

Making Sense of the Mess: Understanding the Grief of Dementia, and the Power of Perspective and Self-Care.”

Kay Adams, LCSW Compassion Works, LLC
303-875-5508 kay@kaymadams.com
www.kaymadams.com



Perspective...

What you see
depends not only on
what you look AT,
but also on
where you look FROM.



-- James Deacon

Perspective is Everything!



Learning Objectives



Identify the most common forms of dementia, and the behavioral changes associated with them.

Describe the concepts of anticipatory grief and ambiguous loss, and how they relate to dementia caregiving.

Understand the power of perspective and self-care for dementia care partners.



What
is
dementia

- Not a specific disease
- Describes a group of symptoms
- Has multiple causes
- Decline in memory or other thinking skills severe enough to impact daily activities
- May see the term ADRD (Alzheimer's Disease and Related Dementias)

Copyright © 2019 Kay Adams. All rights reserved.



Umbrella of Dementia

- Alzheimer’s Disease
- Vascular Dementia
- Lewy Body Dementia
- Frontotemporal Dementia

Alzheimer’s Disease

- Is a degenerative brain disease. The most common cause of dementia--6th leading cause of death 65+
- Symptoms: Difficulties with memory, language, problem-solving and other cognitive skills that affect a person’s ability to perform everyday activities.
- Difficulties occur because nerve cells (neurons) in parts of the brain involved in cognitive function have been damaged or destroyed (brain failure).

Alarming Statistics:

Source: 2019 Alzheimer’s Association Facts and Figures

- **Currently 5.8 million Americans age 65+ are living with Alzheimer’s.** By 2050, that number is projected to be 13.8 million barring the development of medical breakthroughs to prevent, slow or cure Alzheimer’s disease.
- **83% of the help provided to older adults in U.S is done so by family, friends and other unpaid caregivers.** The 18.5 billion hours of care provided to people living with dementia is valued at nearly \$234 billion.

More Alarming Statistics:

Source: 2019 Alzheimer’s Association Facts and Figures

- 1 in 10 people age 65 and over in the United States has Alzheimer’s disease. Of those people, 2/3 are comprised of women.
- Between 2000 & 2017– Deaths from heart disease have decreased by 9% while deaths from Alzheimer’s have increased by 145%.
- 1 in 3 seniors die with Alzheimer’s or another dementia. It kills more than breast cancer and prostate cancer combined.

More Alarming Statistics:

Source: 2019 Alzheimer’s Association Facts and Figures

- **Dementia is one of the costliest conditions to our society.** It is estimated that Alzheimer’s Disease and Other Dementias will cost \$290 billion in 2019 for health care, long-term care, and hospice.
- The total per-person health care and long-term care payments in 2018 for all sources for Medicare beneficiaries with Alzheimer’s or other dementias was **3 times greater for PLwD** than for the same age group without dementia (\$48,977 compared to \$13,976 per person).

Normal brain vs Brain with Alzheimer’s



Alzheimer's Disease

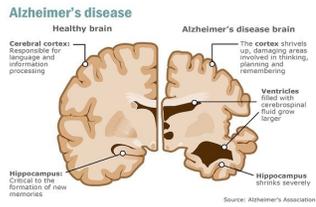
- Is a degenerative brain disease. The most common cause of dementia--6th leading cause of death 65+
- Symptoms: Difficulties with memory, language, problem-solving and other cognitive skills that affect a person's ability to perform everyday activities.
- Difficulties occur because nerve cells (neurons) in parts of the brain involved in cognitive function have been damaged or destroyed (brain failure).

"It's been said that Alzheimer's is like having a thin sliver of your brain shaved off every day... It's been said that, in 25 years, there will be two kinds of people in the world: those with Alzheimer's and those caring for someone with the disease."



Greg O'Brien-- from On Pluto: Inside the Mind of Alzheimer's

Hippocampus



Positron Emission Tomography (PET)

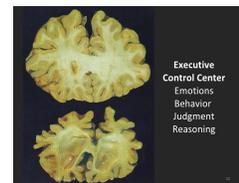
Alzheimers Disease Progression vs. Normal Brains



Changes in Occipital Lobe



Changes in Executive Control Center



- Remember
- Plan, process and Reason
- Organize and multi-task
- Regulate mood, behavior, & impulses
- Communicate— comprehension & speech
- See— visual/spatial changes (driving)
- Coordinate fine motor skills

Dementia

Impacts

Ability

To:

