

Welcome!

A Look at Grief and Loss through a Lens of Hope

May 16, 2022



Today's Speakers

Jane Nichols

Wife Sharing a Journey of Grief

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Moderator

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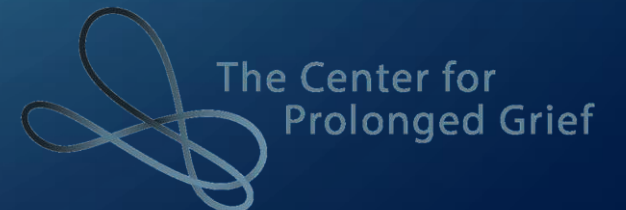
5th Annual OAMHAD Symposium
May 16, 2022

A LOOK AT PROLONGED GRIEF DISORDER THROUGH A LENS OF HOPE

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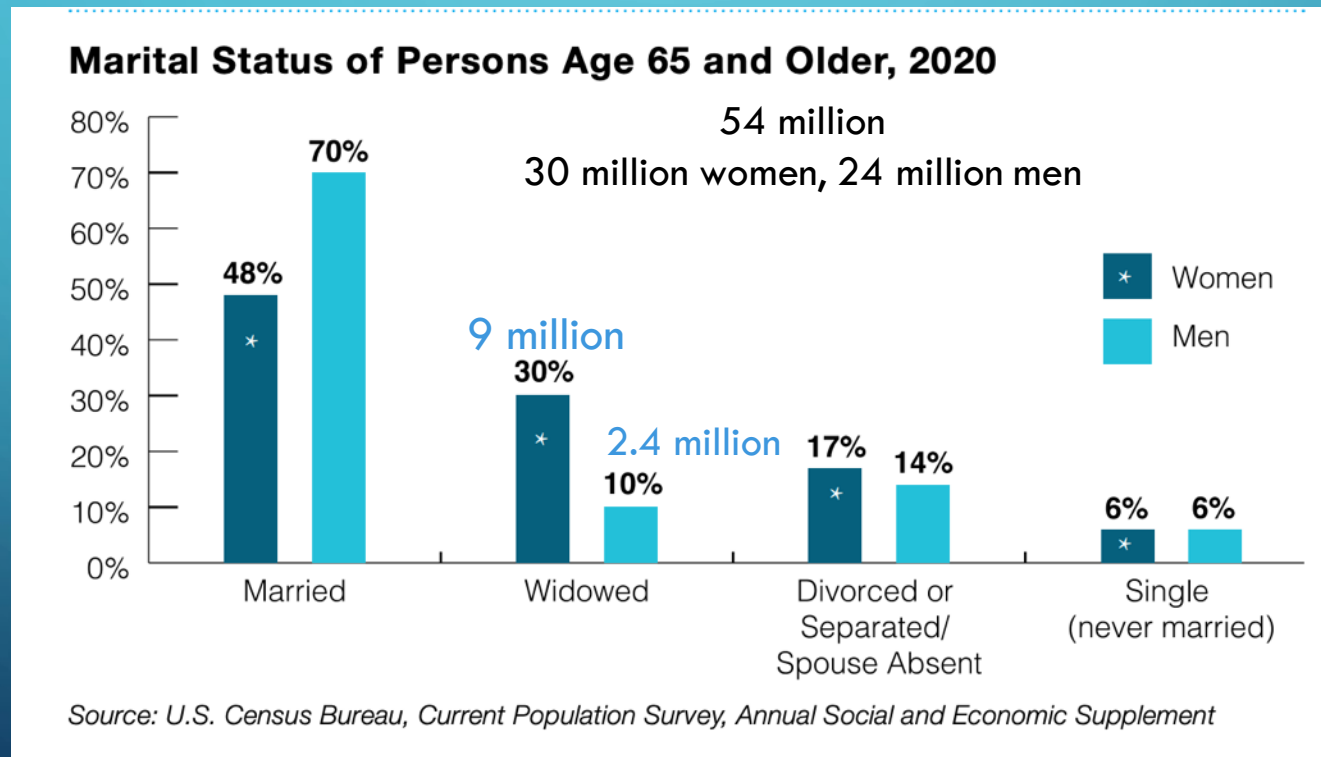


What this talk is about

- ★ What is Prolonged Grief Disorder (PGD) and how is it different from usual continuing grief and from depression?
- ★ How does PGD happen?
- ★ How can we help people with PGD?

At least 3 million older adults likely have Prolonged Grief Disorder (PGD)

More than 11 million older adults in the US are widowed and at least twice this number have lost someone else close (parent, child, close friend or relative)





September 23, 2021

“Prolonged grief disorder is the newest disorder to be added to the DSM. After studies dating back several decades suggested that many people were experiencing persistent difficulties associated with bereavement that are substantially prolonged beyond culturally normed expectations, and **a two-year process of review and public comment**, APA’s Board of Trustees and Assembly approved it last fall for inclusion in the DSM. It will be included in the new text revision of DSM-5 (DSM-5-TR), which is slated for release in March 2022.”

