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Wading in Emotional Quicksand: The Powerful Role of Anticipatory Grief and Ambiguous Loss in Dementia Care

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Front Row Seat to Anticipatory Grief

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Learning Objectives

• Describe the role that anticipatory grief and ambiguous loss play in the caregiving process.

• Identify coping strategies to effectively deal with the multiple losses involved in caring for someone with a dementia.
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Anticipatory Grief:
The emotional pain and sadness that arises far in advance of an expectant loss or death.

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

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CASE PRESENTATION:
ROSIE AND VINCE
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**Signs & Symptoms of Anticipatory Grief**

- Tearfulness
- Fear
- Anger
- Fatigue
- Loneliness
- Emotional Numbness
- Anxiety & Depression
- Poor Concentration
- Guilt
- Forgetfulness
- Desire to Talk

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**Brene Brown: From: Rising Strong**

**GRIEF:** The emotion we perhaps fear most.

The 3 most foundational elements of grief:

**LOSS, LONGING & FEELING LOST**

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**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.
• The more difficult it is for us to articulate our experiences of loss, longing, and feeling lost, the more disconnected and alone we feel.
• Coping strategies—writing down experiences of heartbreak and grief. Making clear to themselves what they were feeling, so they could articulate it to others without having to explain or justify their feelings.
STAGES OF GRIEF

DENIAL
ANGER
BARGAINING
DEPRESSION
ACCEPTANCE

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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

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ANGER

Frustration with the person
Resenting the demands of caregiving
Resenting family members who can’t or won’t help
Feeling abandoned
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**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 done...”

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**DEPRESSION**
- Feeling overwhelmed by loss
- Crying Frequently
- Withdrawing from social events or needing more connection with others
- Withholding your emotions or displaying them more openly

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**ACCEPTANCE**
- Learning to live in the moment
- Finding personal meaning in caring for someone and realizing they are doing the best they can
- Embracing your grief instead of living in resistance
Quicksand: "Loose wet sand that yields easily to pressure and sucks anything resting on or falling into it.

Avoiding Emotional Quicksand...

Starts by recognizing common quicksand areas

Common Quicksand Areas

- Receiving a diagnosis of dementia
- Loss of Normalcy and time to yourself
- Loss or change in the relationship.
- Loss of driving privileges and financial stability.
- Loss of independence, and hope for the future that you had planned for.
Look for ripples:
Be on the lookout for ground that appears unstable

Test the ground in front of you with your walking stick

How to get OUT of emotional quicksand
Seven Rules for Survival
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RULE #1: Don’t PANIC!!!

Know that your feelings of anxiety, fear and overwhelm are normal.

Find an outlet for your feelings and express them in an environment that feels safe.

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Rule #2: If you are wearing something heavy (like a load of grief, guilt and regret), unstrap it immediately and drop everything!

Understand that it is “real grief” that you need to work through.

Figure out ways to “let go” so grief doesn’t stop you in your tracks and sink you.

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RULE #3: If you feel your feet (or spirit) getting stuck... take steps backward and re-assess before the quicksand takes hold.
Rule #4: Lay back and relax... and BREATHE!

Sit down and lean back if your feet are stuck fast.

Breathe deeply...it will help you remain calm and buoyant in hard times.

Rule #5: Take your time

Frantic movements will only hurt your cause.

Take it slow so that the steps you do take really count when it matters.

Rule #6: Use a Stick

- Carry a walking stick (a support person) any time you’re in quicksand country.
- It can be helpful to shift your focus from the anticipated decline or death of a person, to celebrating what you still have left.
- Cry and grieve the loss of what was, so you can move forward and be effective as a caregiver.
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RULE #7: Take frequent breaks

Extracting yourself alone from quicksand can be exhausting. Conserve your energy before you become too fatigued.

Grief must be fully experienced before you can move on. You need to take breaks and allow yourself to grieve the losses (and there are many!) along the way.

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Kay’s Bonus Rule #8: Laugh through your tears

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An Action Guide to Reviewing the Steps

Take Action!
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Being in Resistance and in denial ... only makes matters worse!

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Reach out to others who understand and can help.

Celebrate the good moments, and grieve what can no longer be.

Use grief to build inner strength as care partners.

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We ALL have our unique journey of grief. Embrace it.
Thank you... for what you do. For who you are. For how you CARE.

THANK YOU