

# The Experience and Journey of Dementia Grief

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1

## Facts of Dementia Journey

- Progressive Loss
- Impacts every family member
- Stigma and fear
- Lack of knowledge
- Delayed engagement of support



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## Realities of The Journey

- Years up to a decade or more
- Forgotten memories
- Behavioral and Psychological Symptoms (BPSD)
- Hurtful accusations
- Difficult conversations
- Roles and Relationships change
- Diminishing contact with family and friends

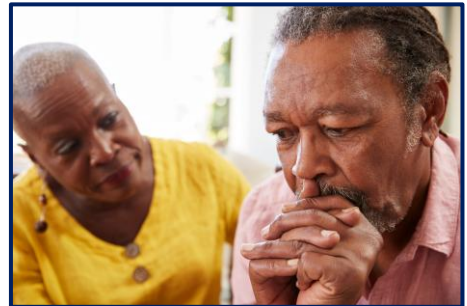


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## The Caregivers

- 13 million provide unpaid care
- 1 in 3 is age 65 or older
- 2/3 are women
- 1/3 are daughters
- 1/4 are “sandwich generation”
- 1 in 3 provide care 4+ years
- Almost 70% report high stress level
- 40% have clinical depression
- 65% have a chronic illness
- 63% mortality rate



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## Loss

- Relationship
- Intimacy
- Companionship
- Communication
- Lifestyle
- Shared activities
- Freedom
- Future plans



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## Grief

- Deep distress from loss
- Various causes and levels
- Intense sorrow
- Oppressive sadness
- Contradictory feelings



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# Physical Symptoms of Grief

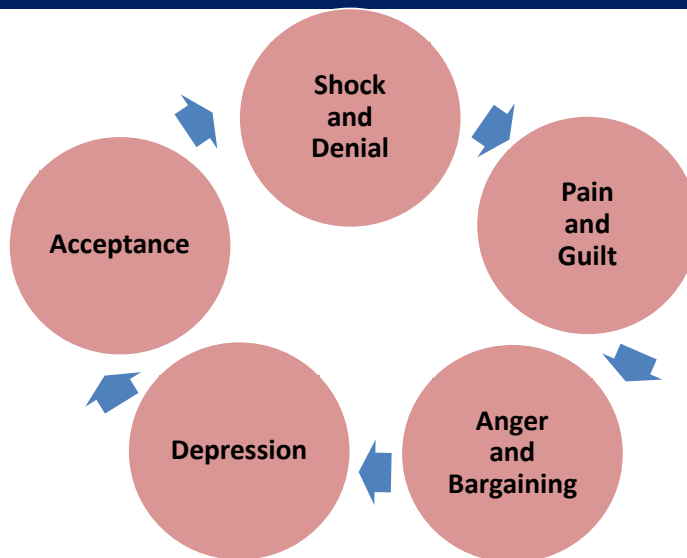
- Difficulty sleeping
- Poor concentration
- Poor appetite
- Increase blood pressure
- Tight throat and chest
- Inflammation
- Tearfulness
- Weakened immune system
- Nausea
- Worsen existing health problems
- Fatigue
- Broken Heart Syndrome



