



**MyNHPCO**

Your Community:  
Connect. Learn. Share.

# Grief in Dementia

**MyNHPCO Bereavement Community Chat**

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## MyNHPCO: Where do I find it, and what is it?

- Visit: <http://my.nhpc.org/home> and use your NHPCO email and password.
- A collaboration of 15 discipline-specific professional communities and issue-based communities.
- Interdisciplinary-focused
- MyNHPCO contains on-line resources, forums and networking will help you grow professionally, find new solutions, contribute to the field, and elevate the national profile of your program.

# MyNHPCO



PROFESSIONAL  
COMMUNITIES



DISCUSSION  
POSTS



MONTHLY  
CHATS



LIBRARY  
ENTRIES



BLOG

# Please contact us...



...if you have questions about membership,



...if you have topics you would like us to discuss,



...if you would like to become a community committee member, and



...stay connected at the Bereavement Professional MyNHPCO Community!

# Housekeeping

- We call this hour a 'chat' for a reason
- Feel free to type in your questions in the chat feature on the side of your screen
- We want everyone to share their experiences
- We will offer suggestions but welcome everyone's participation and input
- You may introduce your self in the CHAT.
- Let's get started!

# What is grief?

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- Grief is a normal and natural response to loss. Grief is a *process* of adjusting to change over time.

“Grieving  
doesn’t make you imperfect.  
It makes you human.”

SARAH DESSEN



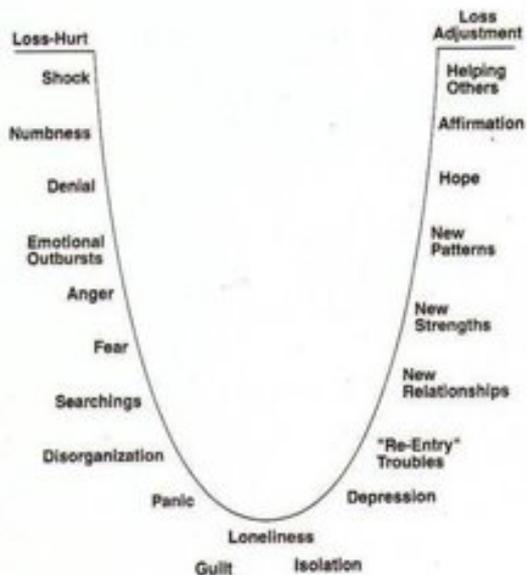


I NEVER KNEW  
HOW EASY IT WAS,  
TO BE HAPPY AND SAD,  
AT THE SAME TIME.

- DAVID JONES

Grief can be very confusing and feel complicated. Grief is emotional, physical, psychological, spiritual and changing.

## STAGES OF GRIEF



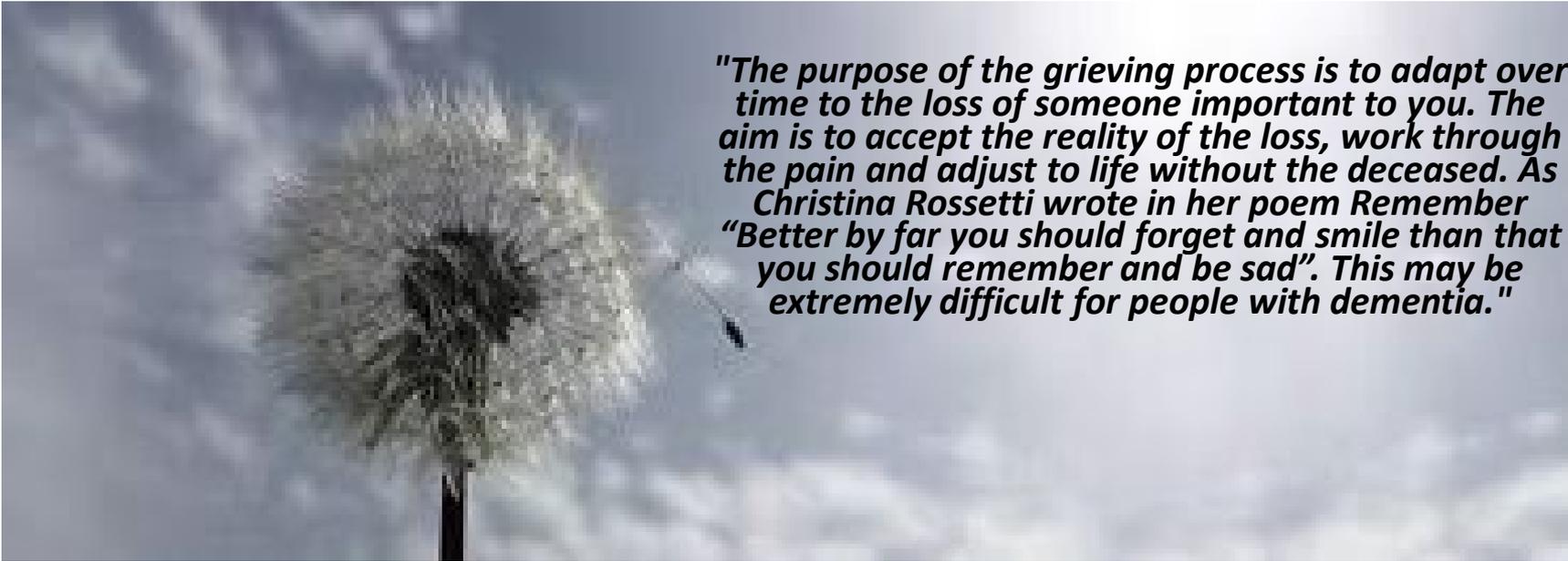
## My experience





Do people with  
dementia grieve?