<https://www.psychiatry.org/newsroom/news-releases/apa-offers-tips-for-understanding-prolonged-grief-disorder>



WHAT IS PGD?

Prolonged grief disorder happens when someone loses someone close, and they experience an intense yearning/longing for or preoccupation with the deceased person. Their bereavement lasts longer than social norms and causes distress or problems functioning.

SYMPTOMS

- Identity disruption (e.g., feeling as though part of oneself has died).
- Marked sense of disbelief about the death.
- Avoidance of reminders that the person is dead.
- Intense emotional pain (e.g., anger, bitterness, sorrow) related to the death.
- Difficulty moving on with life.
- Emotional numbness.
- Feeling that life is meaningless.
- Intense loneliness (i.e., feeling alone or detached from others).



Is PGD different from usual grief? Yes and No

More than a year after the death, PGD differs from usual continuing grief in pervasiveness of

- ✓ Preoccupation and yearning
- ✓ Other grief symptoms
- ✓ Disruption of ongoing life

Common Grief symptoms	Usual continuing grief	Prolonged Grief Disorder
1. Yearning/longing, preoccupation	Come and go - can be intense	Persistent and pervasive
2. Identity confusion, disbelief, avoidance, emotional pain, numbness, loneliness, etc.	Come and go, minimal role in dealing with the loss	Persistent and pervasive, important way to deal with the loss
3. Disruption of ongoing life	Mostly re-engaged or clear progress in reconnecting	Mostly not re-engaged in life; functioning compromised

Is PGD different from depression?

Dr. Benjamin Saddock NY Times April 2, 2022
voices a common misconception

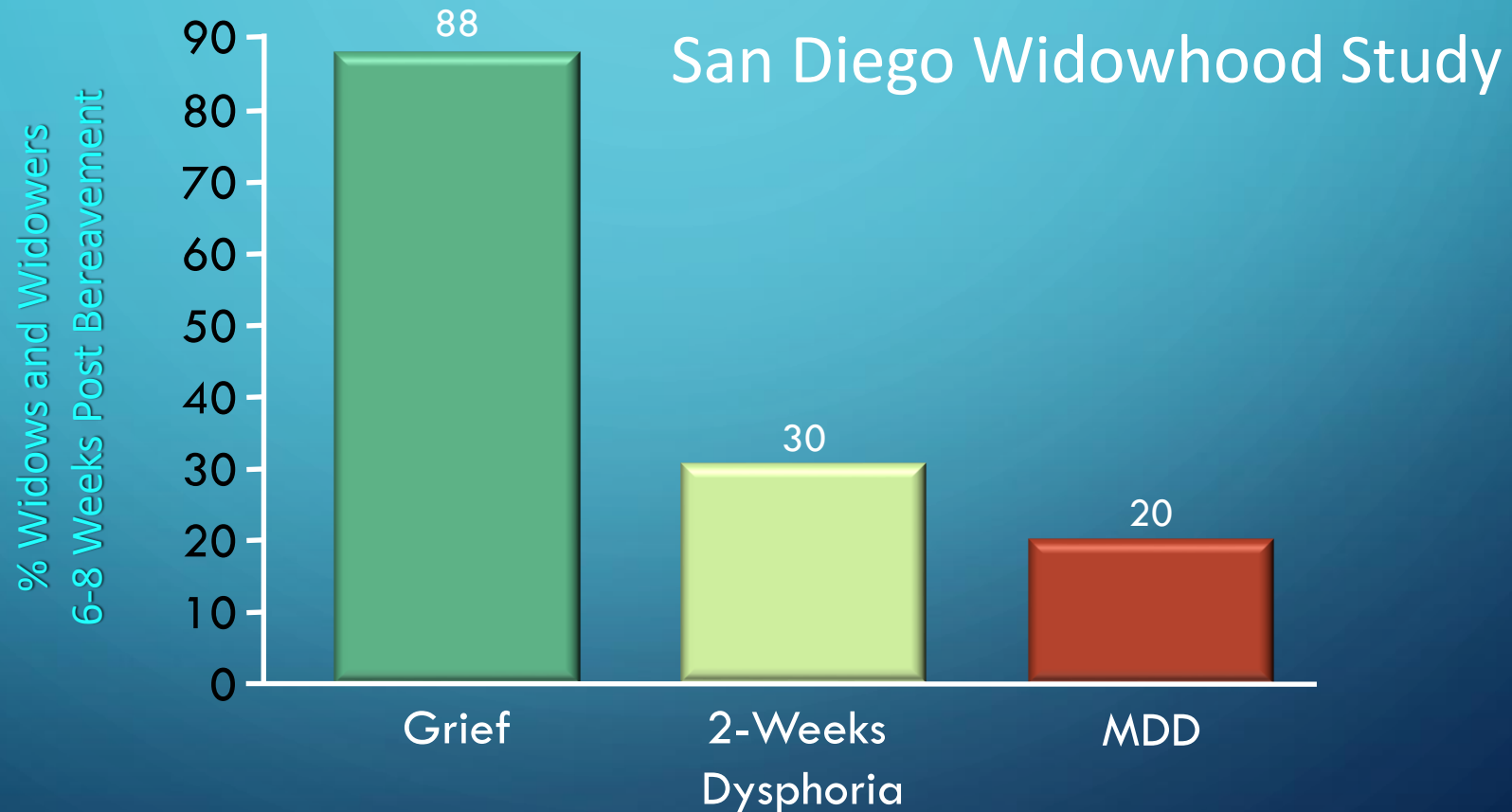
“In rare instances, prolonged grief progresses to melancholia, a well-recognized disorder that encompasses all of the symptoms of major depression. However, a diagnosis of prolonged grief, a disorder that is unnecessary, unwarranted and one that may stigmatize those so diagnosed.”

