



WELCOME to
Palliative Care ECHO 5.0

October 2025 –
June 2026

Schedule

10/7/2025	<u>Moral Distress/Injury</u>
11/4/2025	<u>VSED-MCF</u>
12/2/2025	<u>Creating a Legacy</u>
	<u>Complicated Bereavement?</u>
1/6/2026	
	<u>Goals of Care for People with Disabilities</u>
2/3/2026	
	Cannabis in Serious Illness
3/3/2026	
4/7/2026	Advanced Agitation
	Palliative Care for Justice Involved
5/5/2026	
	Palliative Care High-Risk Perinatal
6/2/2026	

Moral Distress and Moral Injury

Christopher Charles, MSN, RN, CCRN

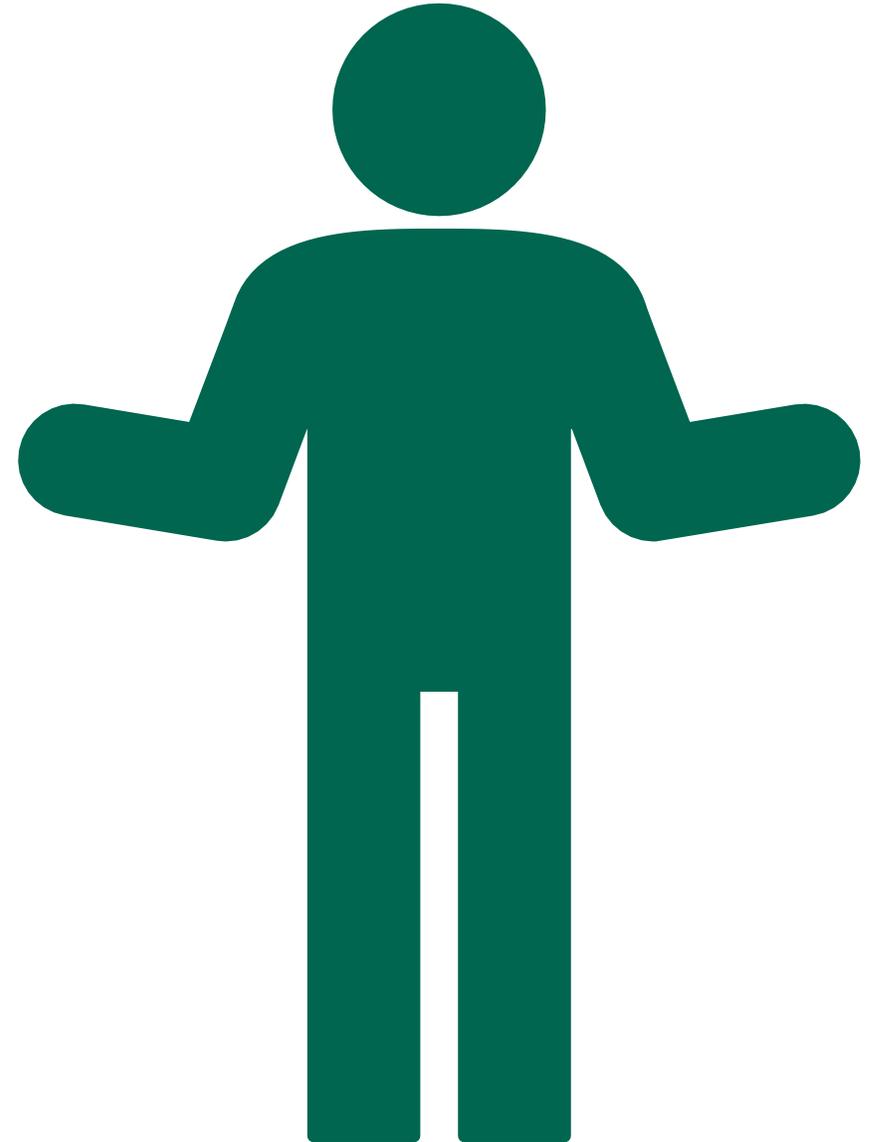
Clinical Ethics Consultant & Clinical Nurse – Dartmouth Hitchcock Medical Center

Doctor of Nursing Practice Candidate – Boston College



Have you . . .

- Had challenges sleeping, waking and wondering if you could have done something differently in the care of patients?
- Felt like you were not a strong advocate for your patient?
- Felt strained by the competing responsibilities of self, family, and profession?



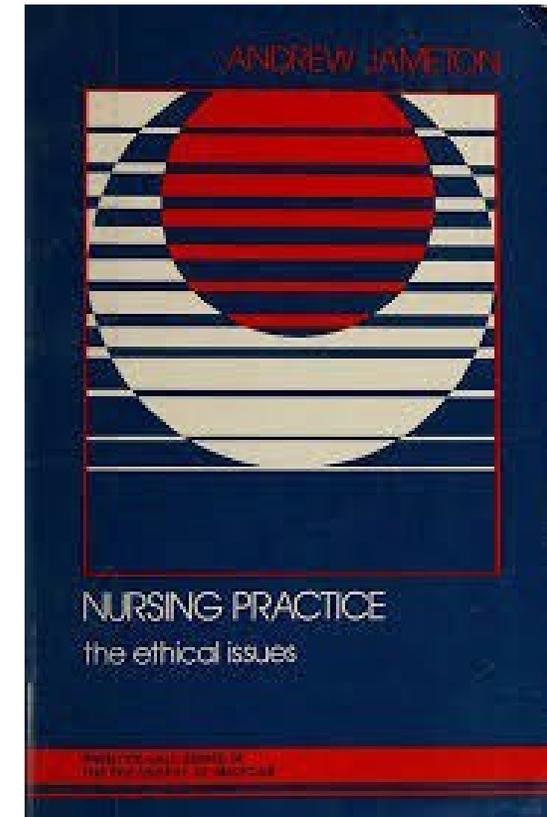
Moral Distress & Injury

- **Moral Distress:** Refers to the psychological unease that results when professionals identify an ethically correct action to take but are unable due to institutional or hierarchical barriers (British Medical Association, 2021).
- **Moral Injury:** Occurs when sustained moral distress results in a reduction in functioning or psychological harm (British Medical Association, 2021).



Moral Distress – Historical Context

- Entered nursing literature in 1984, Andrew Jameton - *Nursing Practice: The Ethical Issues*
 - Drawn from descriptions of bioethical conflicts that included:
 - Appropriate care for terminally ill patients
 - Limits of life support
 - Communication and decision-making with patients and families.



(Jameton, 1984)

Moral Distress

- Healthcare professionals encounter situations where they feel unable to act according to what they feel is right, due to institutional or hierarchical barriers (Jameton, 1984; Grace & Uveges, 2023).
- Moral distress may result in:
 - Migration from clinical areas of high stress
 - Emotional distancing from patients, compassion fatigue, and poor outcomes.
 - Attrition from the profession (Allen & Butler, 2016; Robinson et al., 2014).
 - Large financial costs associated with attrition of trained staff

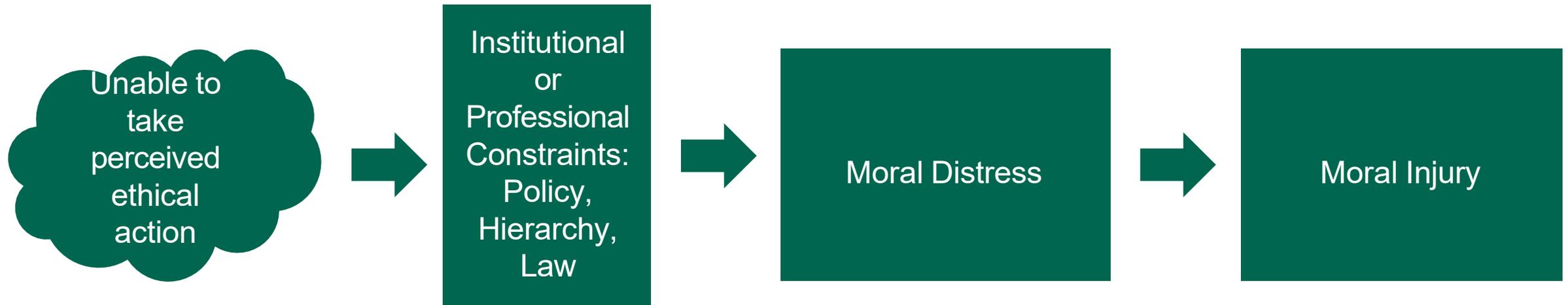
Moral Injury – Historical Context

- Introduced in 1994 by Dr. Jonathan Shay, a military psychiatrist, who identified a syndrome among Vietnam War Veterans (Nash, 2012).
- Dr. Litz, in 2009 - “Moral Injury and moral repair in war veterans: A preliminary model and intervention strategy.”
- Euripides identified the syndrome, “miasma”– to describe any violation of moral values (Koenig & Al Zaben, 2021).



Moral Injury

- Is described as a significant cognitive and emotional response that follows instances where there have been transgressions against an individual's ethical code (Williamson et al., 2021).
- Can yield:
 - Feelings of shame or guilt
 - Changes in cognition
 - Changes in self-image
 - Maladaptive coping (Williamson et al., 2021).



Strategies to Address Moral Distress and Injury

- Developing moral agency among healthcare professionals (Robinson et al., 2014).
 - Provide ethics education that speaks to everyday ethical issues.
 - Empower clinical staff:
 - Identify a problem
 - Sort out nuances
 - Conceptualize and act.

Strategies to Address Moral Distress and Injury

- American Association of Critical Care Nurses 4 A's (Rushton, 2006).
 - Ask
 - Affirm
 - Assess
 - Act
- Moral Distress Consult Service (Epstein & Delgado, 2010).



(The 4A's to Rise Above Moral Distress, n.d.)

Strategies to Address Moral Distress and Injury

- Policy development for recurrent issues.
- Interdisciplinary collaboration to foster support and pooled resources to navigate challenges



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VSED: A Primer

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November 4, 2025

Outline

Define Terminology & Overview

Explore who Chooses VSED and why?

