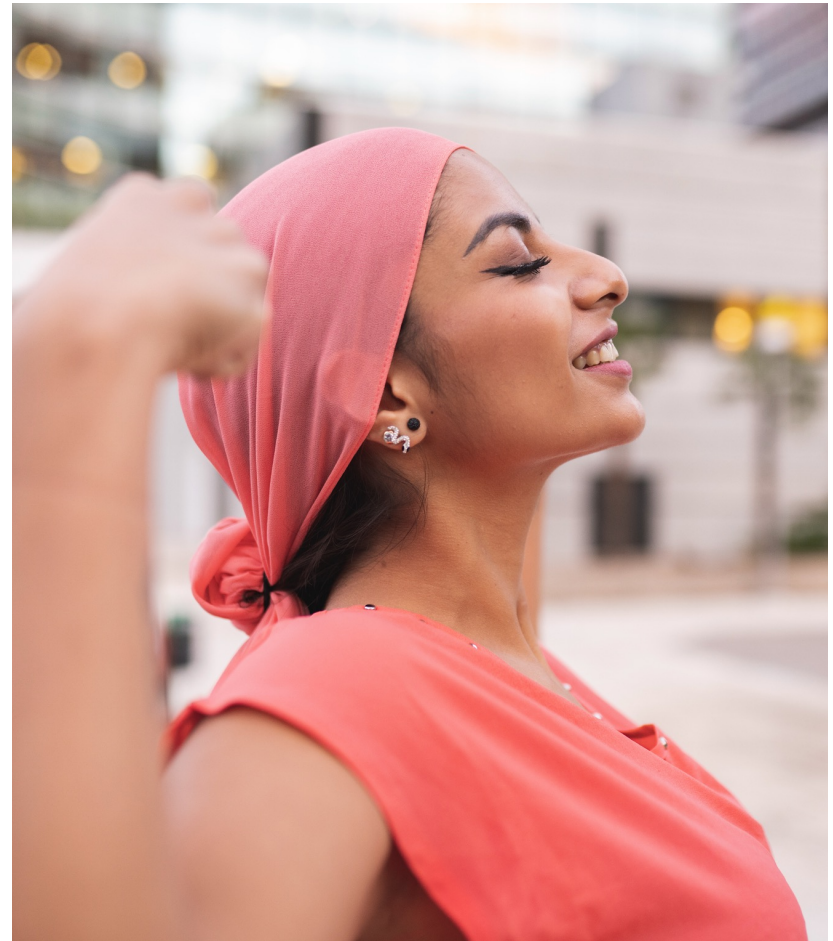
- Physically present but psychologically gone or markedly altered
- Emotions are unusual and uncertain

