

**2022 Caring for the Human Spirit  
Health Care Chaplaincy Network**

**Supporting Care Partners of  
People Living with Neurologic Illness**

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# Objectives

In this presentation you will learn about:

- Common issues affecting care partners of people living with neurologic illness
- The process of grief and loss among care partners of people living with neurologic illness
- Some approaches for promoting care partner resilience in the context of neurologic illness



# Care Partners in Neurologic Disease

- Since 2009, the need for informal care partners has risen 49% and will continue to rise with the aging of populations around the world.
- Neurologic disease often affects an individual's functioning and results in long-term disability.
- As neurologic conditions progress over time, there is increasing demand on care partners.
- Care partner distress is twice as prevalent among care partners of patients with neurologic conditions than among others.



# Care Partner Distress

- The most cited contributors to care partner distress are:
  - Physical demands of care
  - Cognitive impairment
  - Behavior disturbances
  - Psychiatric/psychological symptoms (e.g., delusions, depression)

# Common Issues in Neurologic Illness

- Loss of function and ability
- Loss of social identity/role
- Loss of personhood
- Anosognosia
- Social Isolation and Loneliness
- Long trajectory of progressive grief and loss
- Uncertainty (“When’s the next shoe going to drop?”)
- Fear of dementia



# Common Symptoms with Cognitive Decline

- Difficulty communicating
- Apathy
- Sleep/wake cycle disturbances
- Anxiety
- Psychosis
- Agitation
- Aggression and abuse



# Impact on Care Partners



# Common Struggles for Care Partners

- Emotional
  - Depression, grief, guilt, anger, burnout, bereavement
  - *Can also feel rewarding, gratifying*
- Physical
  - Poor sleep, heart disease, possibly increased mortality rate, stress and worry
  - *Can also improve physical well-being*
- Social
  - Isolation, change in relationship and roles with friends and family
- Financial
  - Cost of in-home-care, loss of income



# Caregiver Needs

- *Individual attention*
- *Emotional support*
- *Education and information*
- *Connection to others*
- ***Time, time, and time!!! (There's never enough)***
- Competence and confidence
- Health and rest
- Connection to outside resources
- Time for self-care
- Time to not be a caregiver
- Financial assistance

# The Difficult Emotion of Grief

- Grief often begins at diagnosis
  - There may be shock or raw grief for both the care partner and the person who's received the diagnosis.
- And it continues as the care partner watches the person they love disappear before their eyes
  - Day after day
  - Week after week
  - Year after year



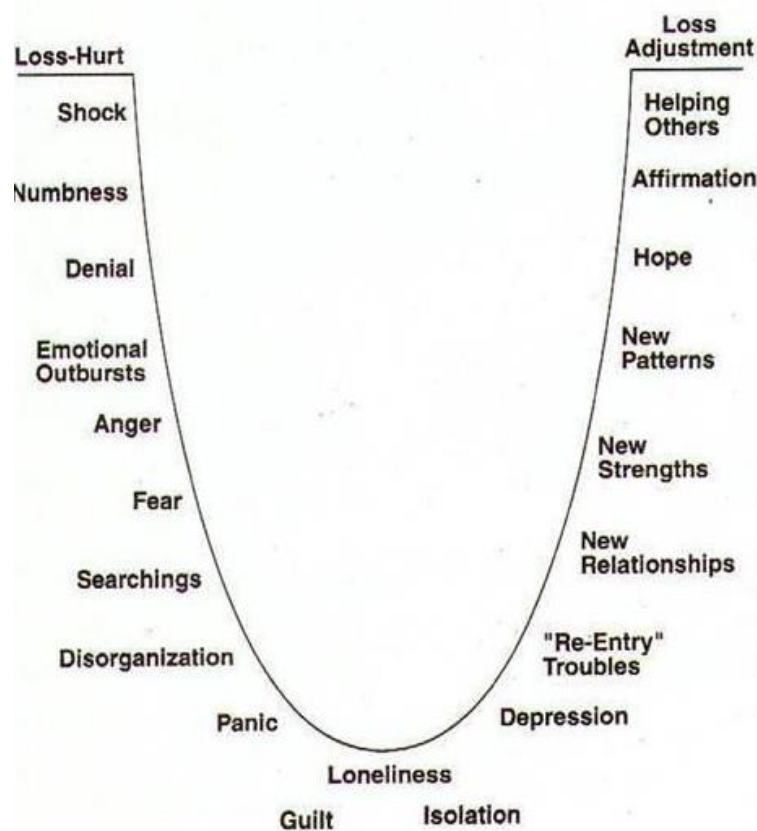
# Kinds of grief a care partner might experience

- *'Pre-death' grief* – grief for the everyday losses here and now
- *'Anticipatory' grief* – grief now for a death in the future
- Bereavement and mourning – grief and mourning after an actual death