Discuss the ethical principles related to VSED

Review Best Practices in supporting VSED

Understand the stages of VSED

Identify basic symptom management

Access Resources



*Vincent van Gogh, "Sunflowers," 1888
Oil on Canvas, The National Gallery (London)*

Terminology

CFO = Comfort Feeding Only

Offering as much or as little food and drink as the patient appears to enjoy without regard for adequate hydration and nutrition

MCF = Minimal Comfort Feeding

The amount of food or fluid offered, self-fed, or caregiver-assisted is the “minimum amount needed for comfort”

VSED = Voluntarily Stopping Eating and Drinking

A deliberate, self-initiated attempt to hasten death in the setting of suffering refractory to optimal palliative interventions or prolonged dying that a person finds intolerable

Unlike other forms of hastening death, VSED:

Is a natural dying process

Is legal nationwide

Does not REQUIRE the assistance of medical professionals, though strongly recommended.

Avoids many ethical and legal concerns associated with MAID or other palliative measures of last resort

Alternative forms of last resort measures require a prognosis of <6 months, VSED is an option for those with slowly progressive disease

“A competent person would have a constitutionally protected right to refuse lifesaving hydration and nutrition.”

-Cruzan v. Director, Missouri Department of Health (1990), Supreme Court of the United States

VSED Eligibility

Individuals near the end of life due to illness or advanced age, in serious or accelerated physical health decline, or facing impending cognitive decline

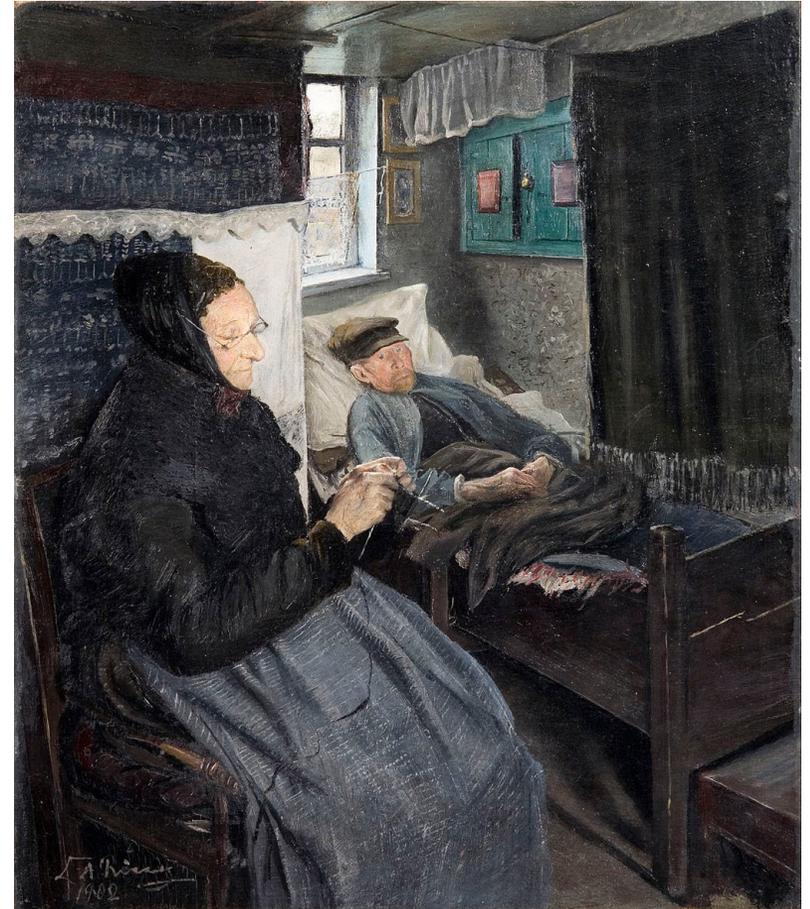
Full decision-making capacity

Voluntary and free from coercion

Not influenced by mental illness or cognitive impairment

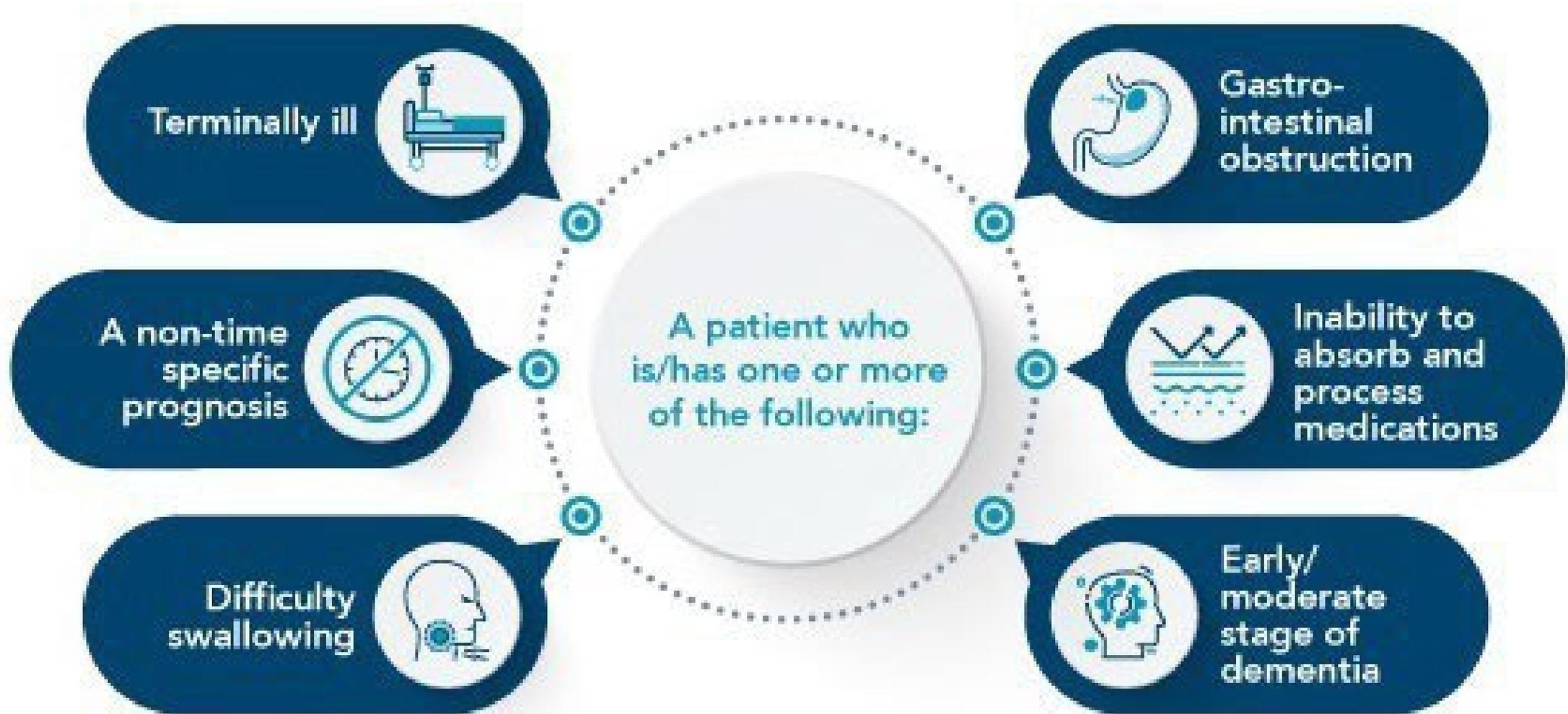
Support from main caregivers

The request for VSED is consistent with well-established patient values



Laurits Andersen Ring "The Sick Man," 1902 Oil on Canvas, [Wikimedia Commons](#)

Who Chooses VSED



Motivations for VSED:

- Control over the timing and manner of death
- A desire to die at home
- Place a high value on independence
- Strong personal resolve and support system
- Poor quality of life
- Ineligible for MAID in their jurisdiction



*Frida Kahlo, "Without Hope," 1945, Oil on canvas
Museo Dolores Olmedo (Mexico City)*

Responding to Requests for VSED

Clinicians

- Seek to understand
- Assess & treat causes of suffering:
 - Symptoms
 - Mental Health, psychiatry
 - Spirituality
 - Ethics
- No secondary gain
- Decision aligns with goals

Patients

- Demonstrate decision making capacity
 - Understanding of illness
 - Risks, benefits, alternatives to VSED
- Identify challenges:
 - Biological drive to eat and drink & management of those symptoms
 - Social & emotional care partner needs
- Consistency in decision making

Ethical and legal protections

Advanced Directives

Completed AD for SED

Ulysses Contract

POLST/COLST/PDNR

Document intention to refrain from eating & drinki
lost decisional capacity

Consider making a short phone video to show your well-thought-out intentions

End of life planning: Cremation/burial, will, etc.

Cause of Death: underlying terminal diagnosis and contributing medical comorbidities.



John William Verelsteyn, "Ulysses and the Sirens," 1891, Oil on canvas, National Gallery of Victoria

Next steps in planning

Identify the support system

Care partners, loved ones, psychosocial

Identify where

Hospice Support

Private Caregivers

Death Doula



Edvard Munch, "Death in the Sickroom," 1893, Tempera and wax crayon on canvas, National Museum of Norway