Transition

The emotions related to the grieving process

Preparing for Grief – Building Resilience

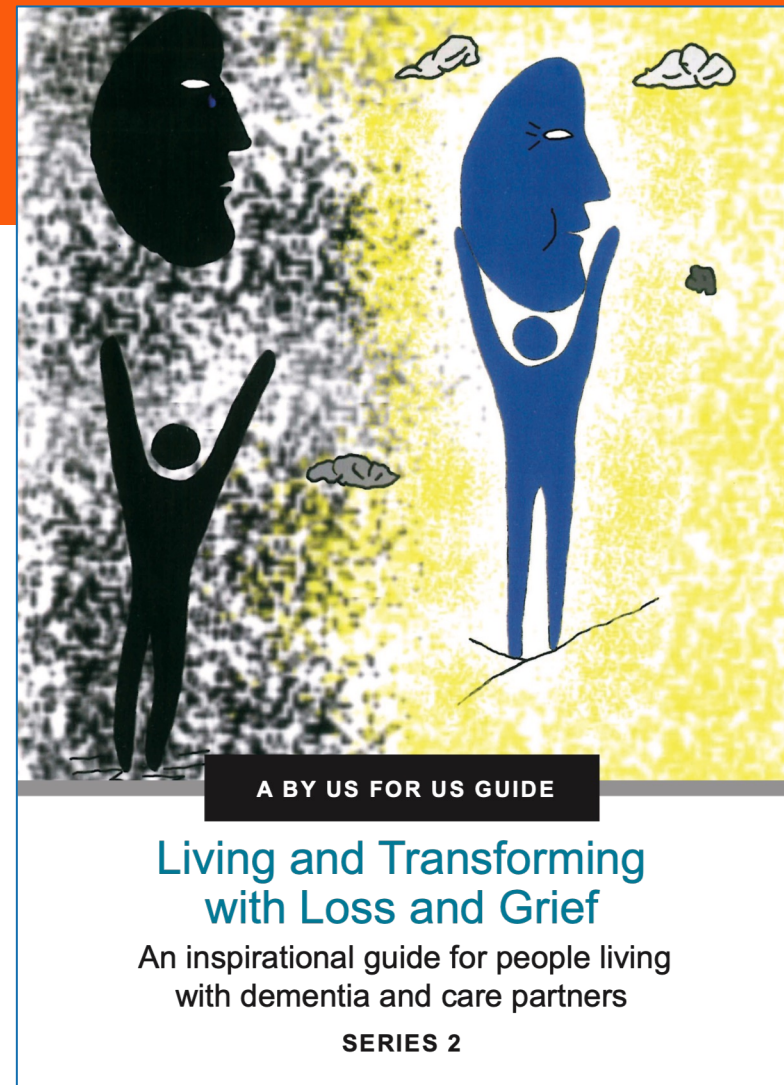
- Preparing
- Getting through acute grief
 - Laughter and joy amid sadness
 - Seeking silver lining
 - Reflecting on life
- Anticipatory grief
 - Correlates with assisting in living in the community
 - Adapting to difficult situations
 - Greater lifestyle constraints



A By Us For Us Guide

The By Us For Us guides are a series of guides created by a group of talented and passionate people living with dementia and care partners. The guides are designed to provide people living with dementia and their care partners the necessary tools to enhance their well-being and manage daily challenges.

Research Institute on Aging
Murray Alzheimer's Research
Education Program



<https://the-ria.ca/resources/by-us-for-us-guides/>

Living with loss and grief continued

Tips for communicating and sharing with others

- ✓ find a person who was always there for you and talk to them - use them as support and let them know that you 'just need to talk'
 - More grief may occur if you tell the wrong person; they pull away and don't acknowledge your feelings and experiences.
- ✓ put others at ease by being open and honest about dementia
 - I'd rather tell them that I have Alzheimer's disease than be embarrassed.
- ✓ don't presume that people know what you need; help them, tell them what you need
- ✓ share advice - this may give you a sense of value, contribution, and being proactive
 - We're pretty much the same and dealing with the same issues and if not, we exchange tips on how to deal with them.



For more information on communicating with others refer to the By Us For Us Guide: **Enhancing Communication.**

Living with loss and grief continued

Transforming with loss and grief

Although the process of dealing with loss and grief can be difficult and ever present in the dementia journey, many individuals have been able to transform their loss and grief and find a "silver lining". This reminds us all that it is still possible to have joy, love, laughter, and hope while living with dementia. This section will highlight the positive outcomes that some people living with dementia and care partners have experienced in transforming with loss and grief.

Positive outlook

Acceptance with respect to a disease that can affect every part of your life may seem difficult, but growing into a new reality can make room for meaningful new possibilities. As illustrated below, some individuals have been able to keep a positive outlook.

- I learned - be patient, remain calm, adjust and accept.
- I still have a very positive attitude. My favourite saying is, "I am still on the right side of the grass"!! I went to friends' funerals this year and they are not here to enjoy life!!!
- Here and now are most important along with lots of laughter. I also make time to do things I like and renew my spirit so I can continue to stay in the moment.

Living the Experience – Richard Taylor



"Am I becoming something or someone that I wasn't, or am I losing something that I was and will no longer be? Is my life filled with new opportunities for growth, happiness, and enjoyment, or has my life been emptied of opportunities as I sadly shrink into someone nobody knows, including myself?"