50% have NO insight

50% ARE aware of changes

- Of them, 30% are anxious
- 20% are angry

Teepa Snow, Positive Approach to Care



Behavioral and Emotional Concerns with Alzheimer's Disease

- **Early Stages**
 - Depression
 - Anxiety
 - Poor Sleep
 - Decreased Activity
 - Increased Isolation
 - Ambiguous Loss

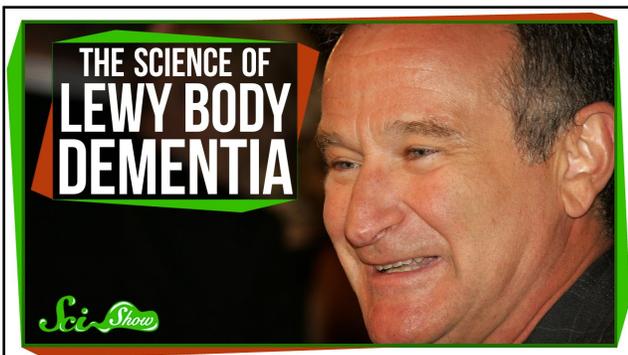


Copyright©2019 (Kay M. Adams) all rights reserved.

From "On Pluto" by Greg O'Brien



"In the space of a bleak afternoon, my identity in the real world... was on hold... The assimilation of urgency was choking—bucket lists of cleaning up relationships, end-time planning that we all like to put off, and the strategies of surviving financially, physically, and emotionally.... I wasn't alone. Yet, I felt so isolated."



Behavioral Symptoms of Lewy Body Disease

- Increased risk of depression
- Rapidly fluctuating cognition
- Acting out dreams: REM sleep disorder
- Recurrent, complex visual hallucinations that are well-formed and detailed
- Delusions
- Movement symptoms—similar to PD



Copyright©2019 (Kay M. Adams) all rights reserved.

Behavioral Symptoms of bvFTD

- Lack of Insight
- Disinhibition/Impulsivity
- Apathy and lack of initiative
- Emotional Blunting
- Compulsive or Ritualistic Behaviors
- Hyperoral Behavior
- Abrupt mood changes



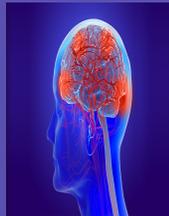
Copyright©2019 (Kay M. Adams) all rights reserved.

Vascular Dementia



Signs & Symptoms of Vascular Dementia

- Confusion
- Trouble with attention/concentration
- Difficulty organizing tasks or activities
- Problems with memory & decision-making
- Restlessness & agitation
- Unsteady gait
- Depression or apathy
- Stair-step progression



CTE-- Chronic Traumatic Encephalopathy

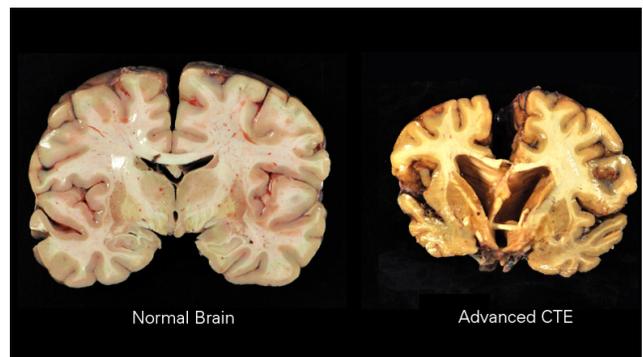


Chronic Traumatic Encephalopathy (CTE)

- Associated with repeated blows to the head
 - "punch-drunk syndrome"
- Problems with thinking and memory
- Personality & Behavioral changes
 - Aggression
 - Depression
 - Suicidal thoughts

Source: Alzheimer's Association

Copyright©2019 (Kay M. Adams) all rights reserved.





Common Behavioral Expressions in Dementia

- Anger, anxiety, agitation, aggression, apathy
- Sleep disturbances
- Sundowning and disinhibition
- Pacing and wandering
- Hallucinations and delusions

Copyright©2019 (Kay M. Adams) all rights reserved.

Behavioral Changes in Later Stages

- Frustration with inability to communicate
- Paranoia due to confusion
- Responding to a perceived threat with fear, aggression
- Restlessness, pacing
- Sleep Disruptions
- Hallucinations
- Delusions



Copyright©2019 (Kay M. Adams) all rights reserved.

Unmet Physical Needs

Hungry or thirsty
Tired or over-energized
Elimination– need to/did
Temperature– too hot/too cold

In Pain:
Mouth, joint, insides (gut, heart, bowels)

Teepa Snow– Positive Approach to Care

Unmet Emotional Needs

Angry, sad, lonely, scared

BORED!