PHASE 1

Approx Days 1-4

Celebrations of life and final goodbyes

Option to stop process

Symptoms: anxiety, restlessness, fatigue, headache, dry mouth/throat, hunger

PHASE 2

Approx Days 5-9

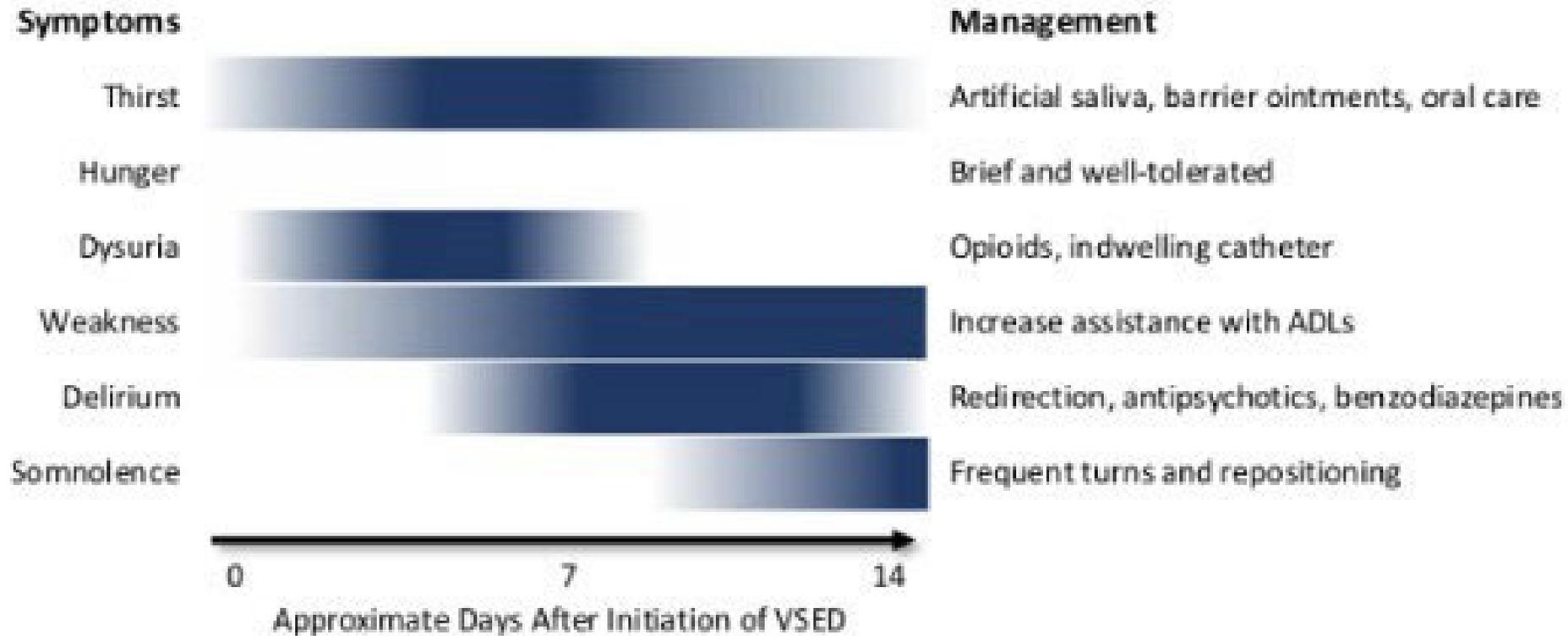
- Most difficult phase
- Symptoms: thirst, some delusions, often lack of capacity, potential agitation, weakness
- Important phase for symptom management to ensure comfort

PHASE 3

Approx Days 10-14

- Actively dying
- Lethargy -> Somnolent -> Coma
- Symptoms: Normal individualized symptoms at EOL
- Focus on care partners and bereavement

Symptom Management

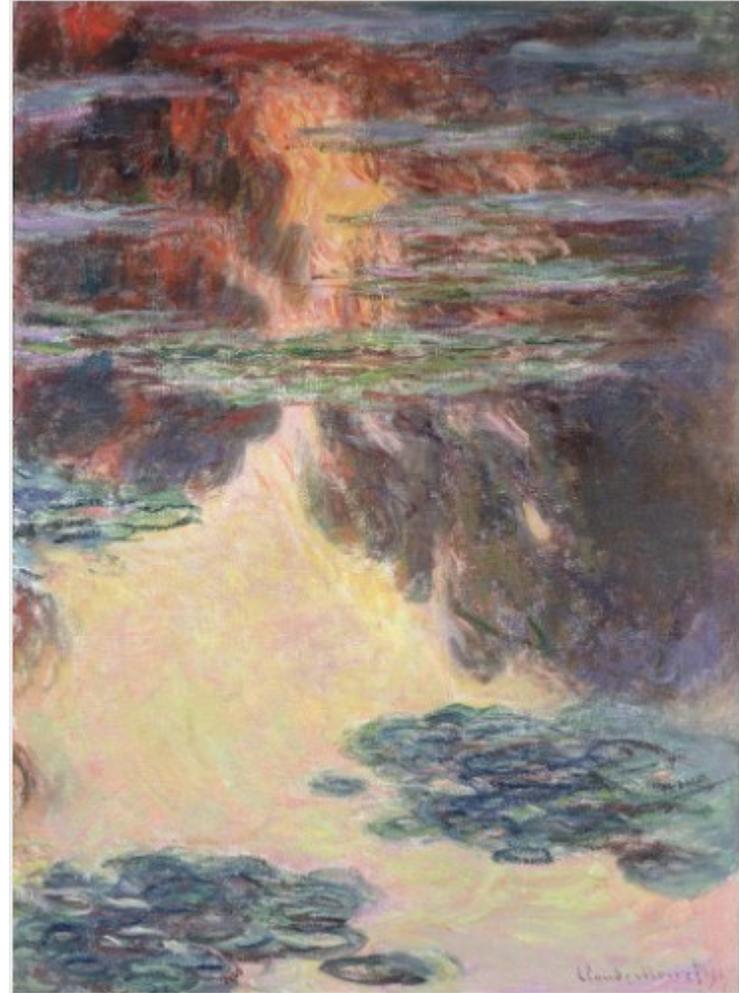


Symptom Management

Thirst & Dry Mouth <ul style="list-style-type: none">• Moist swabs,• Lip balm• Oral spray/rinse• Humidification	Dry Skin <ul style="list-style-type: none">• Lotion• Cooling cloths	Pain <ul style="list-style-type: none">• Frequent repositioning• Personal care• Opioids	Anxiety & Delirium <ul style="list-style-type: none">• Psychosocial Support• Benzodiazepines ie. lorazepam• Antipsychotics ie. haloperidol
Constipation & Cramping <ul style="list-style-type: none">• Recommend cleanse prior to starting• Bowel regimen: Senna/Colace	Hunger <ul style="list-style-type: none">• Distraction• Time with loved ones• Music/Movies,• Memento making• Reiki,• Massage	Safety <ul style="list-style-type: none">• Hospital bed• Bedside commode• Urinal• Indwelling catheter• Walker/cane/lift assist	Psychosocial & Spiritual <ul style="list-style-type: none">• Anticipatory Guidance• Clear plan for requests for food or fluid prior to initiation

Summary

Legal protected right to hasten death
Requires thorough and thoughtful planning with loved ones and medical teams
Documentation of decisions and wishes with appropriate legal protections
Strongly recommend engagement with hospice
Acknowledge that bereavement may have different characteristics d/t the manner of death, ensure access to bereavement support



Claude Monet, "Nymphéas," 1907, Oil on Canvas, Musée Marmottan Monet, Wikimedia Commons

Resources

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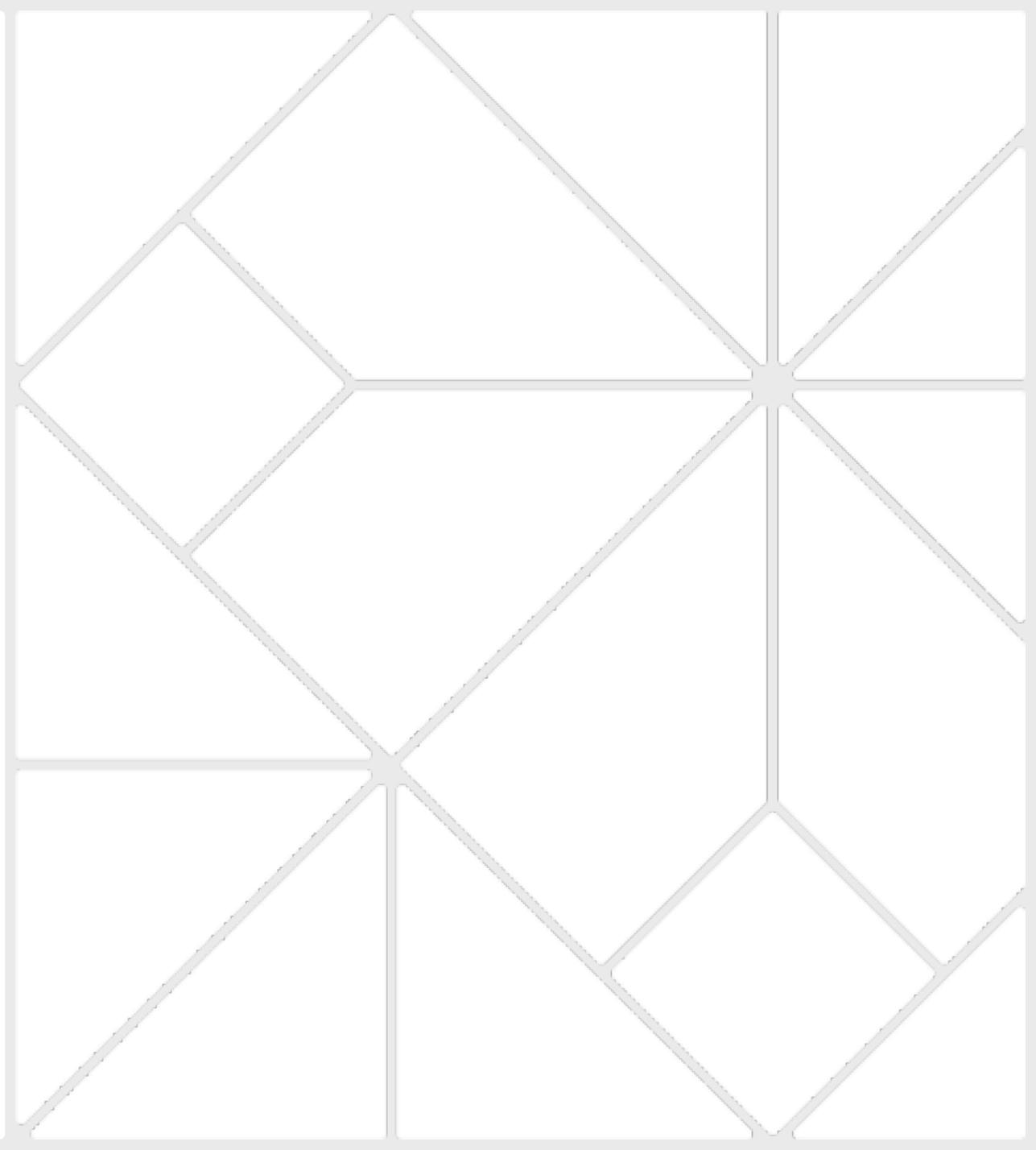
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How to Create a Legacy

Connolly Huddleston, MAPS, BCC

ECHO 5.0

December 2, 2025



Takeaways

- **What is legacy**
- **Barriers**
- **The benefits of legacy**
- **How to find, create, and build a legacy**



What is legacy?