**YES**

A close-up photograph of a dandelion seed head, showing the intricate structure of the seeds and the dark center. The background is a soft, out-of-focus sky with light, wispy clouds. The overall mood is contemplative and serene.

***"The purpose of the grieving process is to adapt over time to the loss of someone important to you. The aim is to accept the reality of the loss, work through the pain and adjust to life without the deceased. As Christina Rossetti wrote in her poem Remember "Better by far you should forget and smile than that you should remember and be sad". This may be extremely difficult for people with dementia."***

-Alzheimer Scotland

# Challenges of grief during dementia

Loss in cognition  $\neq$  loss of emotion  
or somatic response

Loss may be vague or seem  
unreachable

Capacity for grief  $\neq$  ability to  
process

Rational, logical, conceptual ability  
compromised

- Dementia is a disease of the brain that impacts memory and function
- People with dementia experience emotion but may or may not be able to process the emotion or make sense of it
- Body memory may be intact, this can be confusing





Frustration,  
agitation,  
restlessness, crying



Confusion, worry,  
missing, sense of  
"not right"



Slipping into the  
past, withdrawal,  
time shift



Pattern of inquiry  
(e.g., morning  
coffee)



Any mood,  
behavioral or health  
changes



Attachment to  
particular objects

# Should I tell them?

- Definitely yes, maybe...
- Does this death impact their life?
- Does this death impact you?
- Consider autonomy and dignity





# Factors to Consider



Stage of dementia (e.g., early denial vs. forgetfulness)



Short vs. long term memory/where they are in time (time hop)



Type of dementia (may impact behavioral response)



Relationship to deceased and frequency of contact/life involvement

## Factors to Consider Continued

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Amount of change that will occur

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Was the death expected

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Ability to express themselves

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Past losses and other deaths

# How do I tell them?

Appropriate time of day and setting

One-on-one, avoid groups

Minimize distractions

Speak slowly, clearly, concisely

Avoid euphemisms



# How do I tell them?

- Allow time for response
- Repeat and clarify as needed
- Use body language/physical touch if appropriate
- Don't add to the confusion or "protect" from the truth

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## What do I say?

- Be truthful (vague/generic may be okay)
- Be consistent
- Be patient
- Listen for the emotion (e.g., worried or concerned vs missing vs practical matter)
- Validate the relationship/role



# What if they forget?

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- Nature of relationship
- Capacity and amount of change
- Forgetfulness vs denial vs confabulation
- Placement of themselves in time
- Issues with recognizing others
- Be truthful



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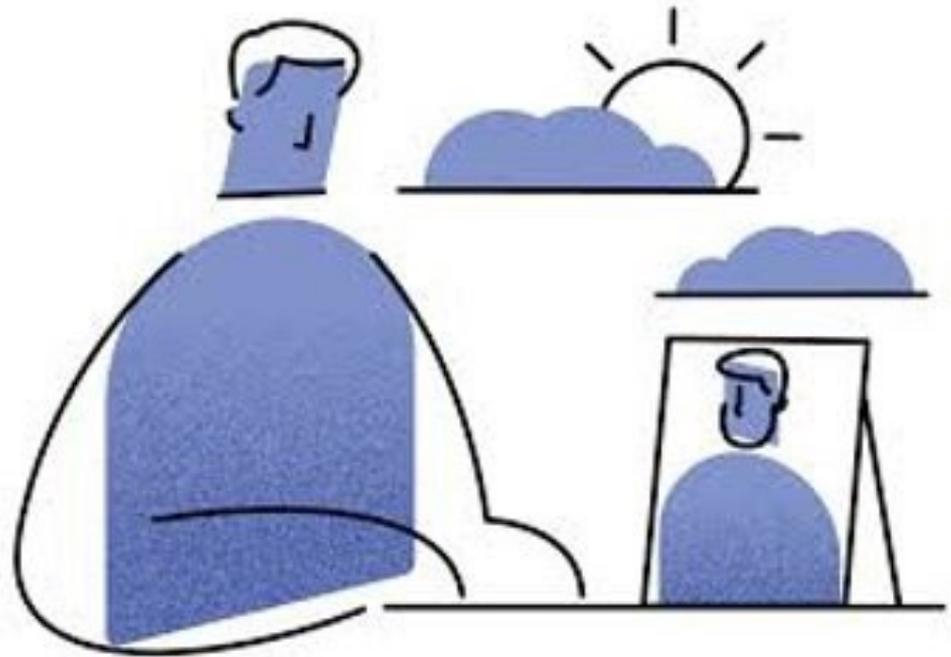
## Funerals

- Ritual, social cues help "appropriate" behavior
- May help cement understanding
- Don't hide emotion (causes confusion)
- Provide support/exit strategy
- Involve *as much as possible*
- Share expressions of sympathy, cards
- Manage expectations



# How can I help?

- Listen, spend time, be patient
- Provide concrete memories, share stories
- Provide photos, mementos, reminders
- Provide consistent messaging across support
- Explore expression through art/music/nature
- Follow their lead/frequency



# How can I help?

- Recognize that change is a challenge
- Spiritual support, if appropriate
- Distraction/redirection
- Use the past tense when speaking
- Don't force reality
- Take care of yourself



Thank you!

Questions?