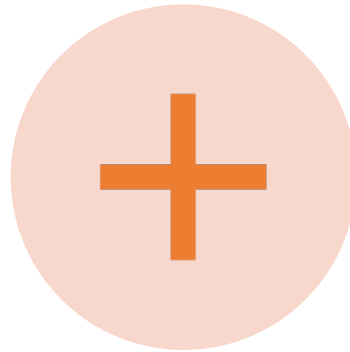
Alzheimer's From the Inside Out, 2007, pg. 104

Richard Taylor, PhD, Person living with the symptoms and the diagnosis of dementia – probably of the Alzheimer's type

Strategies for Ambiguous Loss



NAME EMOTIONS



EMBRACE “BOTH/AND”
THINKING



EXPAND YOUR TEAM



CONTINUE FAMILY
RITUALS



FIND SOMETHING NEW
TO HOPE FOR

Complicated Grief



- May benefit from specialized therapy
- Learn new skills
- Support groups for grief

Responding to Grief – The Six Needs of Mourning

The Journey Through Grief: The Six Needs of Mourning - by Alan D. Wolfelt, PhD

- Need 1: Acknowledging the reality of the death
- Need 2: Embracing the pain of the loss
- Need 3: Remembering the person who died
- Need 4: Developing a new self-identity
- Need 5: Searching for meaning
- Need 6: Receiving ongoing support from others

<https://www.centerforloss.com/2016/12/journey-grief-six-needs-mourning/>

Transition

Adapting to the grieving process

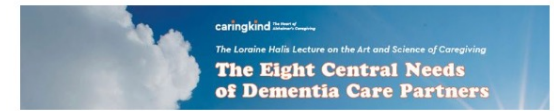
8 Central Needs of Dementia CarePartners

1. Tell and retell your story
2. Educate yourself
3. Adapt to changing relationships
4. Grieve your losses
5. Take care of yourself
6. Ask for and accept help from others
7. Prepare for what's ahead
8. Explore existential and spiritual questions to find meaning

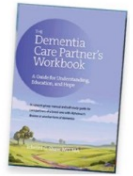
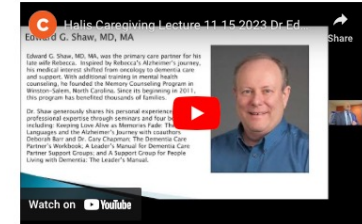
Edward Shaw, MD, MA. (2019.)

A Leader's Manual for Dementia Care-Partner Support Groups, p. 96-97.

<https://caringkindnyc.org/caregivinglecture/>



With Edward G. Shaw, MD, MA
Wednesday, November 15, 2023



Based on Dr. Shaw's book *The Dementia Care Partner's Workbook*, this talk describes the eight most important needs all dementia care partners have in their caregiving role to a loved one with Alzheimer's disease or another form of dementia. This framework provides understanding, education, and hope for dementia care partners on their long journey of caregiving.

Edward G. Shaw, MD, MA, was the primary care partner for his late wife Rebecca. Inspired by Rebecca's Alzheimer's journey, his medical interest shifted from oncology to dementia care and support. With additional training in mental health counseling, he founded the Memory Counseling Program in Winston-Salem, North Carolina. Since its beginning in 2011, this program has benefited thousands of families.

Dr. Shaw generously shares his personal experiences and professional expertise through seminars and four books including: *Keeping Love Alive as Memories Fade: The 5 Love Languages and the Alzheimer's Journey with coauthors Deborah Barr and Dr. Gary Chapman*; *The Dementia Care Partner's Workbook: A Leader's Manual for Dementia Care Partner Support Groups*; and *A Support Group for People Living with Dementia: The Leader's Manual*.

We wish to extend deepest gratitude to The Hallis/Scolin Family for their extraordinary support of our caregiver programs and services.