“**Legacy** is broadly defined as ***what one leaves behind after death***, and its potential ***extends beyond leaving wealth or possessions***.

Creating a legacy is ***valuable for meaning-making*** and can ***foster symbolic immortality***, the feeling of living on after death, by ***providing a way for an individual to be remembered*** in the lives of those who survive them.”

Legacy is...

“the process of passing oneself through generations, creating continuity from the past through the present to the future”



Why do people *want* to leave a legacy?

- **Generativity**
- **Personal contribution**
- **Personal accomplishment**
- **Set their family/loved ones up for success**
- **Find peace, reconciliation, consolation, forgiveness**



Barriers

- **Fear of dying**
- **Exposes a “weakness”**
- **Shock**
- **Denial**
- **Overanalyzing**
- **Complex family dynamics**
- **Perception of others**



What are the benefits?

- **Emotional benefits**
- **Symptom management**
- **Spiritual well-being (existential distress)**
- **Promotes self-awareness**
- **Brings comfort**



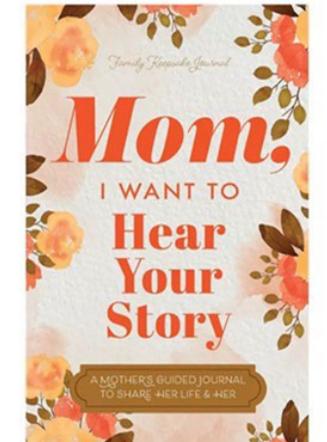
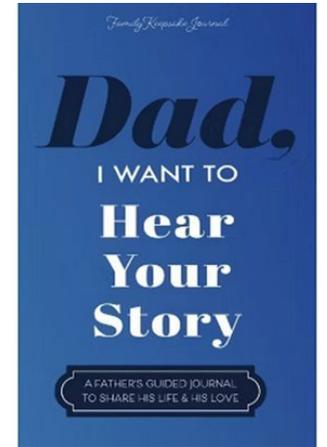
Benefits cont.

- **Fosters hope, gratitude, and peace**
- **Maintain dignity**
- **Creates a continuous connection**
- **Sense of autonomy**



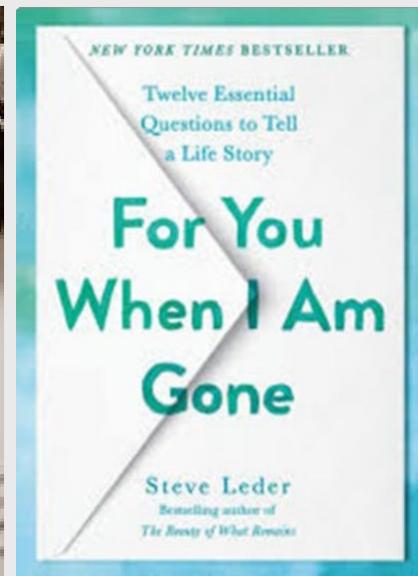
Legacy Builders

- Talk about it
- Age-appropriate items
- Cards for milestone events
- Family heirlooms
- Journaling



Builders cont.

- Voice/video recordings
- Donations to charities
- End of life preparation documents
- Recipes
- Funeral arrangements
- Memory boxes



Legacy Creating Specialists

- **Chaplains**
- **Child-Life**
- **Death Doulas**
- **StoryCorps**
- **Memory Keepers**
- **Local Hospice Agencies**



Palliative Care as Legacy Specialists



To palliate: “to make (a disease or its symptoms) less severe or unpleasant without removing the cause”

“

**“I alone cannot change the world,
but I can cast a stone across the
waters to create many ripples.”**

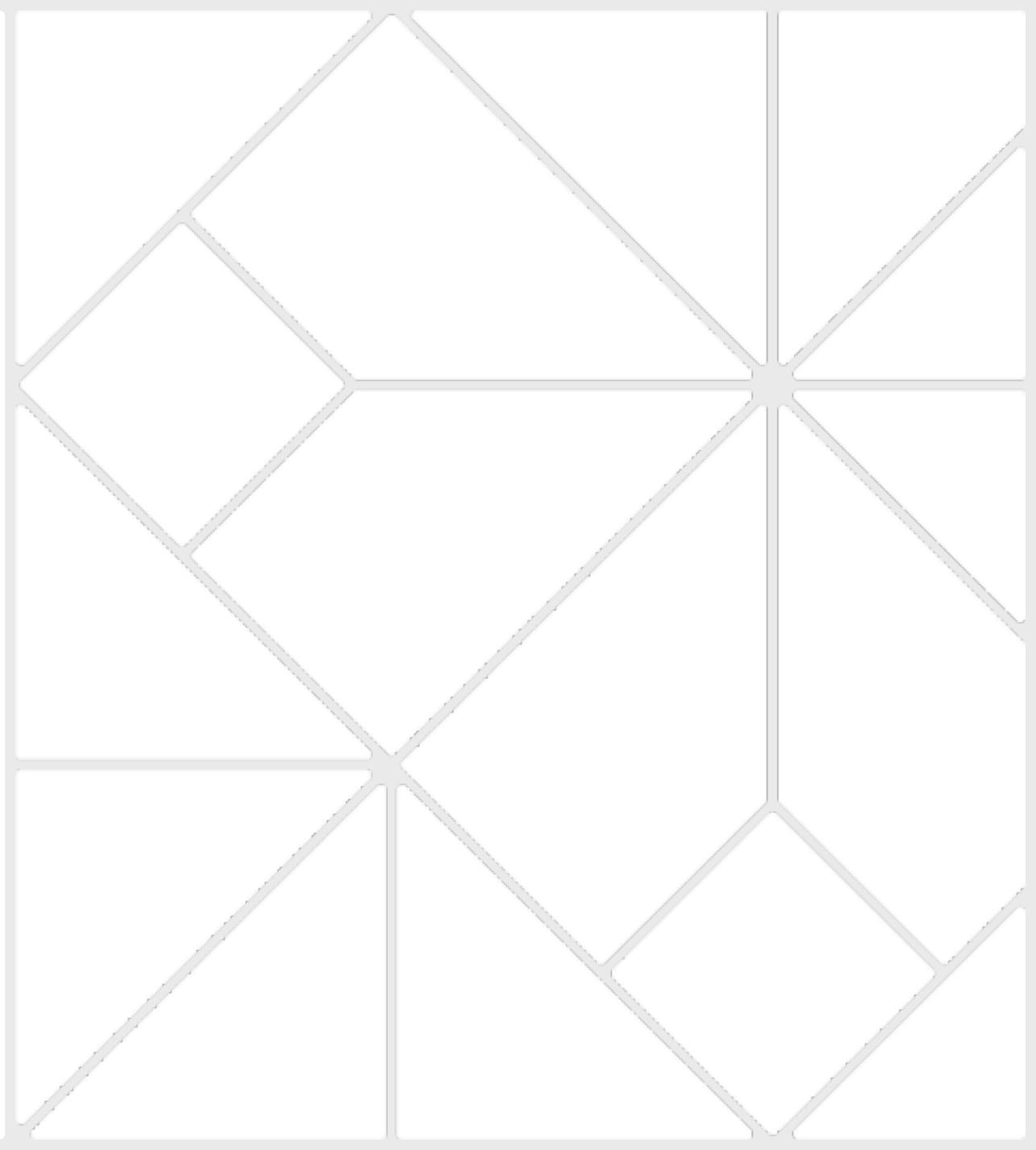
-Mother Teresa

”



Thank you!

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Prolonged Grief Disorder:

Clarity, controversy, treatment and support



Kristen Johnson, MS, CCLS, FT, GC-C

Palliative Care Program Manager, Bereavement Programs

DISCLOSURES:

- Artificial Intelligence (AI) was not used
- Perspective of a thanatologist
- I welcome further conversation outside of this presentation

The Weight of Grief
by Celeste Roberge

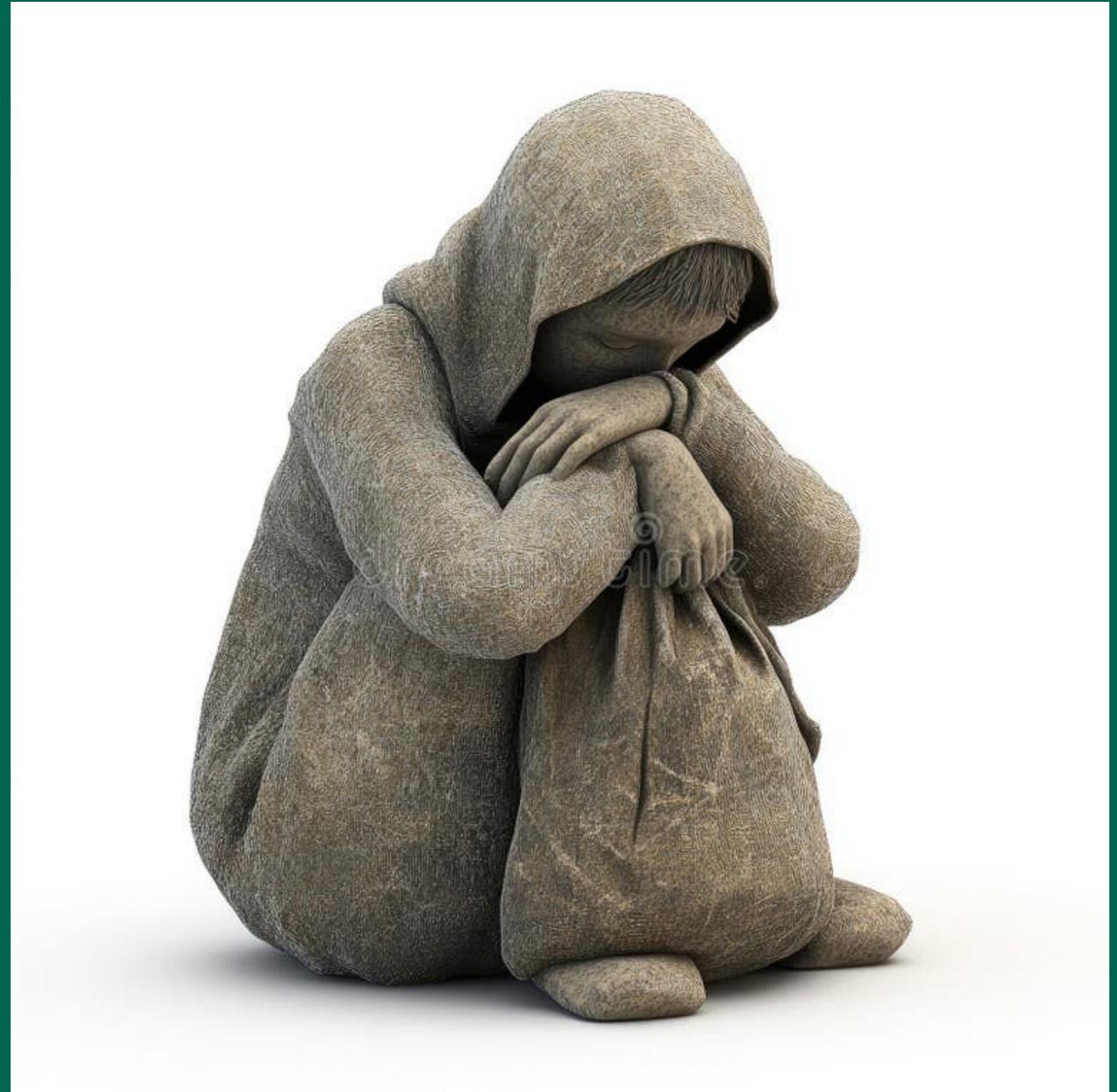
“There is no grief like the grief
that does not speak.”

