

Grief Characteristics by Caregiver Type and the Stage of Dementia

Dementia Stage 2 (Mild Cognitive Impairment) & Stage 3 (Dementia)

Adult-child Caregiver

- *Denial and avoidance of the disease presence
- *Refusal to acknowledge future implication of the disease
- *Focused exclusively on the present
- *Very task oriented and intellectualized
- *Emphasis is on PWD maintaining current competencies
- *Avoidance of loss-related discussion until pushed
- *Losses are self-focused on lost personal freedom
- *Avoids or minimizes feelings
- *Struggles to contain all grief
- *Predominant Feelings: Surface –None, Underlying – fear, helplessness, anger, jealousy
- *Holds onto the present
- *Little manifested grief
- *No talk of memory care placement

Dementia Stage 4 (Moderate Dementia) & beginning Stage 5 (Severe Dementia)

- *Rapid transition to the reality of necessary care
- *Burden of care is greater than expected
- *Raw emotions: Predominant – Frustration, anger
Secondary – guilt, wishing parent would die, fatalism, pining, sadness for what was
- *Grief is self-focused
- *Efforts to maintain normalcy have vanished
- *Loss focused on the other parent
- *Beginning to discuss memory care placement with reluctance and dread
- *Anticipatory grief—expectation of continued grief with some relief after death of parent
- New Emotion: Fear of genetic transmission

Dementia Stages 5, 6 & 7 (Very Severe Dementia – End of Life)

- *Burden lifted primarily by memory care
- *Memory care stops being a major theme
- *New theme of interpersonal regret over the loss of the relationship
- *Losses: Lost relationship, lost opportunities
- *Emotional shift from earlier stages – raw to reflective
Predominant feelings of sadness, longing, loneliness, resignation, finalized loss
Secondary feelings of anger and frustration
- *Focus on other and conjoint (such as lost parent, lost relationship, lost opportunities)
- *Memory care placement produces feelings of: Initial feelings of turmoil and grief, but secondary feelings of relief
- Broadened philosophical perspective

*Grief expressed as being at an apex – additive across time to this stage

*Anticipatory grief – expectation that death will bring relief

Dementia Stage 2 (Mild Cognitive Impairment) & Stage 3 (Dementia)

Spousal Caregiver

Lack of denial and avoidance

Reality oriented with regard to future

Focus on present but projects into the future

Acceptance of current competencies and changes

Recognition and acknowledgement of losses

Losses are conjoint-focused, e.g. loss of companionship, intimacy, friendship

Openly sad

Openly experiencing grief

Predominant feelings are sadness, little resentment, jealousy or fear

Allowance for slippage in the future

Anticipation of escalation of grief

Talk of avoidance of memory care placement

Dementia Stage 4 (Moderate Dementia) & beginning Stage 5 (Moderately Severe Dementia)

Smooth transition to the reality of care

Increasing burden accepted with dignity and responsibility

Emotions are deeply felt but raw

 Predominant – sadness

 Secondary – compassion, empathy, mild frustration

Grief is focused on the other

Maintaining the relationship becomes important

Normalcy vanished early on

Loss is focused on self – being alone

Thought of memory care placement brings increased sense of loss, grief and guilt

Anticipatory grief – belief that grief is at an apex and death will bring relief

Dementia Stages 5, 6 & 7 (Severe and Very Severe Dementia – End of Life)

Burden of care eased by memory care placement

New burden of caring for self

Losses include: identity as a couple, identity as a spouse, distance from family and friends

Increase in emotional intensity and rawness

 Predominant – uncertainty about the future, confusion, frustration, aloneness

Secondary – anger about situation and noncaring others

Focus on self – building a new, single identity

Memory care placement produces: initial feelings of relief, secondary feelings of concern for self

Grief expressed as bitterness and sadness

Anticipatory grief – less certain death will bring relief