



Grief and Loss in Dementia Care

JENNIFER PHILLIPS, MPA

KNIGHT ALZHEIMER DISEASE RESEARCH CENTER

WASHINGTON UNIVERSITY SCHOOL OF MEDICINE

KnightADRC | WASHINGTON
UNIVERSITY
ST. LOUIS
Alzheimer's Disease Research Center

Questions to Consider

- ▶ What are bereavement, grief, and mourning?
- ▶ When, what, and why?
- ▶ What makes dementia different?
- ▶ What is the grieving process?
- ▶ How do we cope?
- ▶ How do we support those who are grieving?

Definitions

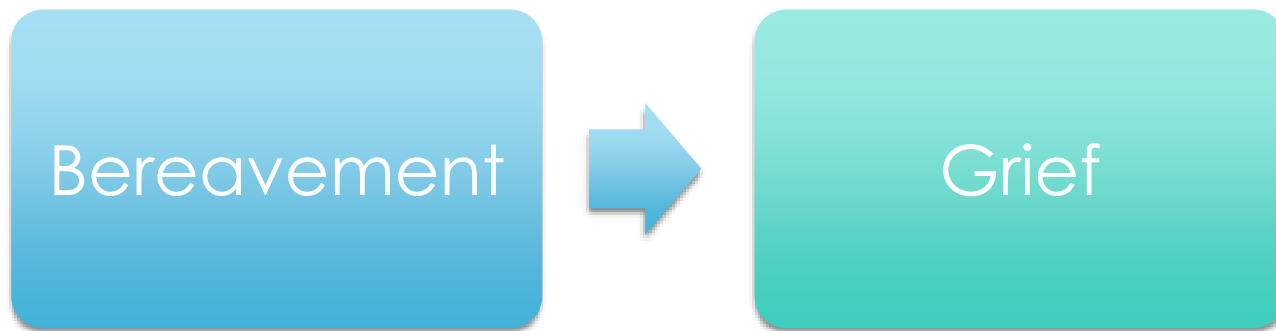
Bereavement

...the **experience** of losing someone important to us *-mind.org*

...the **state** of loss when someone close to an individual has died *-Psychology Today*

...the **period** of grief and mourning after a death. When you grieve, it's part of the normal process of reacting to a loss *-medlineplus.gov*

Definitions



...the **anguish** experienced after significant loss, usually the death of a beloved person.

American Psychological Association

...the **acute pain** that accompanies loss. Because it is a reflection of what we love, it can feel all-encompassing. *-Psychology Today*

...a strong, sometimes **overwhelming emotion** for people, regardless of whether their sadness stems from the loss of a loved one or from a terminal diagnosis they or someone they love have received *-MayoClinic.org*

Definitions



...an **expression** of grief or a time of grieving that follows a loved one's death or other serious loss –*vocabulary.com*

...the **act** of sorrowing –*mirriam-webster.com*

...the outward **expression** of our grief –*Canadian Mental Health Association*

When Do We Grieve?

- ▶ Specific loss
 - ▶ Important relationship / person
 - ▶ Future plans and dreams
 - ▶ Support, partnership, companionship
- ▶ Anticipation of a loss
 - ▶ A compilation of smaller subtractions
 - ▶ Waiting for the inevitable final loss
- ▶ Ambiguous loss
 - ▶ Psychological loss, not physical loss
 - ▶ Can be complicated by hope
 - ▶ Can be cumulative
 - ▶ Hard to resolve because it is hard to quantify or even identify
- ▶ A life-altering change
 - ▶ Accepting a new reality
 - ▶ Adjusting to new future

Both Care Partners and Patients Grieve

- ▶ At diagnosis, throughout the progression, and at the end of life.
- ▶ Loss of Identity.
- ▶ Loss of safety and/or physical, emotional, and mental well-being.
- ▶ Loss of autonomy.
- ▶ Loss of dreams or expectations.

What Does Grief Feel Like?

- ▶ Sadness
- ▶ Depression
- ▶ Isolation
- ▶ Hopelessness
- ▶ Numbness
- ▶ Shock
- ▶ Denial
- ▶ Anger
- ▶ Fear
- ▶ Helplessness
- ▶ Worry
- ▶ Exhaustion
- ▶ Overwhelm
- ▶ Yearning
- ▶ Gratitude
- ▶ Relief
- ▶ Resentment
- ▶ Shame
- ▶ Guilt
- ▶ Confusion
- ▶ Healing

The therapeutic purpose of grief and mourning is to get you to the place where you can live with the loss in a healthy way. There is no single or correct way to grieve.

Why Do We Grieve?

- ▶ Evolutionarily: humans are hardwired to form bonds for our survival.
- ▶ Physiologically: relationships affect portions of our brain and lead to production of oxytocin and dopamine in our reward centers. Broken bonds increase stress hormones and make us want the person/relationship/item that originally produced those feel-good chemicals.
- ▶ Emotionally:
 - Learning to live in the world now.
 - Learning to be a person who carries absence.
- ▶ Practically:
 - Adapting to all the tiny little habits and predictions that we have to learn in a new way.