Transitions

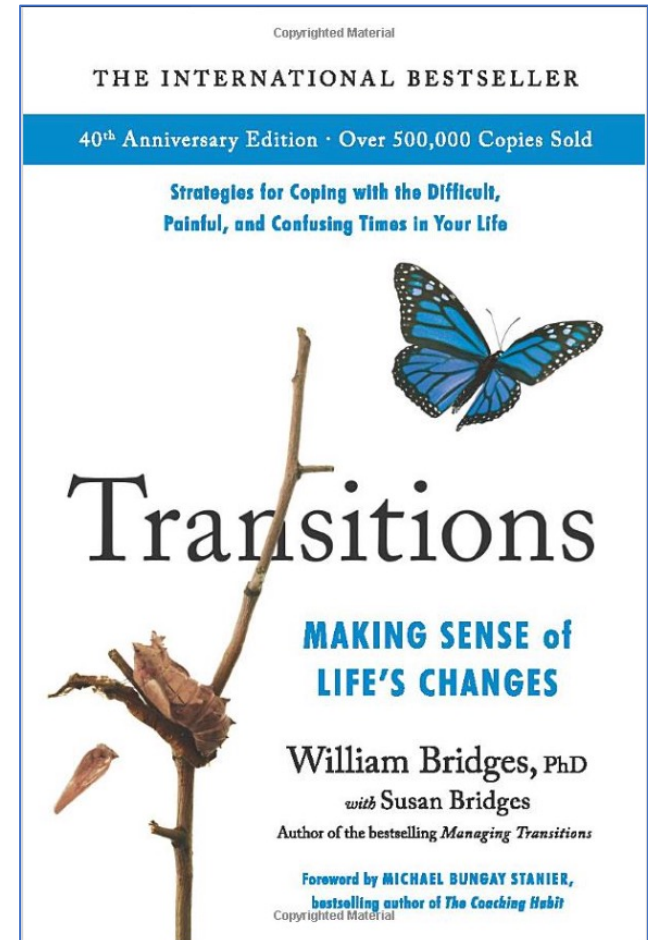


Transitions – William Bridges

Three Phases of Transition

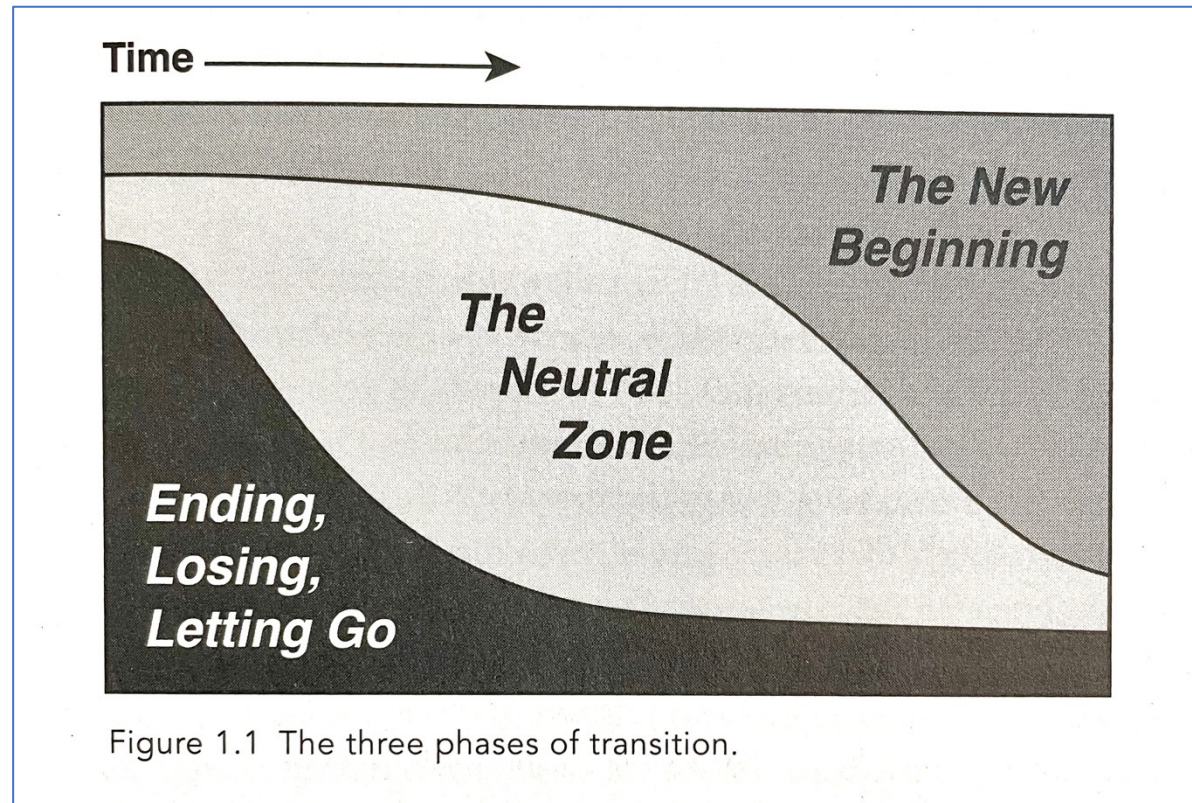
1. Ending, Losing, Letting Go
2. The Neutral Zone
3. The New Beginning