A common misconception

Is PGD different from depression?

Survey Studies say no

Grief and Depression Are Distinguishable in the First Two Months of Bereavement



Zisook S, Schucter SR (2001), Am Behav Sci 44(5):782-797

Is PGD different from depression?

Treatment studies say no

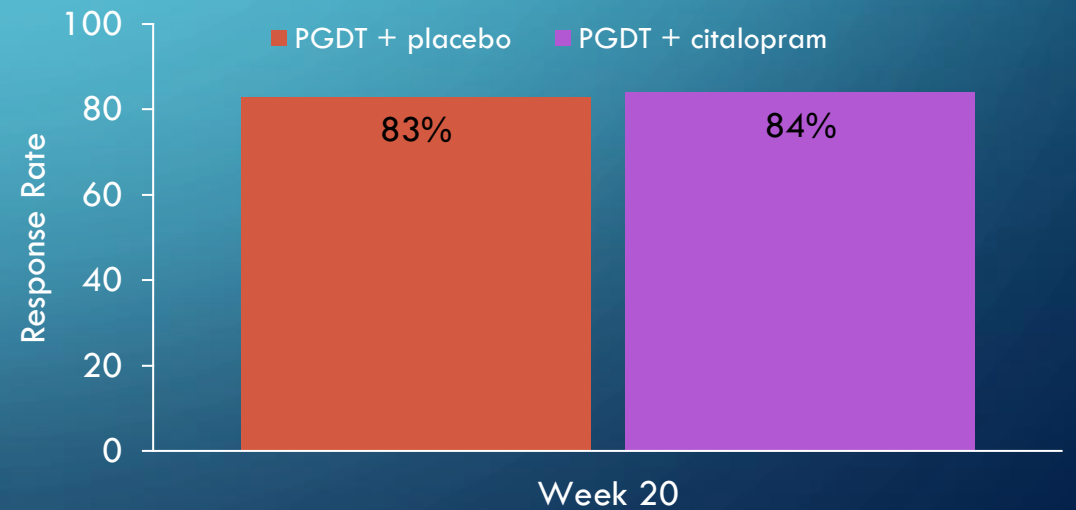
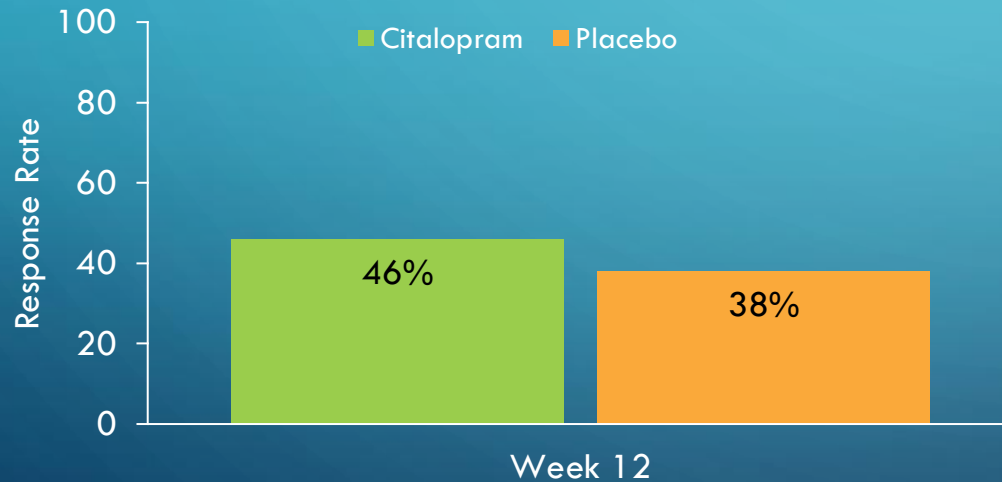
Efficacy of antidepressant medication for PGD

funded by National Institute of Mental Health

Duan, Reynolds, Shear, Simon, Zisook

Antidepressant medication had little effect and was not better than placebo for PGD

PGDT had a strong effect for PGD and was not improved by adding medication



Shear et al. JAMA Psychiatry 2016;73:685-94

Note: antidepressants did help symptoms of depression

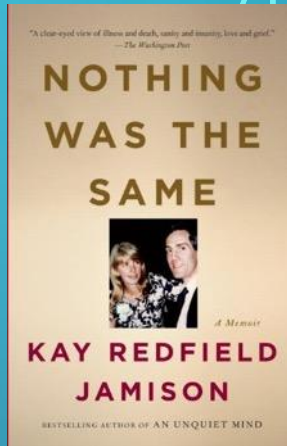
Is PGD different from depression?