Copyright©2019 (Kay M. Adams) all rights reserved.

BREAK TIME



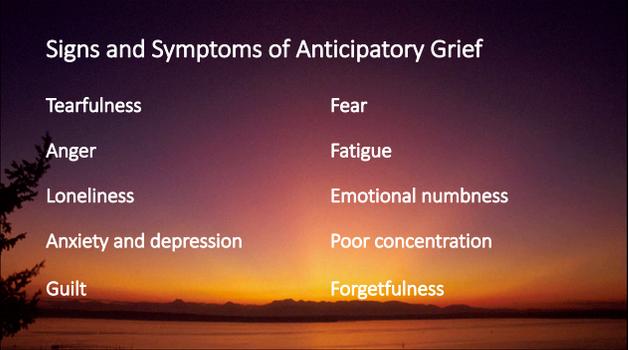
Anticipatory Grief:
The emotional pain and sadness that arises far in advance of an expectant loss or death.



Copyright©2019 (Kay M. Adams) all rights reserved.

Signs and Symptoms of Anticipatory Grief

Tearfulness	Fear
Anger	Fatigue
Loneliness	Emotional numbness
Anxiety and depression	Poor concentration
Guilt	Forgetfulness





Ambiguous Loss:

Interacting with someone who is not fully present socially or psychologically.

Copyright©2019 (Kay M. Adams) all rights reserved.



Sandwich Story

Copyright©2019 (Kay M. Adams) all rights reserved.

Profound Impact that Dementia Has on Relationships



SONG– Blank Stares by Jay Allen
<http://smarturl.it/BlankStares>



Copyright©2019 (Kay M. Adams) all rights reserved.

The Water Bottle Story



The longer we hold it, the harder it gets.



Copyright©2019 (Kay M. Adams) all rights reserved.

Grief is...

The natural process of reaction and adjustment to loss and change.

Intense sorrow: mental, physical, emotional, spiritual and physical suffering.

A transforming experience



Grief-- The Emotion We Perhaps Fear Most

3 most foundational elements of grief:

Loss, Longing and Feeling Lost



LOSS...

Of what could be

Of what we thought we knew or understood about something or someone.



LONGING...

Not Conscious wanting.

An Involuntary yearning for wholeness, opportunity, for meaning.

For the opportunity to regain or even simply touch what we've lost.

Can come out of nowhere and be triggered by something you didn't even know mattered.



FEELING LOST...



Grief... requires us to reorient ourselves to every part of our physical, emotional and social worlds.

— Brene Brown



Loss— from the perspective of a PLWD



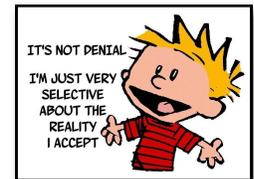
“The trip to Pluto, a metaphor of survival instinct for my flight from reality, can be a comfort, a release from the angst, fear, sadness, and rage—a surrender to the numbness, those unfathomable blank stares, to feel peaceful again, avoid the pain of losing control.... There are days I have to prompt myself to come back.”

-- Greg O'Brien



DENIAL

- Hoping that the person is not ill
- Expecting the person will get better
- Convincing yourself that the person hasn't changed
- Attempting to normalize problematic behaviors



ANGER

Frustration with the person

Resenting the demands of caregiving

Resenting family members who can't or won't help

Feeling abandoned

BARGAINING/GUILT

Wondering if you did something to cause the illness

Feeling bad if you enjoy life, or feeling like a failure

Wishing the person would go away

Having unrealistic expectations of yourself... "I should have"

DEPRESSION

Feeling overwhelmed by loss

Crying frequently

Withdrawing from social events or needing more connection with others

Withholding emotions or displaying them more openly



Acceptance

Learning to live in the moment and let go of the past

Finding personal meaning in caring for someone and realizing the PLWD IS doing the best they can

Embracing grief instead of living in resistance



BREAK TIME



Perspective



The donut, or the hole?



Naming The Elephant in the Room





"The thing about perspective is:
Something happens.
It means nothing.
We make up a story about what it means based on what *we feel*.

This story becomes our truth."

- Ram Dass

What stories have YOU been telling yourself?



"PERSPECTIVE"

Redefining "Strength"



Asking for help is not a sign of weakness. It's evidence of self-awareness, courage and strength.

PEARNA WONG



7 Guidelines for the Journey

(Pauline Boss)

1. Find Meaning

Being able to understand your experience is essential to avoid feeling helpless and hopeless.