-Henry Wadsworth Longfellow



Universal support:

- **Recognizes** individuality and uniqueness of grief
- **Honors** the pain of loss
- **Hold spaces** for grief
- **Understands** grief is something one learns to carry & live with
- **Extends** another layer of support when wanted/needed



GRIEF IS A SPECTRUM...



Anticipatory Grief < > Acute Grief < > Integrated Grief

GRIEF IS A SPECTRUM...

Anticipatory Grief < > Acute Grief < > Integrated Grief

...experienced in a
NONLINEAR path



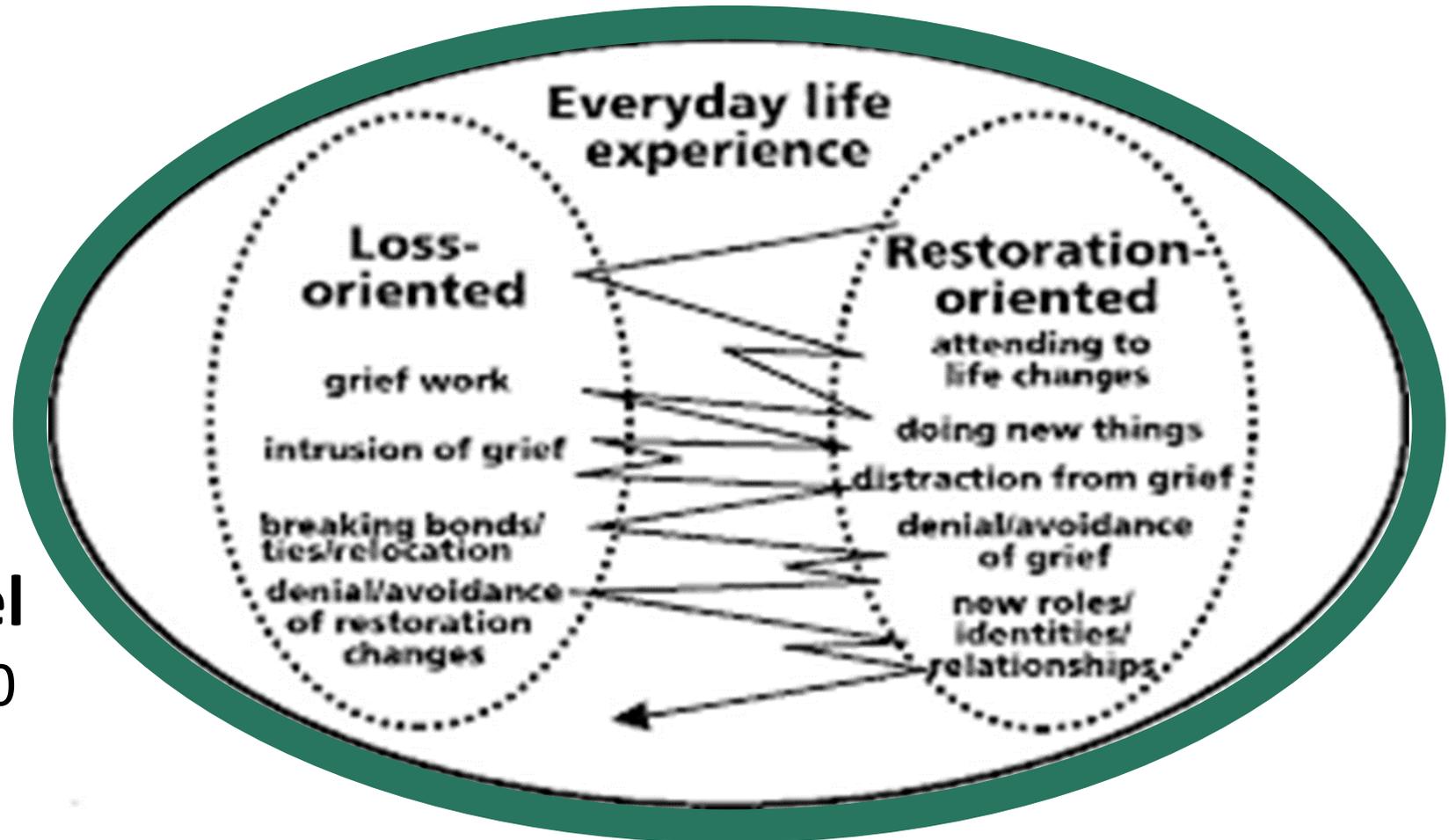
GRIEF IS A SPECTRUM:[^]

Meaning Reconstruction Model

Robert Neimeyer

“A central process in grieving is the attempt to reaffirm or reconstruct a world of meaning that has been challenged by loss.”

GRIEF IS A SPECTRUM:[^]



Dual Process Model
Stroebe & Schut, 2010

Labels Matter:

Outdated terms:

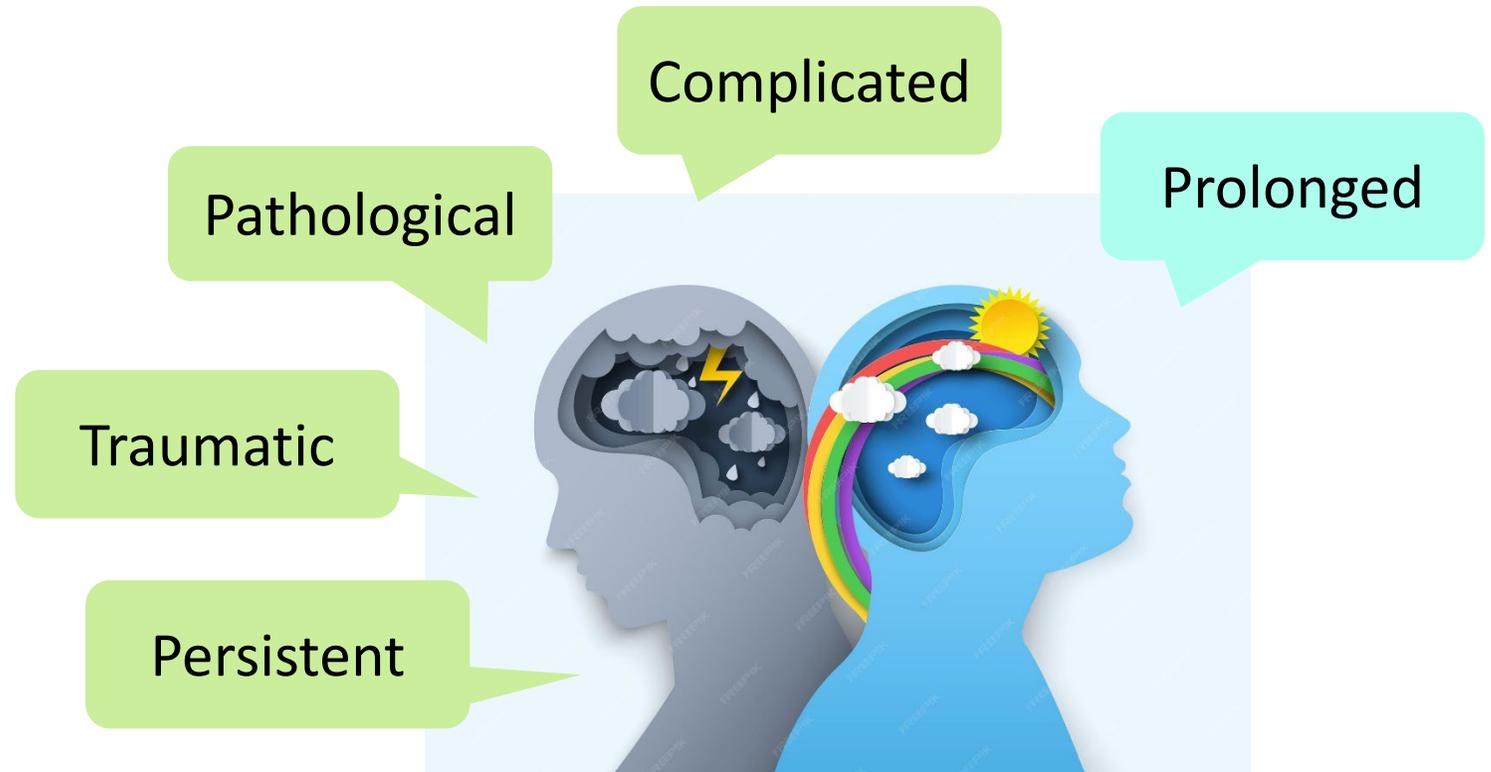
Complicated grief

Pathological grief

Traumatic grief

Persistent complex
bereavement disorder

Preferred term: Prolonged grief disorder
(after *at least* 12 months post loss with
persistent pervasive yearning and longing)



Labels Matter:

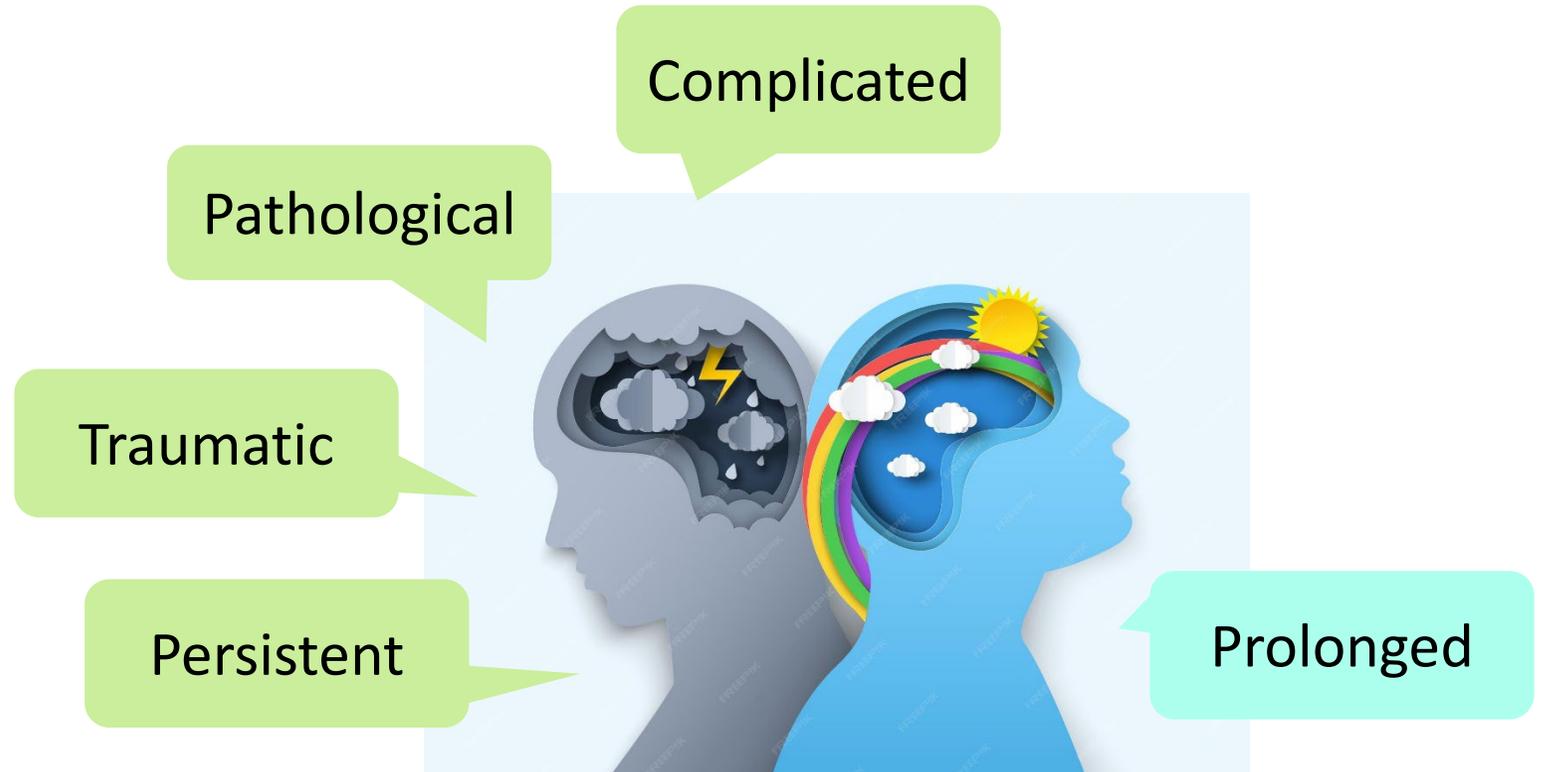
Outdated terms:

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Pathological grief

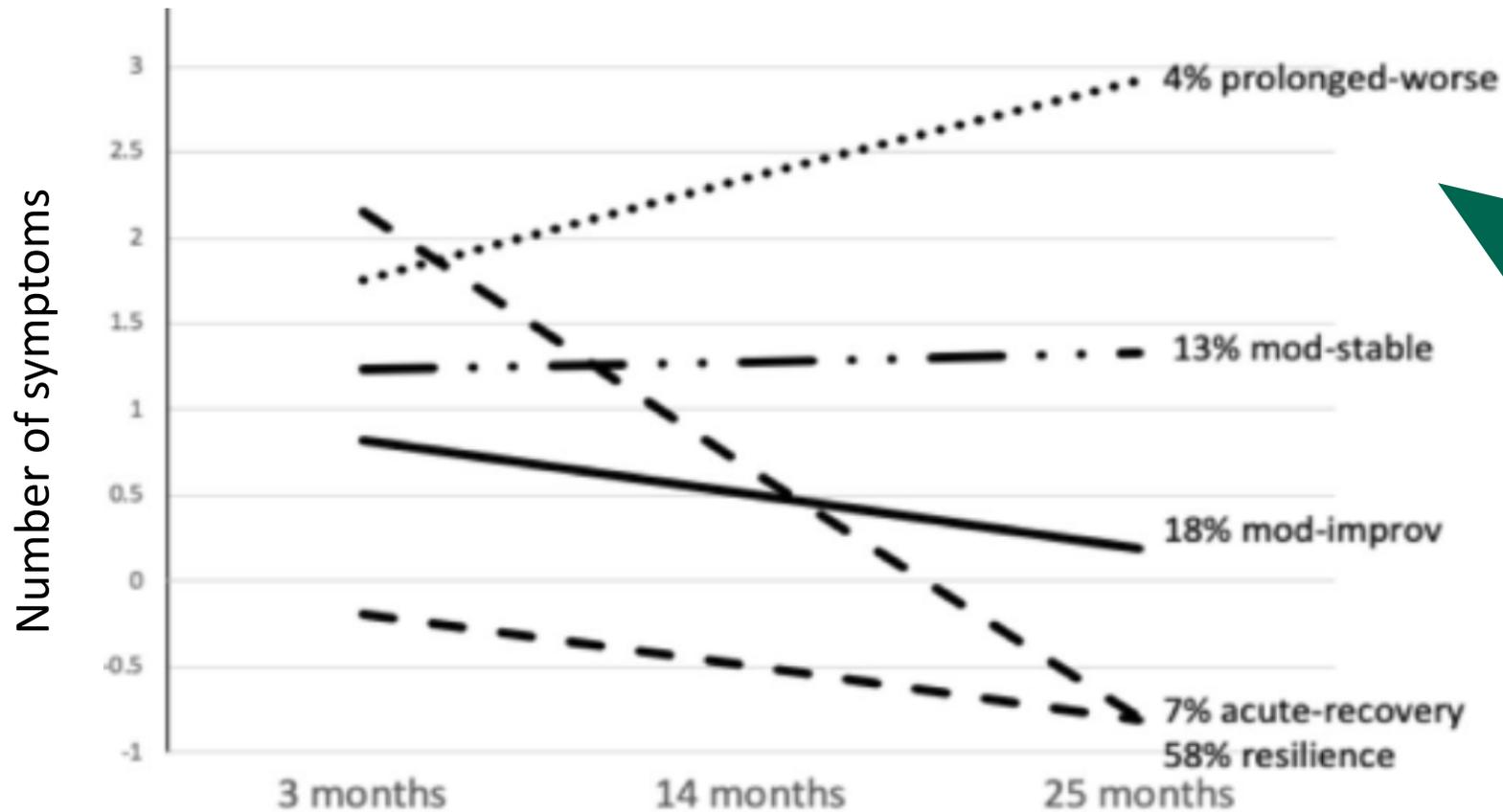
Traumatic grief

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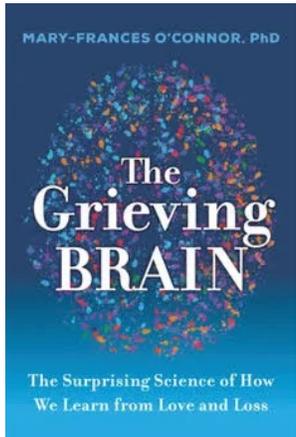
Preferred term: Prolonged grief

Trajectories of grief, by DSM-5 and ICD 11 diagnosis



Difficult/disordered grief is a **SMALL SUBSET**— affects ~4-10% of bereaved, yet takes up to 90% of the literature and most of the clinical attention

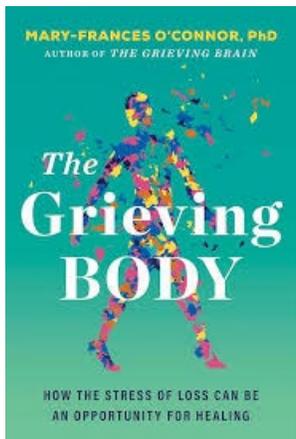
BIOPSYCHOSOCIAL RESPONSE TO LOSS Mary Frances O'Connor, PhD



Figuring out how to regain the equilibrium in our physiological systems, doing everything without our loved one, is a (largely) unconscious process in grieving

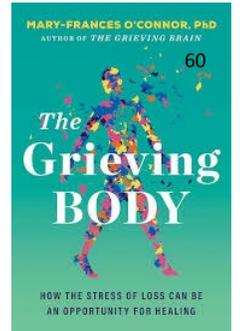
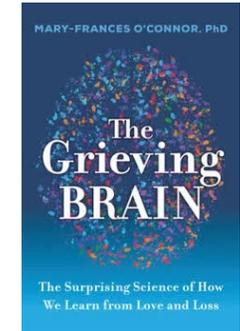
Attempting to re-regulate during grieving looks like:

- Fatigue or brain fog
- Restlessness, low tolerance
- Being more susceptible to illness



BIOPSYCHOSOCIAL RESPONSE TO LOSS

Mary Frances O'Connor, PhD

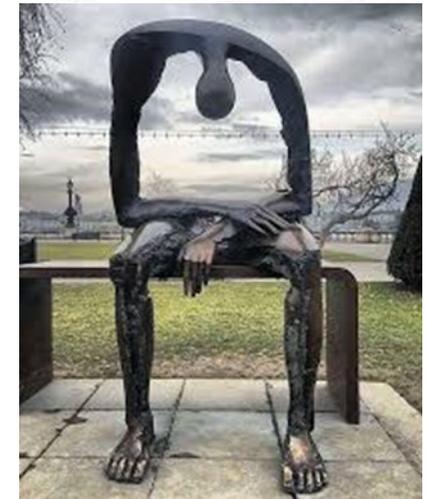


Cardiovascular reactivity

A man is almost twice as likely to die of a heart attack in the first 3 months

Viewing bereavement as a heightened time for medical risk

While a risky time for people, most people will do fine
Education, literacy, and a way to check in and follow up when needed is beneficial