Psychologist Kay Redfield Jamison says no.

“The capacity to be consoled is a consequential distinction between grief and depression.”

”...you come out of it genuinely stronger, and with a much better understanding of the person you lost and ... yourself, your vulnerabilities and your strengths Grief forces you to do a kind of introspection that is really remarkable....

My mind knew that everything about me needed tending. Solitude allowed tending, and grief compelled solitude. Time alone in grief proved restorative. Time alone when depressed was dangerous. The thoughts I had of death after Richard’s death were necessary and proportionate. They were of his death, not my own. ..In grief, death occasions the pain. In depression, death is the solution to the pain. My mood, fixedly bleak during depression, was not so during grief. It was mutable and commonly rose in response to the presence of my family and friends. I was generally able to meet the demands of the world.Even during the worst of my grief I had some sense that this would happen, that the weather would clear. I did not have this faith during the merciless months of depression.”



What do we know about grief?

- The natural response to loss - more than an emotion - complex and multi-faceted
- Long-lasting, but usually finds a place in our mind and life
- Changes over time but not in defined stages or any predictable way
- Unique to every person and every loss - still there are commonalities

A stressor and stress response

Death of a loved one is a major life stressor

A form of love

Separation response of attachment system

Modified as we adapt

Changes as adapting progresses

Grief is a Stress Response

Loss of someone close is one of life's most severe stressors

Loss of the person is a big stress in itself - but there are also many other stressful consequences of an important loss

and also a Stressor

The power and complexity of grief adds to the stress: the intense emotional pain; confusing thoughts; mixed feelings, for example...

Wanting grief to go away and also wanting to hold onto it

Wanting to be free of pain but also feeling we should be in pain

Wanting to move on in our life and not wanting to at the same time

Feeling a need for other people but finding it hard to connect

Knowing the loss is real but having trouble understanding it

Craving closeness to the person who died but thinking we need to avoid reminders of the loss

Not wanting to stop thinking about our loved one we but feeling frustrated because the thoughts are all we have

Grief is a form of love

It is the natural way love manifests itself “the next phase of the dance” (CS Lewis)

It contains the value of what was lost and the continuation of our relationship

It's the form love takes when someone we love dies

Grief changes as we adapt to the loss

Adapting is changing our automatic expectations to adjust to the differences.

Accept the Reality

- Finality of the loss
- Presence of grief
- A changed relationship to the deceased
- Other changes that accompany the loss

Restore Well-Being

- Rediscover ourselves - what has purpose and meaning for our lives
- Sense of competence and agency
- Feeling of belonging and mattering; promise of satisfying relationships

Adapting reduces stress and promotes growth

Healing Milestones: a way to think about adapting to loss

Understand and accept grief

Manage grief-emotions

See a promising future

Strengthen relationships

Narrate the story of the death

Learn to live with reminders

Connect with memories

PGD is what happens when we can't adapt

Most often it's when we can't let go of some common early ways of coping

Disbelief, protest
Imagining alternative scenarios
Caregiver self-blame or anger
Worry about grief
Reluctance to move forward
Wariness of closeness to others

Holding onto these natural coping strategies makes it harder to accept the reality and/or restore the capacity to thrive

What might make it harder to let go

Person or relationship-related

history of depression, prior loss/trauma, difficult early relationships

a very close relationship with the person who died and lack of other close relationships

Circumstances related to the death and its aftermath

younger age of the person who died, sudden death, distressing conditions or incidents surrounding the death, associated losses and stresses – e.g. loss of income, need to move, loss of social connections

How we think about Prolonged Grief Disorder

Continuation of intense grief beyond the time it usually takes to come to terms with a loss

Not a completely different way of grieving

Early ways of coping persevere, taking up too much mental space

Adapting to the loss is derailed, stalling the usual evolution of grief

Treatment: address “derailers” and help get adapting back on track

Prolonged Grief Disorder

Healing Milestones

Understand and accept grief

Manage grief emotions

See a promising future

Strengthen relationships

Narrate the story of the death

Learn to live with reminders

Connect with memories

Common derailers

Disbelief, protest

Imagining alternative scenarios

Caregiver self-blame or anger

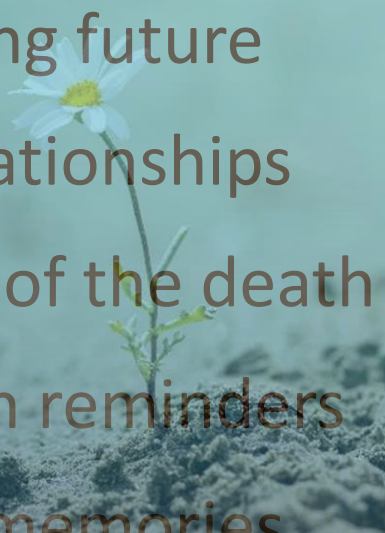
Worry about grief

Reluctance to move forward

Wariness of closeness to others

Prolonged Grief Disorder Therapy

Healing Milestones

- ✓ Understand and accept grief
 - ✓ See a promising future
 - ✓ Strengthen relationships
 - ✓ Narrate the story of the death
 - ✓ Learn to live with reminders
 - ✓ Connect with memories
- 