Transitions: Making sense of Life's Changes, 2004. William Bridges, PhD.



Transitions – begin with ending... finish with beginning

Because transition is a process by which people unplug from an old world and plug into a new world, we can say that transition begins with an ending and finishes with a beginning.



Managing Transitions: Making the Most of Change, 4th Edition, 2016. William & Susan Bridges. Page 5

3 Phases of Transition

Ending, Losing, Letting Go

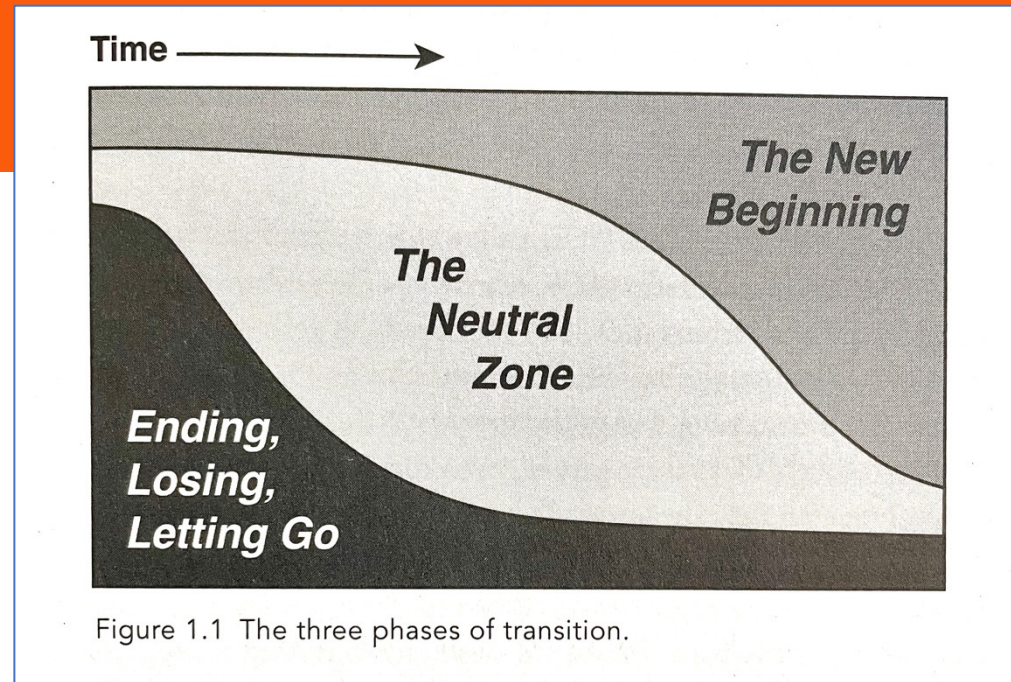
Letting go of the old ways and the old identity people had. This first phase of transition is an ending and the time when you need to help people to deal with their losses.

The Neutral Zone

Going through and in between time when the old is gone but the new isn't fully operational. We call this time the neutral zone: it's when the critical psychological realignments and repatterning's take place.

The New Beginning

Coming out of the transition and making a new beginning. This is when people develop the new identity, experience the new energy, and discover the new sense of purpose that makes the change begin to work.



