

## Understanding Grief and Loss in Alzheimer Disease

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## Personality

The quality of being a person; existence as a self-conscious human being; personal identity; the essential character of a person.

Merriam-Webster On-line

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## Death of the personality...

"... witnessing the death of a beloved ego is even more intolerable than the experience of physical death. Senility represents a progressive and agonizingly slow death of the human slow death of the human side of existence, for its ultimate residue is no longer recognizable as a person."

Cath 1978

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**There is no grief like the grief that does not speak.**

Anonymous

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## Caregivers and Ambiguous Grief

**"I'm frustrated at not having a marital status—I'm neither single nor married."**

55 year old female spouse caregiver

**One of the most difficult things for me is having a body in the house, but no one to talk with, to share news with, etc."**

65 year old female spouse caregiver

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## Loss, Grief and Bereavement

- ☐ Kubler-Ross introduced stages of grief and coping with loss or anticipated loss
  - Not everyone experiences these stages
  - Stages are not linear



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## Stages of Grief

### ☐ Shock and Denial

- Hoping/believing that the person is not ill.
- Expecting the person to get better.
- Convincing yourself that the person hasn't changed.
- Attempting to normalize problematic behaviors.
- Seeking multiple opinions from multiple physicians.

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## Denial

"... There have been so many misunderstandings of our mother's words and actions between my brothers and myself since they did not accept or believe she was ill. I have watched my mother change and decline over the last four years knowing there had to be something wrong... Denying seems to be their way of coping with this horrible disease and I have learned to accept that."

Eldest daughter caregiver

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## Denial

"It took me a long time to realize that my husband was really ill and didn't do things intentionally..."

79 year old spouse caregiver

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## Denial

"I wish my brothers and sisters could feel and see in 24 hours what it's like to be fully responsible...They love Mom as much as I do, but hide that something is wrong and shut their eyes or minds that I am human too."

44 year old eldest daughter

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## Stages of Grief

### □ Anger

- Being frustrated with the person with dementia.
- Angry at physicians, providers, insurance providers, government.
- Resenting the demands of caregiving.
- Resenting family members who cannot or will not help provide care.
- Feeling abandoned and resenting it.

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## Anger

"I lose my patience with her too easily. I might also lose my sanity. I'm not sure I love her anymore."

49 year old only child

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## Anger

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"Most frustrating is that friends stop calling on us. I'm unable to participate in a normal social life."

78 year old male spouse caregiver

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## Anger

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"I feel anger towards the medical profession which has given no help or understanding and contradictory evaluations."

59 year old female spouse caregiver

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## Anger

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"There is a lot of pressure on me to get rid of him and I think it's because family and friends would be relieved to know they won't be called upon to help me as time goes by."

61 year old female spouse caregiver

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## Anger

“...four years is a long time without one bit of help. We have three children, only the daughter will visit the home.”

74 year old male spouse caregiver

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## Stages of Grief

### ☐ Bargaining

- Making “deals” with God, yourself
  - ☐ If my mother gets better, I will donate the house....
  - ☐ I will give up drinking....etc...
- I will never ask for anything again
- Please let this be a mistake

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## Stages of Grief

### ☐ Depression

- Realize that this is the reality
- Pwd will not get better
- This is not a mistake
- ☐ Feeling despair or depression.
- ☐ Withdrawing from social activities.
- ☐ Not expressing emotions.
- ☐ We can treat depression...talk to your physician

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## Conflicts

"Our family is not working well together ... living with this conflict is terrible. My aunt and I want what we feel will make Mother most happy for her remaining years. My stepfather is nervous about losing everything (finances). One year ago, if someone would have told me we would be acting like this, I would not have believed it."

40 year old only child

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## Guilt and Frustration

All those years of 'doing without' to pay for the farm to and to college educate four kids – looking forward to the day we could eat out, travel, etc. I now find it was only a dream... I am so frustrated because I can't go and do the things I fee like doing. When—if—this nightmare ever ends, I expect to return to my former active life—if my life is still good...I hope you'll understand when I say I with it would end..."

65 year old female spouse caregiver

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**If you suppress grief too much, it can well redouble.**

Moliere

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## Stages of Grief

### ☐ Acceptance

- Finding personal meaning in caring for someone who is terminally ill.
- Seeing how the grieving process affects your life and carrying on.
- Appreciating the personal growth that often comes from surviving loss.

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## AD and Loss

- ☐ With AD, caregivers experience a series of losses.
- ☐ The person they knew so well becomes more like a stranger.
- ☐ More painful is that caregivers become strangers to the pwd -- no longer recognized as daughter, son or spouse.
- ☐ These kinds of incremental losses cause two kinds of grief at the same time:
  - ☐ **Immediate grief** that comes with many losses accumulating as the dementia advances is accompanied by **anticipatory grief** that is due to our keen sense of the inevitable death ahead.

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## Anticipatory Grief

- ☐ Emotional pain associated with losing a relative that's felt before the relative dies.
- ☐ Common among caregivers of people with Alzheimer's disease, terminal cancer, and other terminal conditions.