GRIEF DERAILERS

Thoughts

Second guessing
Self or other
questioning/judging
Existential distress



GRIEF DERAILERS

Thoughts

Second guessing
Self or other
questioning/judging
Existential distress

Feelings

Dysregulated
Intensely negative
Low positive



GRIEF DERAILERS

Thoughts

Second guessing
Self or other
questioning/judging
Existential distress

Feelings

Dysregulated
Intensely negative
Low positive

Behaviors

Escape
Avoidance
Negative
health patterns





There is a crack in everything,
that's how the light gets in.
—Leonard Cohen

RISK FACTORS

- history of mood or anxiety disorders
- alcohol or drug abuse
- multiple losses
- sudden death
- under unnatural circumstances (inclusive of death in the ICU)
- inadequate social support



PROLONGED GRIEF DISORDER (PGD) DIAGNOSIS ICD-11 and DSM-5-TR

1 Loss of a loved one at least 12 months ago

2 Intense persistent yearning/longing for the loved one or preoccupation with thoughts or memories of the deceased for at least the last month

3 At least 3 of the following symptoms, nearly every day, for at least the last month:

- **Identity disruption**
- Marked sense of **disbelief** about the death
- **Avoidance** of reminders of reality of the loss
- Intense **emotional pain** related to the death
- **Emotional numbness** since the loss
- Feeling that life is **unfulfilling, empty, or meaningless**
- **Intense loneliness**



PROLONGED GRIEF DISORDER (PGD) DIAGNOSIS ICD-11 and DSM-5-TR

continued

4 The disturbance causes **significant distress or impairment** in social, occupational or other important areas of functioning

5 The **duration of bereavement reaction clearly exceeds expected** social, cultural, or religious norms for the individual's culture and context

6 The disturbance is **not better accounted for by another mental disorder** (e.g. major depression, PTSD, etc.)



DIFFERENTIAL DIAGNOSIS for Prolonged Grief Disorder (PSD)

Depression	Grief
Preoccupied with self-critical and pessimistic rumination and feelings of worthlessness	Preoccupied with thoughts, images, and memories of the deceased

- **Is grief the main challenge?**
 - If yes, is this PGD...or a heightened period of natural grief
- **Is there another diagnosable disorder?** (e.g., Depression, PTSD)
 - If yes, is grief the primary challenge?
- **Is there a co-occurring condition that needs treatment first?**
 - Psychotic disorder
 - Substance use disorder
 - Bipolar disorder
 - Imminent suicidal risk



SCREENING & ASSESSING Prolonged Grief Disorder (PSD)

Tools for screening:

- PG-13-Revised (PG-13-R)
- Inventory of Complicated Grief (ICG)
- Brief Grief Questionnaire (BGQ)

Instruments to distinguish symptoms

- Typical Beliefs Questionnaire (TBQ)
- Grief Related Avoidance Questionnaire (GRAQ)
- Structured Clinical Interview for PGD (SCI-PGD)
- Grief-related Work & Social Adjustment Scale (WSAS)

PROLONGED GRIEF DISORDER (PG-13-Revised)

Q1. Have you lost someone significant to you? Yes No

Q2. How many months has it been since your significant other died? Months

For each item below, please indicate how you currently feel?

Since the death, or as a result of the death...	Not at all	Slightly	Some-what	Quite a bit	Overwhelmingly
Q3. Do you feel yourself longing or yearning for the person who died?	<input type="radio"/>				
Q4. Do you have trouble doing the things you normally do because you are thinking so much about the person who died?	<input type="radio"/>				
Q5. Do you feel confused about your role in life or feel like you don't know who you are any more (i.e., feeling like that a part of you has died)?	<input type="radio"/>				
Q6. Do you have trouble believing that the person who died is really gone?	<input type="radio"/>				
Q7. Do you avoid reminders that the person who died is really gone?	<input type="radio"/>				
Q8. Do you feel emotional pain (e.g., anger, bitterness, sorrow) related to the death?	<input type="radio"/>				
Q9. Do you feel that you have trouble re-engaging in life (e.g., problems engaging with friends, pursuing interests, planning for the future)?	<input type="radio"/>				
Q10. Do you feel emotionally numb or detached from others?	<input type="radio"/>				
Q11. Do you feel that life is meaningless without the person who died?	<input type="radio"/>				
Q12. Do you feel alone or lonely without the deceased?	<input type="radio"/>				

Q13. Have the symptoms above caused significant impairment in social, occupational, or other important areas of functioning? Yes No

Questions Q3 through Q12 in the PG-13-R are rated using a 5-point scale ranging from 1=not at all to 5=overwhelmingly. A PG-13-R symptom score of 30 or greater identifies syndromal-level PGD symptomatology. COURTESY/HOLLY G PRIGERSON, PHD, JIEHUI XU, M.S., PAUL K MACIEJEWSKI, PHD

YOUR SUMMED SCORE IS

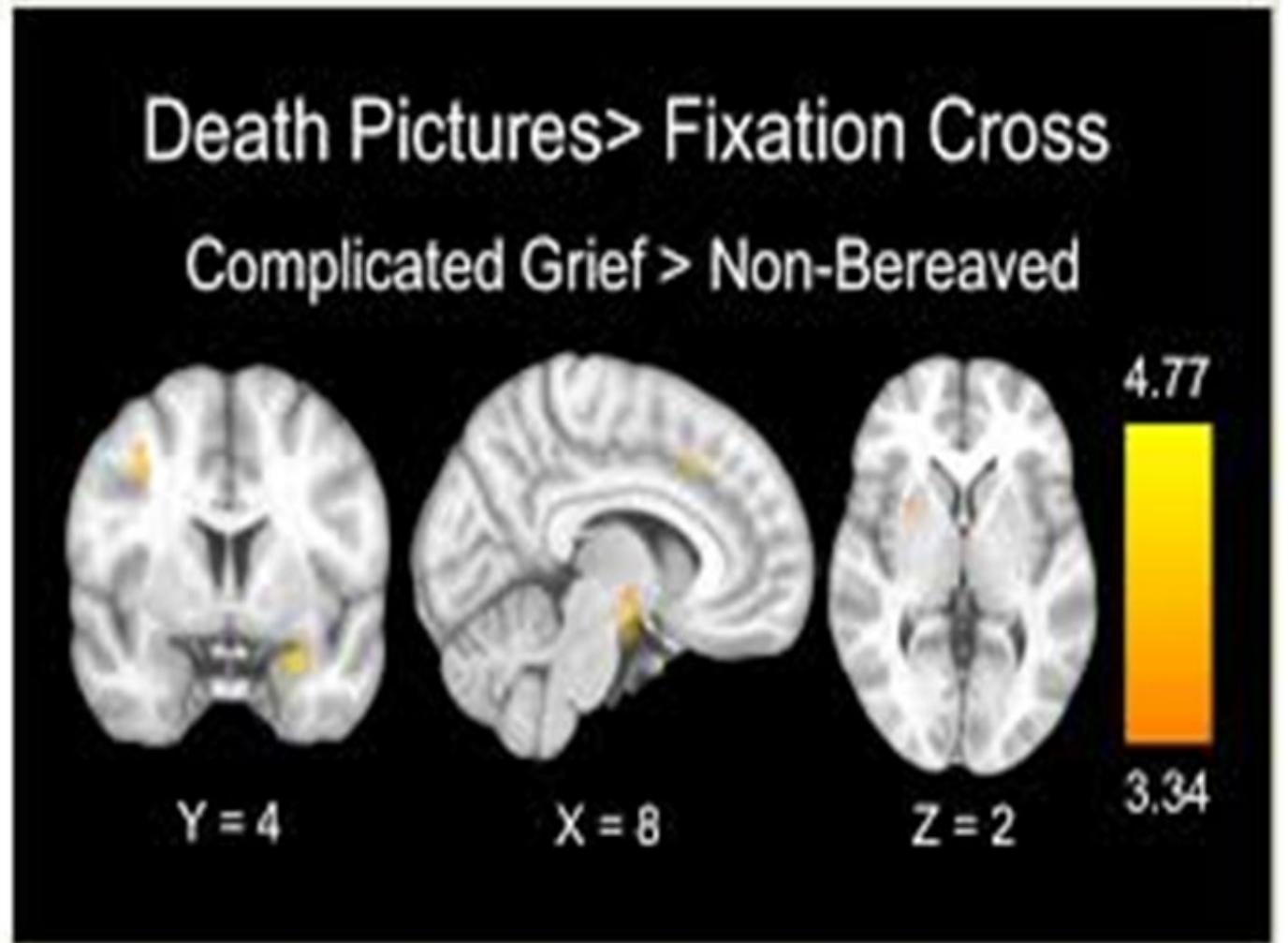
CURRENT STUDIES

1. fMRI

2. DREAM Lab (Medical College of Wisconsin)

3. Pharmacology (Naltrexone treatment)

4. Center for Prolonged Grief - Prolonged Grief Therapy



- 19 bereaved and 19 non-bereaved individuals
- Bereaved individuals showed distinct brain activations

CURRENT STUDIES

1. fMRI

2. **DREAM Lab** (Medical
College of Wisconsin)

3. Pharmacology
(Naltrexone treatment)

4. Center for Prolonged Grief
- Prolonged Grief Therapy



- Screened 190 potential patients
- 19 individuals enrolled in Iyengar Yoga study
- 20 individuals to active control health education
- Seven non-bereaved participants to complete 10 week study

CURRENT STUDIES

1. fMRI

2. DREAM Lab (Medical
College of Wisconsin)

**3. Pharmacology
(Naltrexone treatment)**

4. Center for Prolonged Grief
- Prolonged Grief Therapy



- Study to consider pharmacology in treating PGD
- Conceptualized PGD as “addiction disorder”
- Intention to disrupt capacity to engage in social bonding and eliminate craving the person who died

CURRENT STUDIES

1. fMRI
2. DREAM Lab (Medical College of Wisconsin)
3. Pharmacology (Naltrexone treatment)
4. **Center for Prolonged Grief - Prolonged Grief Therapy**



The Center for Prolonged Grief

- Prolonged Grief Treatment
- 3 studies
- 16 sessions
- Results: Prolonged Grief Treatment (PGT) twice as effective as Interpersonal Psychotherapy (IPT)

EFFECTIVE SOURCES OF SUPPORT AND TREATMENT

Psychoeducation with Social Support (PSS)

Accelerated Resolution Therapy (ART)

Exposure Therapy

Cognitive Narrative Therapy

Music Therapy

Multimedia Therapy



COUNTERPOINT AND CONTROVERSY

- **Wish** western society gave as much time to grieve as other cultures
- **Worry** labeling a human experience as disordered could be hurtful
- **Wonder** if the new diagnosis helps or hurts

The New York Times

*How Long Should It Take to Grieve?
Psychiatry Has Come Up With
an Answer.*

The latest edition of the DSM-5, sometimes known as “psychiatry’s bible” includes a controversial new diagnosis:

Grief is non-linear and without a timeline

Creating a Loss-Informed World

- A hope that we can create and nurture a world that doesn't yet exist – one that is loss informed
- A world where grief can be openly shared, witnessed, supported and understood.

