



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?

- 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



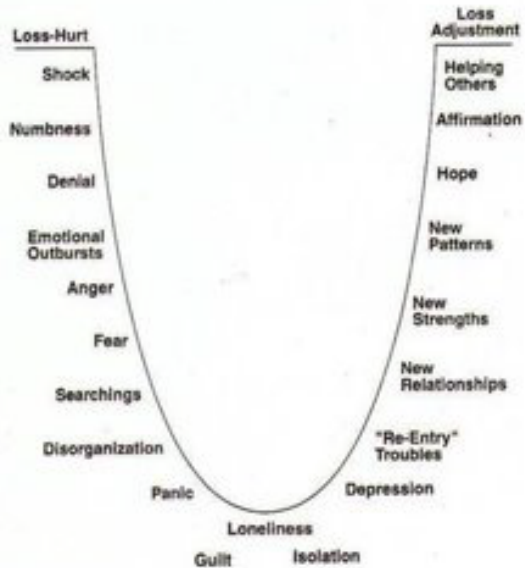


I NEVER KNEW
HOW EASY IT WAS,
TO BE HAPPY AND SAD,
AT THE SAME TIME.

- DAVID JONES

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

STAGES OF GRIEF



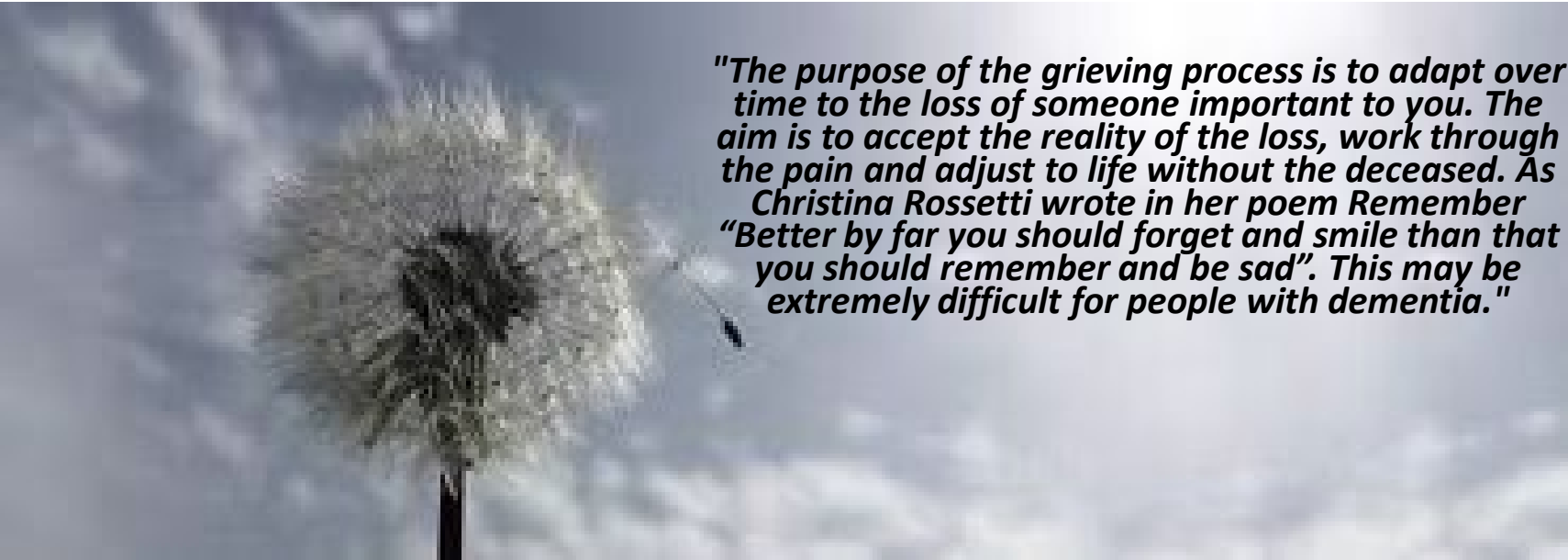
My experience





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 clouds. The image is used as a visual backdrop for the text on the left side of the slide.

"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

Amount of change that will occur

Was the death expected

Ability to express themselves

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

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?

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



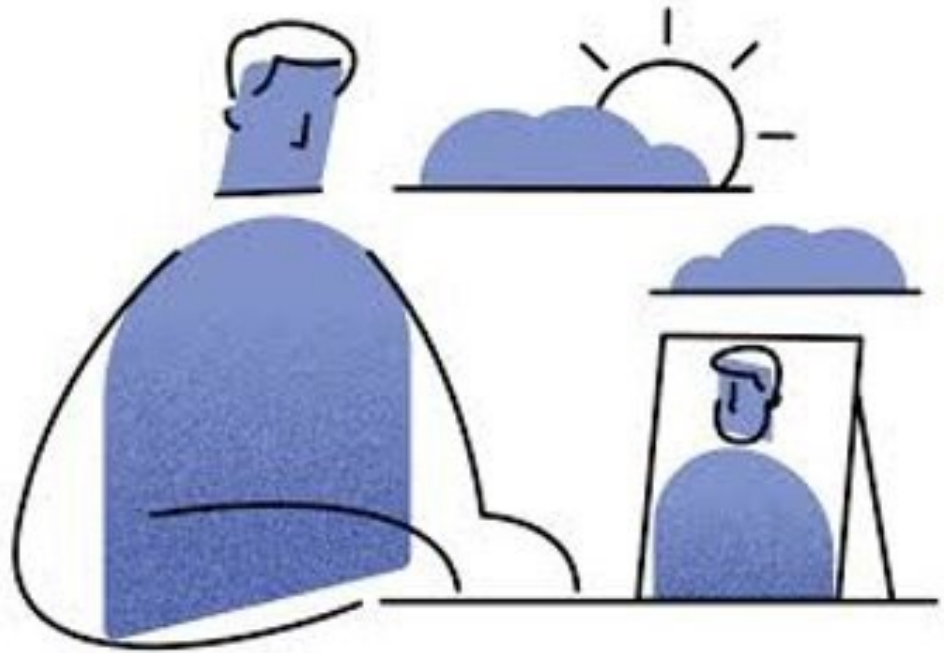
Funerals

- 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?