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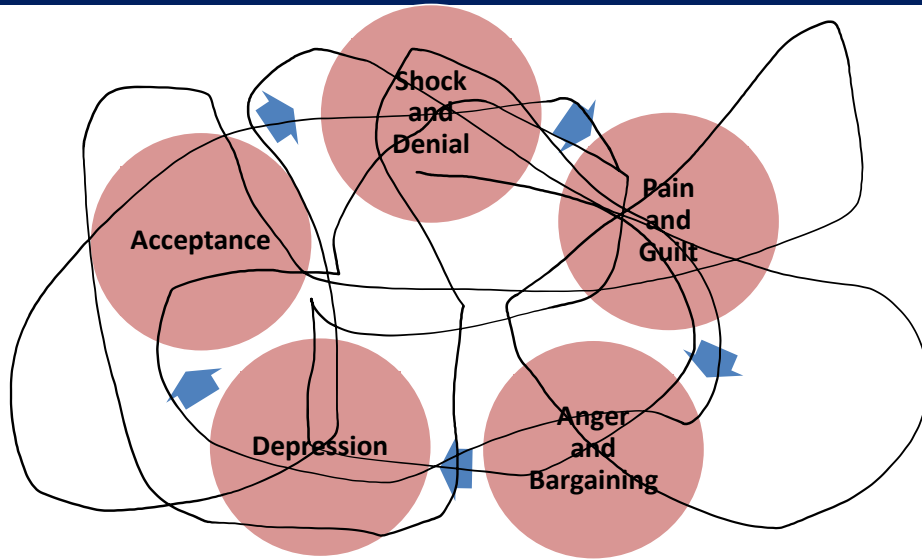
# Theory of Traditional Grief



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# Reality of Traditional Grief



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# Family in Denial



- Shock
- Deep sadness
- Contradictory Feelings



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## Expressions of Anger

- Blame
- Fear and sadness underneath
- Passive aggression
- Open aggression
- Assertive anger



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## Feelings of Pain and Guilt

- Profound sadness
- At fault
- Blamable
- Culpable
- Shameful



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## Family begins to Bargain

- Deep anger
- Negotiation
- Wish
- Pray
- Hope



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## Family Experiences Depression

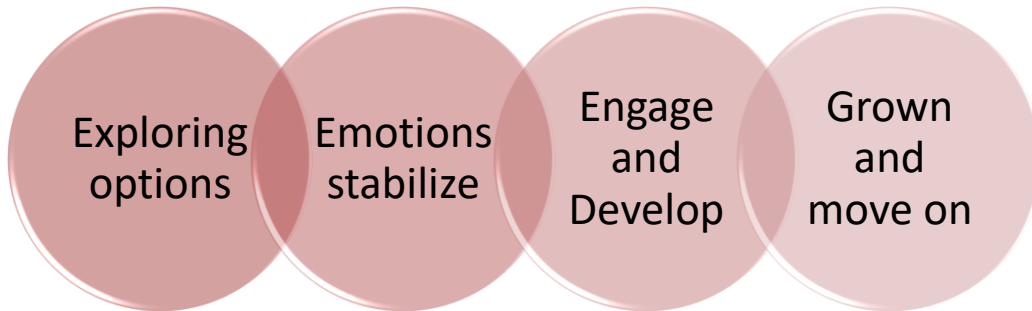
- Prolonged sadness
- Processing loss
- Powerlessness
- Hopelessness



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# Eventually Acceptance and Hope



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# The Children

- Younger children
- Teenagers
- Older teenagers
- Family response
- Different challenges