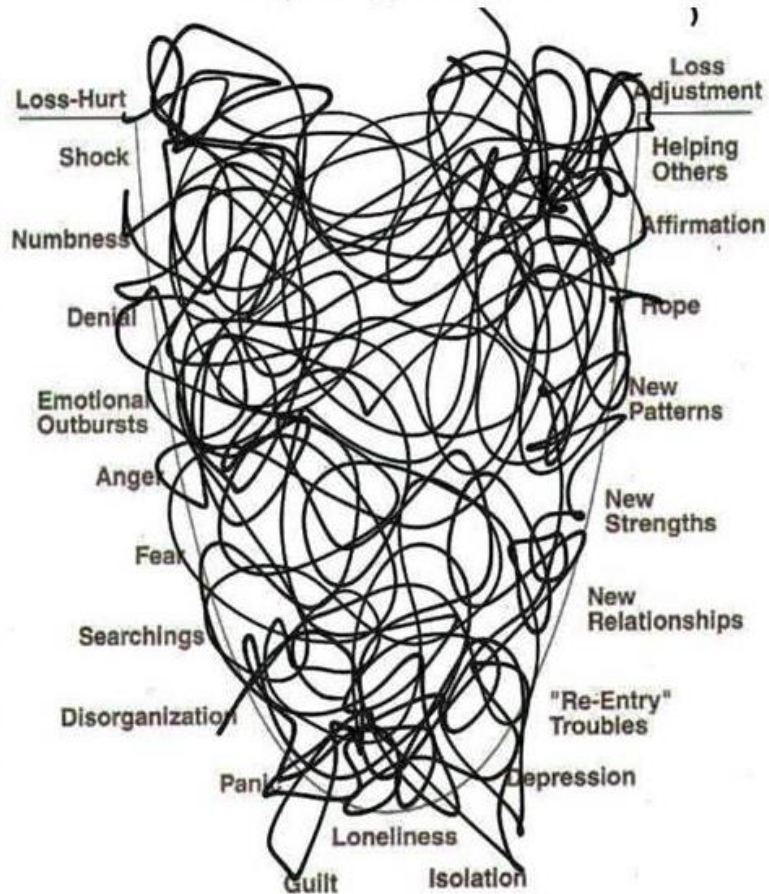


# Stages of Grief

## STAGES OF GRIEF



## My experience



# Pre-Death Grief --

## allowing the everyday grief now

- Care partners often feel they shouldn't grieve now because their person is still alive.
- Yet studies show that letting themselves grieve now (even while muscling through) can lead to healthier adaptation later, after the actual death, with lowered incidence of prolonged grief.
- **We can help normalize this for care partners.**



# Preparing for Later Bereavement

- We can also help care partners consider who they hope to be in the future, after the death, informed by this experience.
- We can also encourage care partners to consider some things they hope to do in the future.
- These practices can foster post traumatic growth, which may, in turn, help offset the inclination of many care partners to believe they didn't do enough.



# Approaches to Promoting Resiliency

- Education – What do I need to know?
- Community – Where can I connect with others who ‘get it’, so I’m not all alone in this?
- Emotional Resilience – How do I make my caregiving sustainable?

# Resiliency – strengthening our ability to recover from set-backs





# Education

- **Understanding this particular illness and dementia, if likely**
- **Learning ways to manage problems**
- **Learning about medications**
- Building a care team (including a back-up plan)
- Sustaining your relationship
- Planning for the future (including placement, end of life, and bereavement)



# Education (a little more granular)

- Durable power of attorney – financial as well as for health care
- Financial / insurance planning if needed
- Back up plan (SOS) in case of care partner absence because of child care, respite, illness, death (pre-deceasing the one receiving care)
- Durable medical equipment
- Placement – if/when/where
- End of life planning



# Community

- Friends, family, social groups, faith community
- Support groups for care partners
- Support groups/activities for people living with neurologic illness
- Dementia-friendly communities

# Emotional resiliency

- Meaning and purpose for the greater good  
vs. meaningless and despair
- Connection (authentic relationships)  
vs. isolation
- Choice (control, sense of agency)  
vs. helplessness



# Meaning and purpose – strengthening positive intention

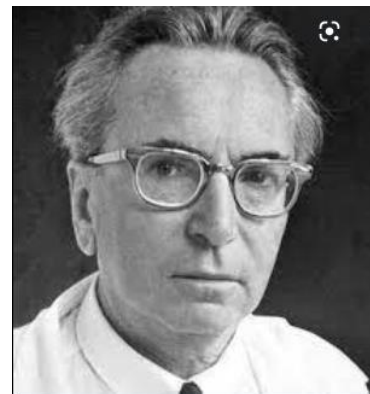
- Regularly recalling, ‘Why am I *really* here?’ (in addition to necessity)
- Note: Recalling why we care, even while we’re busy, can be sustaining both physiologically and emotionally.

# Connection –authentic relationships

- Choosing to connect
- Emotions 101 and meeting difficult emotions
- Self-compassion
- Challenging relationships
- Re-framing chronic sorrow

# Choice – choosing one's own attitude

- *“Everything can be taken from a man [or woman] but one thing: the last of the human freedoms—to choose one's attitude in any given set of circumstances, to choose one's own way.”* -Viktor Frankl, '**Man's Search for Meaning**'.



# Choice in daily life (a few possibilities)

Choosing what makes sense:

- Grounding yourself to calm your emotions when feeling stressed
- Meeting difficult emotions skillfully, so you don't get stuck in them
- Setting a positive intention to help you remember what matters most
- Choosing to connect
- Practicing self-compassion (kindness) instead of self-criticism





# Choice in daily life (a few possibilities) – cont'd

- Working with challenging relationships without getting overwhelmed
- Finding balance in the presence of suffering
- Cultivating a gratitude practice to encourage a positive mindset
- Keeping a personal wellness practice journal



# The Importance of Caregivers



# Summary

- Care partners of people living with neurologic illness
  - Are impacted emotionally, physically, socially, and financially
  - Experience profound grief starting at diagnosis
  - Can strengthen their resiliency through education, community, and developing emotional resiliency

# Key References & Reading

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