By accepting 2 ideas simultaneously: Your relationship is strangely lost, yet it still exists.

Finding meaning takes time.

2. Balance Control with Acceptance

May be tempted to think about person as "already gone" from your life or deny that anything is wrong.

Better we learn to tolerate ambiguity & have faith that things will turn out, even if we can't understand how in the moment.

When we can't master what is going on around us, we CAN master our thoughts, reactions & internal selves... with PRACTICE!



3. Broaden Your Identity

When can't clarify if PLWD is in or out of our lives, our identity becomes confused... Husband whose wife no longer knows him wonders if he's still married; he doesn't feel like he is.

Daughter of mother with dementia wonders if she is still a daughter or now her mother's parent.

Goal = Revise your identity to fit the ambiguity. "Both-and" thinking helps. You're *both* child *and* parent to a parent. You may feel *both* married *and not* married.



F. Scott Fitzgerald



"The test of a first-rate intelligence is the ability to hold two opposing ideas in mind at the same time and still maintain the ability to function."

4. Manage Your Mixed Emotions



Mixed emotions/ambivalent feelings are typical when taking care of PLWD.

Normal to *feel* anger and guilt– even to wish for it to “be over.”

Challenge is to acknowledge and then manage such ambivalence. Therapist, support group, etc. may help.

5. Hold On And Let Go

Due to dementia, relationship is more one-sided than before. With no closure possible, shift perceptions of attachment to one of *both-and*: My person is *both* here *and* gone.



Attachment often ruptured by dementia, still have choices.

We can close PLWD out as if he or she were already gone- or settle for partial relationship, one that is less than perfect.

I'll Do The Remembering– Ashley Campbell



<https://youtu.be/iosdKzCTwjc>

6. Imagine New Hopes And Dreams

To stay strong, everyone needs hope and a good imagination to find it in midst of dementia.

Need to trust more in what is unknown & temper need for certainty. Opens up new options.

Can laugh more easily at absurdity, become less controlling and more patient. Accept paradox: find meaning in meaninglessness & hope in hopelessness.





When we are no longer able to change a situation, we are challenged to change ourselves.

-- Viktor Frankl

7. Take Time To Mind Yourself

Responsibility for your health is more than yours alone. Lean on your friends, neighbors, relatives, faith community, other caregivers or experts who can provide information and support you need.



Can be a difficult balancing act. Minding yourself is *not selfish*. You can't drink from an empty cup.

"Self-care is not about self-indulgence. It's about self-preservation."

-- Audrey Lorde

10 Symptoms of Caregiver Stress

1. **Denial** about the disease and its effect on the person who has been diagnosed.
2. **Anger** at the person with Alzheimer's or frustration that he or she can't do the things they used to be able to do.
3. **Social withdrawal** from friends and activities that used to make you feel good.
4. **Anxiety** about the future and facing another day.
5. **Depression** that breaks your spirit and affects ability to cope.

Copyright©2019 (Kay M. Adams) all rights reserved.

10 Symptoms of Caregiver Stress, cont...

6. **Exhaustion** that makes it nearly impossible to complete necessary daily tasks.
7. **Sleeplessness** caused by a never-ending list of concerns.
8. **Irritability** that leads to moodiness and triggers negative responses and actions.
9. **Lack of Concentration** that makes it difficult to perform tasks
10. **Health problems** that take a mental and physical toll.

• Alzheimer's Association, 2018

Copyright©2019 (Kay M. Adams) all rights reserved.

Asking for Help Activity

1. What kinds of self-care activities do you practice to keep yourself afloat?
2. Where or who could you turn to for help in your family or community?
3. What is stopping you from asking?
4. What's one small step you could take NOW to improve your self-care?



Build it...

and

They will come



“You are never strong enough that you don’t need help.”



-- Cesar Chavez

Kay’s Bonus Rule 8: Laugh through your tears



Helpful Tips to Support Families



Copyright©2019 (Kay M. Adams) all rights reserved.

- Emotional support– including grief & loss
- Encourage self-care– physically & emotionally
- Maintaining relationships with others
- Learning to control guilt & prioritize differently



Disease education:

- Understanding changing behaviors
- Adapting communication methods to person’s ability

Copyright©2019 (Kay M. Adams) all rights reserved.

The smallest change in perspective can transform a life. What tiny attitude adjustment might turn your world around?

-- Oprah Winfrey



Kay Adams, LCSW

Compassion Works, LLC

303-875-5508

kay@kaymadams.com

www.kaymadams.com