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# Anticipatory Grief

- Pre-death grief
- Emotions similar to post-death grief



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# Dementia Grief Includes

Compounded  
Serial Loss

Ambiguity

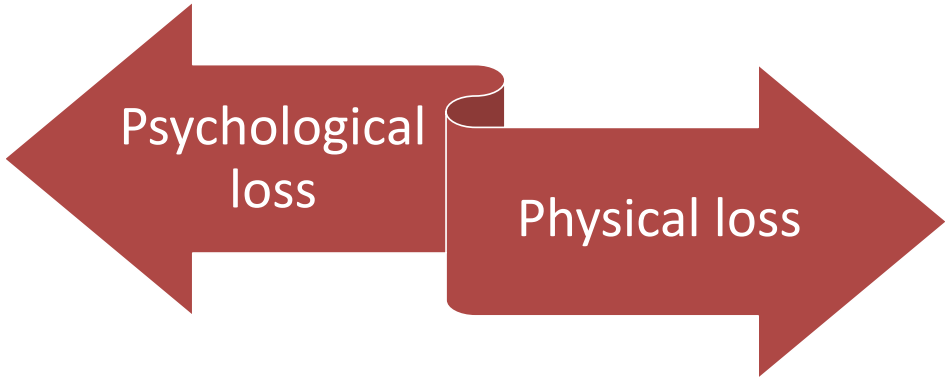
Receding of the  
known self



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# Paradoxical Disconnection



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# Complicated Grief

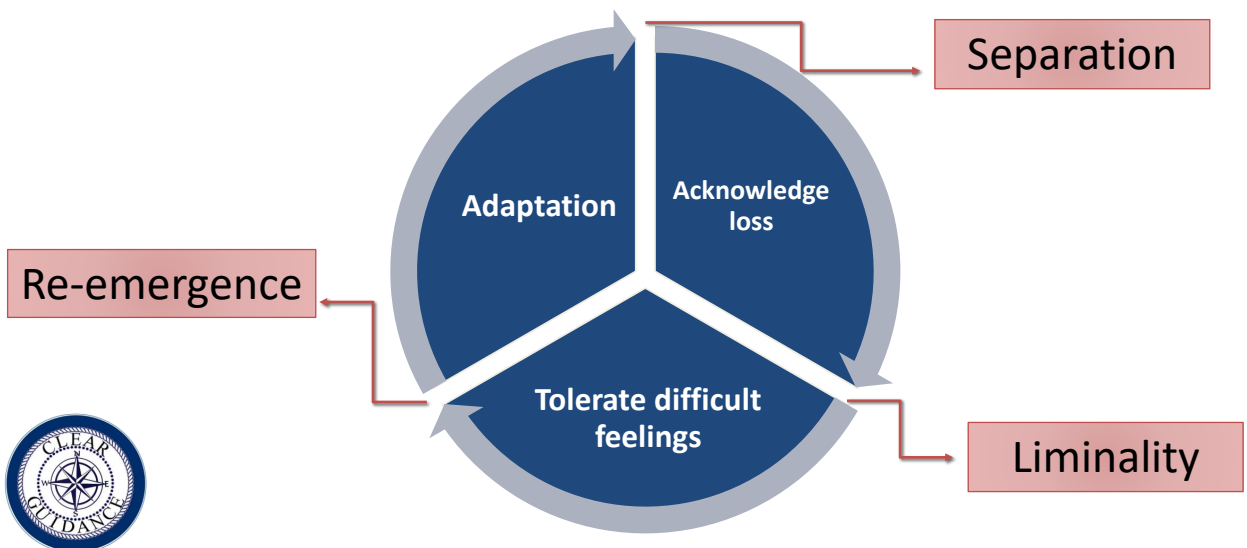
- Persistent Complex Bereavement Disorder
- Difficulty recovering from the loss
- Prolonged and severe
- Occurs in 20% of caregivers of person with dementia