Common derailers

Disbelief, protest
Imagining alternative scenarios
Caregiver self-blame or anger
Worry about grief
Reluctance to move forward
Warmness of closeness to others

Takeaways

- ✓ Prolonged Grief Disorder is a new diagnosis, known to occur in countries around the world, causing considerable health, mental health and functioning problems
- ✓ PGD is different from usual continuing grief and from depression
- ✓ Understanding grief as a stress response, a form of love and as being modified as be adapt to loss can help us understand PGD
- ✓ From this perspective, PGD occurs when early ways of coping are not set aside
- ✓ PGD can be treated effectively by facilitation healing milestones

Learn more at prolongedgrief.columbia.edu

A Look at Grief and Loss Through a Lens of Hope

5th Annual Older Adult Mental Health Awareness Day Symposium

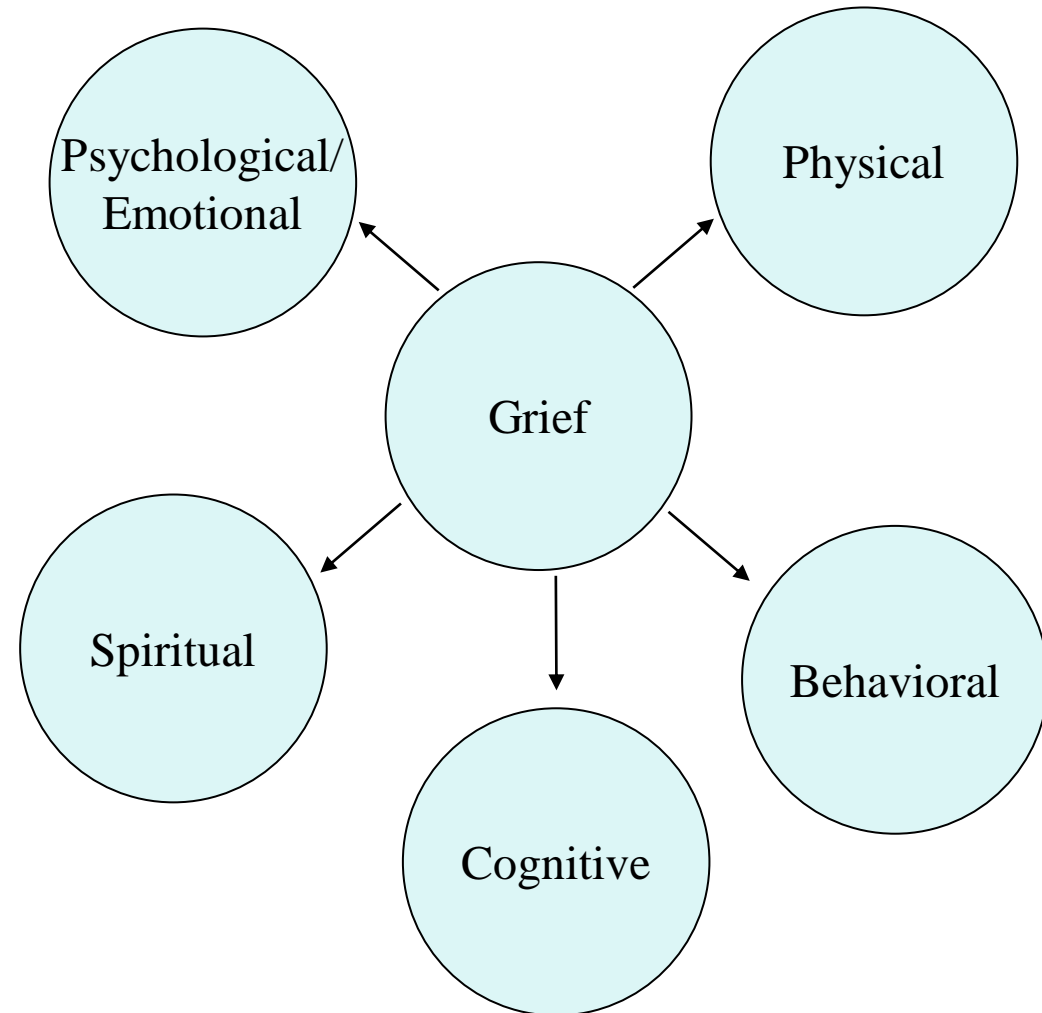
National Council on Aging



ERICA G. SRINIVASAN, ASSOCIATE PROFESSOR, PSYCHOLOGY

UNIVERSITY OF WISCONSIN-LA CROSSE

Understanding Grief as an Approach for Cultivating Hope



- In your own grief process, how do you experience these different dimensions?
- Is there one you tend to experience more than others?
- Are there some you experience equally and/or together?
- Are there some you don't experience at all?
- Do you respond to grief through emotions, or in cognitive ways, like keeping busy, or in other ways?
- How do you feel? How would you like to feel?