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## Anticipatory Grief

- ☐ Often more complicated because of the nature of AD
- ☐ Impairment of executive function may interfere with advance planning, participation in care, closure
- ☐ Person with AD looks good for so long unlike a person with cancer
  - ☐ Others don't realize the challenges nor acknowledge the grief

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## Ambiguous loss

- ☐ Confusing feelings that caregivers have when they interact with their loved ones
  - ☐ Especially in the later stages of AD
- ☐ Others do not acknowledge the loss
- ☐ Seems as though the person is still physically alive but no longer there mentally or socially
  - ☐ Successful relationships are reciprocal

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## Anticipatory Grief: Emotional and physical symptoms

- |   |  |
|---|--|
| <input type="checkbox"/> Denial                             | <input type="checkbox"/> Guilt               |
| <input type="checkbox"/> Mood swings                        | <input type="checkbox"/> Weight loss or gain |
| <input type="checkbox"/> Forgetfulness                      | <input type="checkbox"/> Sleep problems      |
| <input type="checkbox"/> Disorganized and confused behavior | <input type="checkbox"/> Nervous behavior    |
| <input type="checkbox"/> Anger                              | <input type="checkbox"/> Anxiety and dread   |
| <input type="checkbox"/> Depression                         | <input type="checkbox"/> General fatigue     |
| <input type="checkbox"/> Feeling disconnected and alone.    |  |

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## Guilt

- ☐ Wondering if you did something to cause the illness or didn't get help early enough
- ☐ Feeling that you've failed.
  - ☐ If you hire help.
  - ☐ When you can't care for your loved one at home.
- ☐ Regretting things about your relationship before the diagnosis.

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## Guilt

"I feel you must, as a caregiver, meet each situation as it arises the best you know how, and go on. Do not torment yourself with 'What should I have done?' "

79 year old caregiver

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## Guilt

- ☐ Thinking you could have done something differently pre or post diagnosis.
- ☐ Being able to enjoy life while your pwd may not.
- ☐ Feelings that you have failed, especially if your loved has been placed in a nursing home.

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## Guilt

- ☐ Negative thoughts about the person with the disease — wishing that his or her suffering would end.
- ☐ Conflicts with family members because they are uninvolved or critical of the care that's being provided.
- ☐ Unrealistic expectations that you place on yourself and thoughts that "I must be perfect" or "I must do everything."

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## Plan Ahead

- ☐ This is important regardless of caregiving role
- ☐ Best strategy to avoid some of the complicated issues that can arise
- ☐ Plan for the worst then hope for the best

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## Anticipatory Grief

- ☐ The pwd has a period of rapid decline, the grief and loss may become more intense then the feelings might level off as pwd stabilizes for awhile.
- ☐ With another setback, the feelings of grief and loss may return.

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## Coping with Anticipatory Grief

- ❑ No easy way through anticipatory grief and ambiguous loss.
- ❑ These are difficult yet normal experiences for caregivers of those with AD and related to dementia.
- ❑ Feelings often occur more than once during the caregiving process.



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## Coping with Grief

- ❑ **Accept and acknowledge your feelings.**
  - ◆ They are a normal part of the grieving process.
- ❑ **Talk to others.**
  - ◆ Share feelings with family and friends.
  - ◆ You may want to talk with a professional who specializes in grief counseling.

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## Coping with Grief

- ❑ **Do things you enjoy.**
  - Caregivers often give up enjoyable activities and companionship
  - Make a lunch or movie date with friends.
  - Taking a break may help you relieve stress and grief, and strengthen your support network.
  - Learn to feel comfortable accepting and celebrating good things in your life.
- ❑ **Let the guilt go.**
  - Find ways to accept the situation, forgive yourself for possible slights the patient already has) and move on.

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## Coping with Grief

### ☐ Join a support group

- ☐ Put you in touch with others who are going through similar challenges.
- ☐ As much as friends and family members want to help you, they may not understand how you can be grieving while the person you're caring for is still alive.

### ☐ Find online support

- ☐ If you don't feel comfortable with the idea of going to a support group try online help
- ☐ caregivers and others share their stories with each other and offer ideas and support.

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## Coping with Grief

### ☐ Write it down.

- ☐ Keeping a journal where you can record your thoughts and feelings privately can be very therapeutic.
- ☐ If you don't like to write longhand, try keeping an electronic journal on your computer.

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## Coping with Grief

### ☐ Seek professional help if necessary.

- ☐ Talk to your physician.
- ☐ Call the Alzheimer's Association Helpline at 1.800.272.3900.
- ☐ If previous suggestions don't help consider finding a mental health professional that specializes in AD, caregiving, and/or grief and loss issues.
- ☐ Call the local mental health center or association (listed in the phone book) and ask for a referral.

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## How will you feel when it's over?

"Two of our sons and I were at his bedside, all with our hands on him when the last breaths came. One of those sons said later – 'It certainly is strange to be happy and sad at the same time'. By noon on that Saturday, I began to feel like a 40 ton load simply lifted off me. Yes, lots of tears were shed, but we feel as sense of relief."

65 year old female spouse caregiver

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## How will you feel when it's over?

"It is like losing a child and a parent at the same time. Having cared for my mother for over eight years, she had in a very real way become like my child, but she was still my mother."

42 year old daughter

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## How will you feel when it's over?

"The time when they don't remember who you are ... they can't talk, you don't know how much they do know – this is the first death. The second death is when life is gone."

75 year old female spouse

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## Roller Coaster of Emotions



"Much of the time I feel like a yo-yo. My feelings are mixed. On the downside I feel resentment, frustration, sadness, guilt and anger. On the upside I feel the satisfaction of providing good care, love of family and friends; acceptance of the reality of the situation, and peace that this must be part of God's plan for me. But I don't seem to be able to stay on the upside for long..."

57 year old daughter-in-law caregiver

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Acceptance occurs not when you get over a loss, but rather, when you learn to live with it.

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**One joy shatters a hundred griefs.**

Chinese proverb

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