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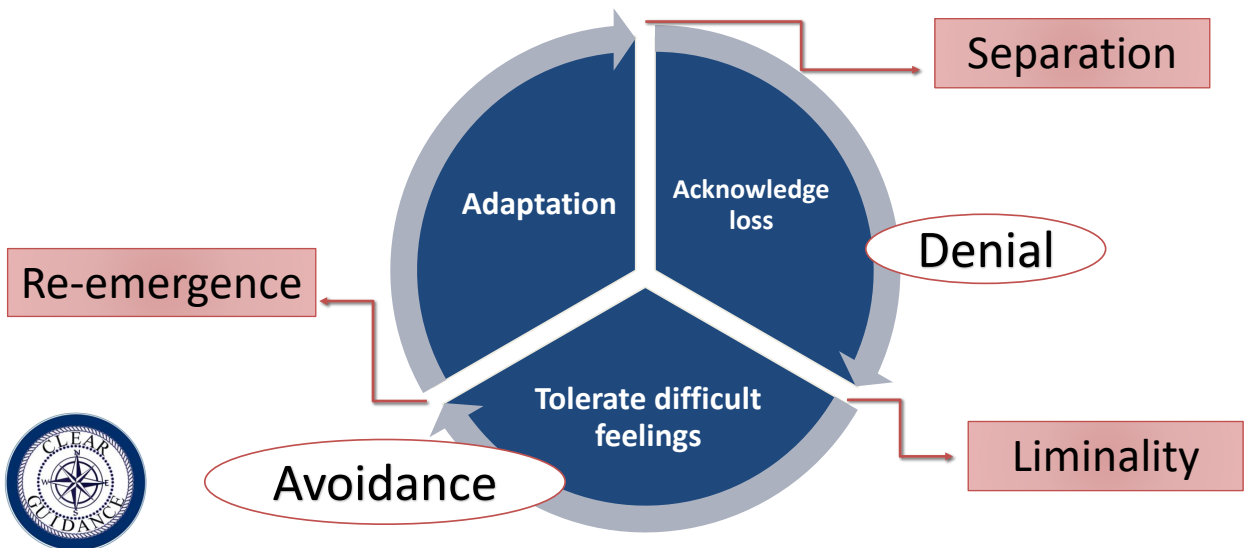
# Dementia Grief Model



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# Dementia Grief Model

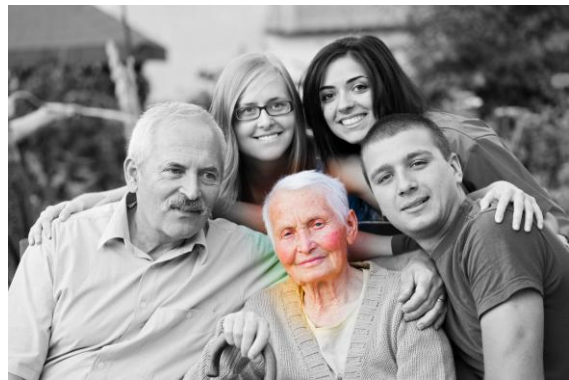


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# Considerations of The Dementia Grief Model

- Individual differences
- Other life demands
- Resilience
- Support System



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## Familial Relationships



- Express own feelings
- Impacts the sexual relationship
- Embarrassment
- Roles change
- Everyone grieves at own pace
- May become closer



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## Length of Grief Process

- Importance of their loss
- Nature of the relationship
- Circumstances of the death
- Past grief experience
- Lack of someone to talk to
- Mental or physical health issues
- Role of self to person who died



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## Healing and Support



- Grief counseling
- Psychiatrist
- Insurance company
- Outpatient treatment program
- Suicide/Crisis Hotline  
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## Interventions for Support

- Support Group
- Hospice Bereavement
- Alzheimer's Association 24-hr Helpline
  - 1-800-272-3900
- Disease specific organizations
- Social media groups
- Reading and Podcasts



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## Positive Aspects of Caregiving

- Insights and acceptance
- Purpose and commitment
- Gratification
- Mastering skills
- Patience and tolerance
- Meaning and humor
- Letting go
- Closer relationship
- Finding support
- Useful to other caregivers



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## Benefits of Caregiving

- Intrinsic
- Extrinsic
- Meaningful
- Unexpected
- Enhanced coping
- Building resilience



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## Building Resilience



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## Strategies for Resilience

- Maintain good relationships
- Unable to change event, but can change response
- Accept change as a part of life
- Develop short-term reachable goals
- Take action and not just wish the problem away
- Make opportunities for self-discovery
- Nurture yourself



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## Coping with Grief

- Feel the pain
- Share the pain
- Fill your cup
- Find comfort
- Pause
- Seek balance
- Find joy



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When someone you love becomes a memory,  
that memory becomes a treasure  
*Anonymous*



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# Clear Guidance

Providing navigation for life's most challenging journeys

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