Grief expression in some form can be helpful for coping with grief and cultivating hope, but sometimes we limit grief expression. What are types of grief impact grief expression and how can we facilitate grief expression?.....

Helpful grief concepts to understand as we explore how to cultivate a lens of hope....

Disenfranchised Grief:

Grief (from any type of loss) that is not or cannot be:

- openly acknowledged
- publicly mourned
- socially supported

Feeling like a loss can't be acknowledged, or no "right" to grieve.

Grief can be intensified when it is "hidden."

Expression in some form becomes important for coping with grief and building a sense of hope and integration.

Doka, K. (1989). *Disenfranchised grief: Recognizing hidden sorrow*. Massachusetts: Lexington Books

COVID-19 and Disenfranchised Grief

Non-death losses are often disenfranchised

- Loss of routine
- Loss of collective gatherings (grief rituals, celebrations of life, birthdays, graduations, reunions)
- Loss of employment
- Loss of access to health care and support services
- Loss of future events
- Loss of face-to-face social connections (personal and professional life)

LOSS OF CONTROL

(Doka, 2021)

COVID-19, Cumulative Loss and Disenfranchised Grief



Cumulative grief/loss: Grief from losses that happen one after another that have not been addressed.

“Cumulative grief is something that can accumulate over the years or even decades, and seriously affect your physical and mental health.”



“While dealing with the full swing of emotions grief brings isn’t something we always have time for in our busy lives. When we don’t address our losses, we allow grief to accumulate and overwhelm us down the road.” (Hart, date unknown, retrieved April 25, 2022, <https://eterneva.com/blog/cumulative-grief/>)

Ambiguous loss

Ambiguous loss: Features of ambiguous loss include a type of loss where there is no verification of death, and a type of loss that leads grievers to question whether or not a loss has occurred.

2 types:

physical absence and psychological presence

physical presence and psychological absence

(Boss, 1999)

Ambiguous Loss (Continued)

Label the ambiguity and learn about the concept

Express grief

Thinking dialectically: giving permission for holding two opposing thoughts or actions

Practice both/and thinking

- I am both a caregiver and a person with my own needs
- I am both sad about my lost hopes and dreams *and* happy that we still have meaningful ways to connect

Building hope: finding meaning; small good steps; increasing approaches that give a sense of control and grounding; creating rituals

It's important to address and name grief so people can talk about it and understand it....

- Betty Anderson, Caregiver grief educator

History and Purpose of Death Cafes

“At a Death Cafe people, often strangers, gather to eat cake, drink tea and discuss death. A Death Cafe is a group directed discussion of death with no agenda, objectives or themes. It is a discussion group rather than a grief support or counselling session. Our objective is *'to increase awareness of death with a view to helping people make the most of their (finite) lives'*.” (deathcafe.com, 2021)

Started in 2011, in the UK, by Jon Underwood and Sue Barskey-Reid

The first death café in the U.S. was started by Lizzy Miles and Maria Johnson in Columbus, OH!



Death Cafes help ease grief, loss in the time of coronavirus

Virtual Death Cafes allow strangers to explore mortality and its impact on the living, preferably while sipping tea and eating cake.