What Makes Dementia Different?

- ▶ The losses are gradual and plentiful. “Death by a thousand subtractions.”
- ▶ The long trajectory and uneven path can lead to hope, uncertainty, or denial.
- ▶ Dementia care can be physically, mentally and emotionally overwhelming.
 - Opens the door to exhaustion and hurtful emotions.
- ▶ The confusion of grieving a person still with you, or who is no longer the same.
- ▶ People do not see the losses you are experiencing and cannot understand.
- ▶ The protracted disease process leads to extensive periods of grief.

Common in the Grieving Process

Denial

- ▶ Hoping that the person is not ill
- ▶ Procrastinating on medical care or diagnosis
- ▶ Expecting the person to get better
- ▶ Convincing yourself that the person has not changed
- ▶ Attempting to normalize problematic behaviors
- ▶ Not telling others about the symptoms or diagnosis

Common in the Grieving Process

Anger

- ▶ Being frustrated with the person
- ▶ Resenting the demands of caregiving
- ▶ Resenting family members who cannot or will not help provide care
- ▶ Feeling cheated out of a future
- ▶ Feeling abandoned

Common in the Grieving Process

Guilt

- ▶ Having unrealistic expectations with thoughts like: “I should have done ...”
“I must do everything for him or her” or “I must visit him or her every day”
- ▶ Feeling bad because you are still able to enjoy life
- ▶ Feeling that you have failed if, for example, you cannot care for the person at home
- ▶ Having negative thoughts about the person or wishing that he or she would go away or die
- ▶ Regretting things about your relationship before the diagnosis

Common in the Grieving Process

Sadness

- ▶ Feeling overwhelmed by loss
- ▶ Crying frequently
- ▶ Withdrawing from social activities or needing to connect more frequently with others
- ▶ Withholding your emotions or displaying them more openly than usual

Common in the Grieving Process

Acceptance

- ▶ Learning to live in the moment
- ▶ Finding personal meaning in caring for someone who is terminally ill
- ▶ Understanding how the grieving process affects your life
- ▶ Appreciating the personal growth that comes from surviving loss
- ▶ Finding your sense of humor
- ▶ Asking for and accepting help from others

How Do We Cope with Grief?

- ▶ Face your feelings.
- ▶ Prepare to experience feelings of loss more than once.
- ▶ Claim the grieving process as your own.
- ▶ Talk with someone.
- ▶ Combat feelings of isolation and loneliness.
- ▶ Know that some people may not understand your grief.
- ▶ Accept yourself.
- ▶ Take care of yourself.

Recognize Small Positives

- ▶ Time to plan and set direction for end of life trajectory.
- ▶ Do the “bucket list” items as possible.
- ▶ Say what needs to be said.
- ▶ Right longstanding wrongs.
- ▶ Reconcile complex relationships.
- ▶ Celebrate the life lived.

How to Help a Grieving Caregiver

- ▶ Listen.
- ▶ Ask questions.
- ▶ Share memories.
- ▶ Don't pretend to have answers.
- ▶ Acknowledge the depth of their losses.
- ▶ Avoid platitudes.
- ▶ Remember grief isn't linear.
- ▶ Don't advocate for closure.
 - Acceptance
 - Integration

Resources and Support

- ▶ Employee Assistance Programs
- ▶ Support Groups
- ▶ Canadian Virtual Hospice mygrief.ca
- ▶ Alzheimer's Association alz.org
- ▶ Our House Grief Support Center
- ▶ Hospice and Palliative Care Organizations www.nhpco.org
- ▶ hospicefoundation.org
- ▶ childrengrieve.org
- ▶ dougy.org (children's grief)
- ▶ fernside.org (children's grief)
- ▶ griefshare.org
- ▶ wendtcenter.org (Wendt Center for Loss & Healing)
- ▶ aarp.org/families/grief_loss.org
- ▶ hopeforbereaved.com
- ▶ healgrief.org
- ▶ compassionatefriends.org
- ▶ caringinfo.org
- ▶ thegrieftoolbox.com
- ▶ griefshare.org (ongoing resource for support groups and information near you)
- ▶ Suicide Prevention Lifeline 1-800-273-8255

Resources and Support

Books:

- ▶ Creating Moments of Joy by Jolene Brackey
- ▶ Ambiguous Loss by Pauline Boss (www.ambiguousloss.com)
- ▶ When Reasoning No Longer Works: A Practical Guide for Caregivers Dealing with Dementia & Alzheimer's Care by Angel Smits

Questions?

KnightADRC | WASHINGTON
UNIVERSITY
ST. LOUIS
Alzheimer's Disease Research Center

Scan with your
camera to
volunteer for
research.



Grief is your way of trying to keep the person who had died in your life while trying to build a new life without them.

and above all.....

There is no right or wrong way to grieve.