Phases of Adjusting to Chronic Illness/Disability

Paterson 2001

Illness

Wellness

Kralik 2002

Extraordinariness

Ordinariness

Jarrett 2000

Uncertainty

Regain Self

Whittemore 2008

Living Illness

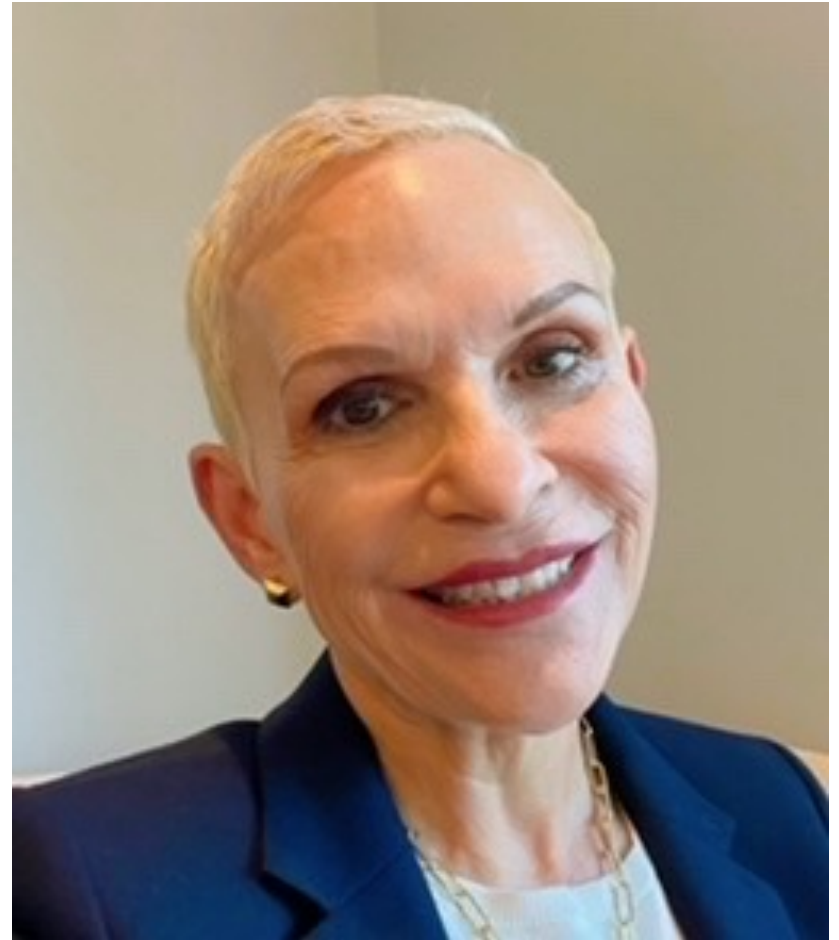
Living Life

Adapting to the Progressive Illness

"I did not want to share my diagnosis for fear that someone would report me, and I would lose another freedom"

Teresa Webb, RN

Your True North pg. 12-13



'Readiness' for change



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Companioning Model of Care – Dr.
Alan Wolfelt

Honoring the spirit, not focusing on intellect

Curiosity, not expertise

Learning from others, not teaching them

Walking alongside, not leading

Being still, not frantically moving forward

Discovering the gifts of sacred silence, not filling every painful moment with words


Listening with the heart, not analyzing with the head

Bearing witness to the struggles of others, not directing those struggles

Being present to another person's struggles and pain, not taking them away

Respecting disorder and confusion, not order and logic

Turning inward and going into the wilderness of the soul with another human being, not thinking you are responsible for helping them find the way out

A young green plant sprout with several leaves is growing out of a crack in the ground. The background is a blurred, textured surface of soil or gravel.

"We bereaved are not alone.
We belong to the largest
company in all the world – the
company of those who have
known suffering."

- Helen Keller

caringkind

Talk to a
Navigator

646-744-2900



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Saturday, October 19, 2024 • 10 am
Central Park Naumburg Bandshell

Join Us at
New York City's
Longest-Standing
Alzheimer's
Awareness Walk and
Brain Health Day
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REGISTER VOLUNTEER [CKWALK.ORG](https://www.ckwalk.org)

For over 45 years CaringKind has been your Trusted Partner in Alzheimer's and related dementia care. Our mission is to be a compassionate ally for everyone, ensuring no one faces this journey alone.

For more information,
contact Samantha Vaccaro
at walk@cknyc.org or 646-744-2979

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QUESTIONS

WE HAVE THE ANSWER