Mourning Walk: Walking support group

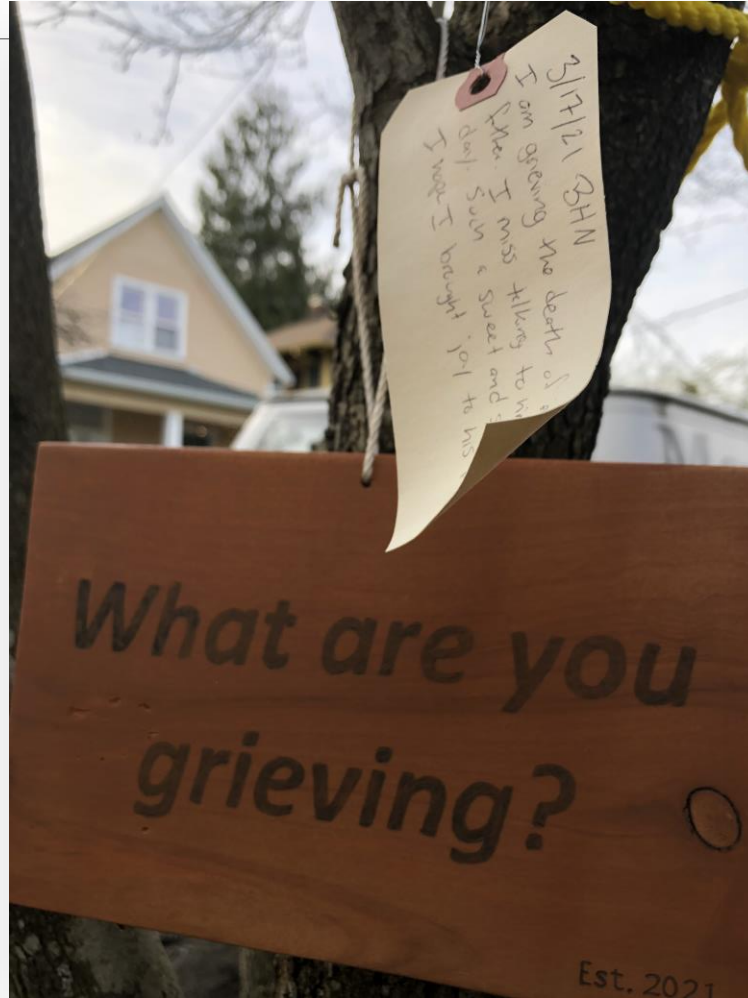
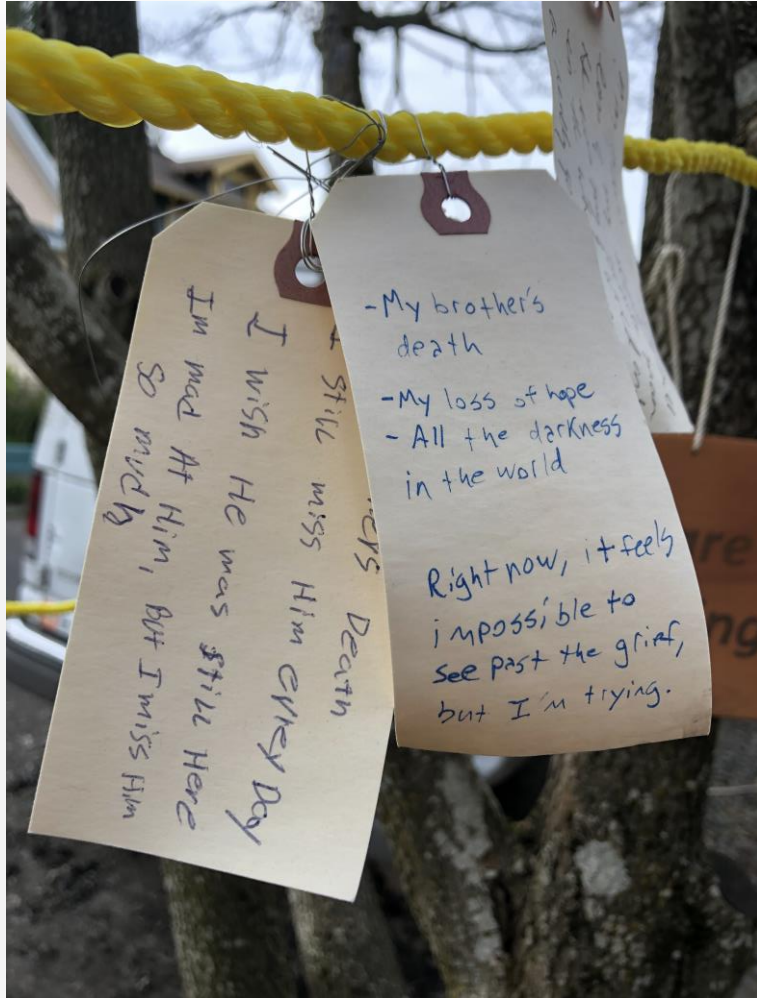
As Mark Spires noted, *“I appreciated the Bereavement Support Group, too, but the walking group really gets you out of your funk. You can just enjoy the exercise and know that you always have a place to go to discuss your loss.”*

“Everybody mourns differently – there’s no right or wrong,” explained Gloria, whose younger brother died a year ago. “The walk is very therapeutic. You see how other people have healed and you hope that one day, the sun will shine for you again.”



<https://www.hopeandcope.ca/mourning-walk-helps-ease-pain-grief-loss/>

Community Grief Sharing Tree



6-word memoir

- In another universe, we got married
- She never got to see Paris
- There's no cell service in heaven
- May 20th will always be ours
- Turns out, you do laugh again
- My dad would've loved your book
- Eventually, every waking minute doesn't suck
- Now my body is always tense
- Want him instead of his money
- So now I'm an only child
- Suddenly, I have to manage everything
- She never knew the "now you"
- I want my #1 cheerleader back
- I don't want to say goodbye

<https://modernloss.com/tag/its-complicated/>

Think about any loss in your life, and write a 6 word sentence about it. Or, write a 6 word sentence about:

- What brings tears
 - What brings relief from grief
 - What releasing emotion feels like
 - What feeling healthy feels like
 - A favorite memory with a loved one
 - A difficult memory of a loved one
 - Thoughts on caregiving
 - How it feels to support someone who is grieving
 - A topic of your choosing
-
- How was the activity for you? Easy? Challenging? How do you feel after? Lighter? Heavier? Neutral?

Writing a letter

Can be helpful for working with feelings and moving stuck feelings

It can be helpful to acknowledge positive and challenging aspects of a relationship or interactions

Can be applied to any loss of relationship, including those where you might not have physically met the person

May need several letters and needs behind the letter might change

Write as a little or as much as you want

Think about a pace that works for your life and schedule

Some people like to read the letter out loud. For others, the act of writing it brings a release and connection. Some people like to burn the letter, with compassion, as a way of completion and release. Some like to keep the letter to reflect on the grief process. Think about what feels right to you. It might change over time or with different losses

Writing a letter (Continued)

Prompts:

After _____, I felt

Sometimes I think that.....

I learned from you that.....

I really wish that.....

I wish that I could have told you.....

What I miss the most is.....

Even though I never met you, I feel.....

It really bothered me when you.....

I'm really grateful that.....

55-word story

1. Think of a compelling story based on your experience (as clinician, patient, other?).
2. Write down everything you can think of.
3. Don't edit, just write (phrases, words, key chunks of memory).
4. Put it away (optional and can be done at any time between # 2 and finishing).
5. Read over your writing and begin to clarify the idea or storyline that you want to convey.
6. Begin editing, sometimes ruthlessly.
7. Share your work with others for reactions and feedback.
8. Keep editing until you get to 55 words. Use your word counter, and also double check manually.
 - a. Title doesn't contribute to word count but shouldn't be more than seven words.
 - b. Contractions count as single words.
 - c. Eliminating articles (the, a, an) can help with word count.
9. If you cannot cut enough words, you probably have material that either would lend itself to a longer essay or become multiple 55-word stories.
10. Given the brevity, formatting can make a big difference. Experiment with line length, indentations, hanging indents, and other use of white space.

Stronger

People. All People, old, young, male, female, fever, weak, vomiting, masks, isolated, lonely, PAIN, healing, phone calls, friends, baking, cards, taking control, getting tested, finding a cure. All people, Stronger.

by Anonymous, program manager

Uninhibited emotional expression through writing

“First Thoughts:”

1. Keep your hand moving (don't pause to re-read the line you have just written. That's stalling and trying to get control of what you're saying.)
2. Don't cross out (that's editing as you write. Even if you write something you didn't mean to write, leave it.)
3. Don't worry about spelling, punctuation, grammar. (don't even care about staying within the margins and lines on the page)
4. Lose control
5. Don't think. Don't get logical
6. Go for the jugular. (if something comes up in your writing that is scary or naked, dive right into it. It probably has lots of energy).

(Goldberg, N., 1986, P.8) Page 7 handouts

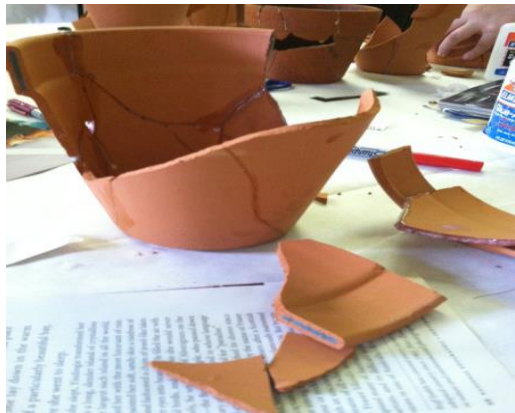
Art Activities

Drawing/Conversation Prompts

Draw a “rollercoaster” of experiences. What were the highs? What were the lows? What do you hold in your seat with you that helps with coping?

Breaking and Re-building a pot:

What made you feel shattered? What can help with strengthening and coping? (Molly Tomoney, 2020)



Kintsugi

Draw your emotions

Create a series of simple abstract drawings (without identifiable objects) that represent some of the emotions you are feeling. Use appropriate colors, lines and shapes to convey these emotions.

Draw your feelings before the loss.

Draw your feelings when the loss occurred.

Draw your feelings now.

Draw how you your grief might feel different in the future

Colors of emotions

What colors do you associate with the following emotions? Draw a big circle, and within the circle, color in the different emotions below, using the colors to represent each emotion:

sad, mad, in pain, lonely, afraid, confused, heavy, anxious, stuck

happy, hopeful, healing, transformed, peaceful, calm, inspired

2-Minute Coping Approaches

Set with intention, 2-minute coping approaches can be very powerful

Deep breathing-longer exhale

Yoga poses

Washing face

Going for a walk

Writing

Drawing

Standing outside-letting the air carry your feelings

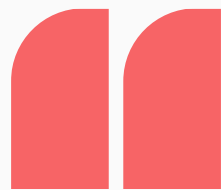
Texting a friend: I feel...I want to feel...I will....

For support providers: listen for and label signs of hope, growth and strength



Thank you!





**Join us for the closing panel at
3:30 p.m. EST.**

Like what you heard? Use the hashtag

#OAMHAD2022

to share on social media