It was love,
and I lived in it.

And
it is grief,
and I will carry it.

-CHLOË PRAYNE.



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Thank you.

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Section of Physical Medicine &
Rehabilitation

DARTMOUTH HITCHCOCK MEDICAL
CENTER

Exploring Goals of Care for Individuals with Persistent Disability

Sarah Durante MD, FAAPMR

ECHO 5.0 February 4, 2026

Outline

- Introduce language used to address disability
- Review disability prevalence in the United States
- Discuss the impact of disability on healthcare access and experience
- Offer strategies for exploring goals of care (GoC) for individuals with disabilities
- Offer resources for healthcare providers working with disabled people



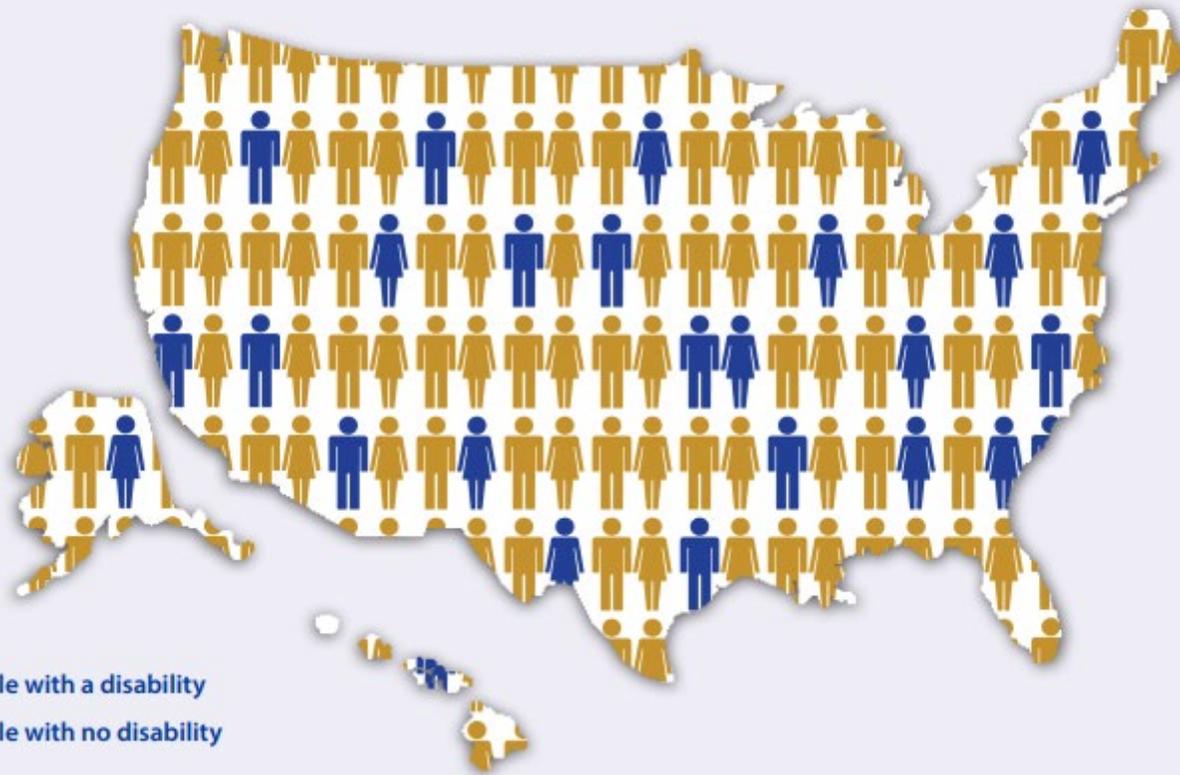
HOW WE ADDRESS DISABILITY MATTERS.

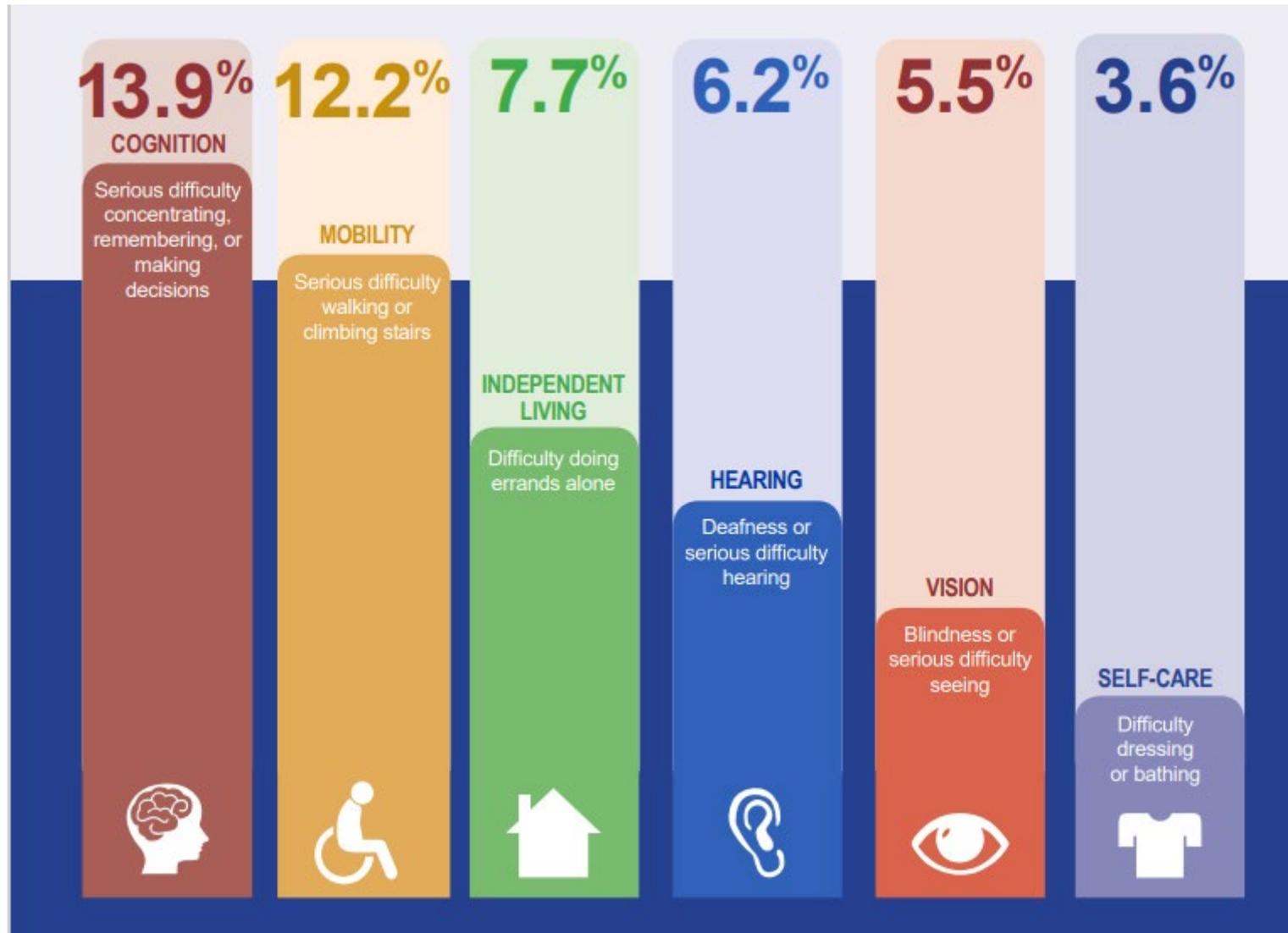


Person-first vs identify-first language

- Medical professionals are taught to use person-first language (e.g. “person with Down syndrome”)
- Identity-first language is preferred by some members of the disabled community (e.g. “autistic person”)
- Both are equally appropriate depending on personal preference

More than **1 in 4** adults in the United States have some type of disability
(28.7%)





**DISABLED INDIVIDUALS FACE SIGNIFICANT
HEALTH DISPARITIES.**

Disability and Healthcare ACCESS

Healthcare access barriers for working-age adults include

Recent Changes to Immigration Policies Have Disastrous Impacts on Disabled People and Long-Term Care

by Rachel Litchman, 2023 Summer Internship Alumni | Jan 9, 2026 | Blog



Photo of Rachel Litchman

(45-64 years)



By Lisa I. Iezzoni, Sowmya R. Rao, Julie Ressler, Dragana Bolcic-Jankovic, Nicole D. Agaronnik, Karen Donelan, Tara Lagu, and Eric G. Campbell

Physicians' Perceptions Of People With Disability And Their Health Care

DOI: 10.1377/hlthaff.2020.01452
HEALTH AFFAIRS 40,
NO. 2 (2021): 297-306
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The People-to-People Health
Foundation, Inc.

84% reported that people with significant disability have worse quality of life than non-disabled people.

40.7% of physicians were confident about their ability to provide the same quality of care to patients with disability.

56.5% strongly agreed that they welcomed patients with disability into their practice.

RESEARCH ARTICLE | THE PRACTICE OF MEDICINE

[HEALTH AFFAIRS](#) > [VOL. 41, NO. 10](#): DISABILITY & HEALTH

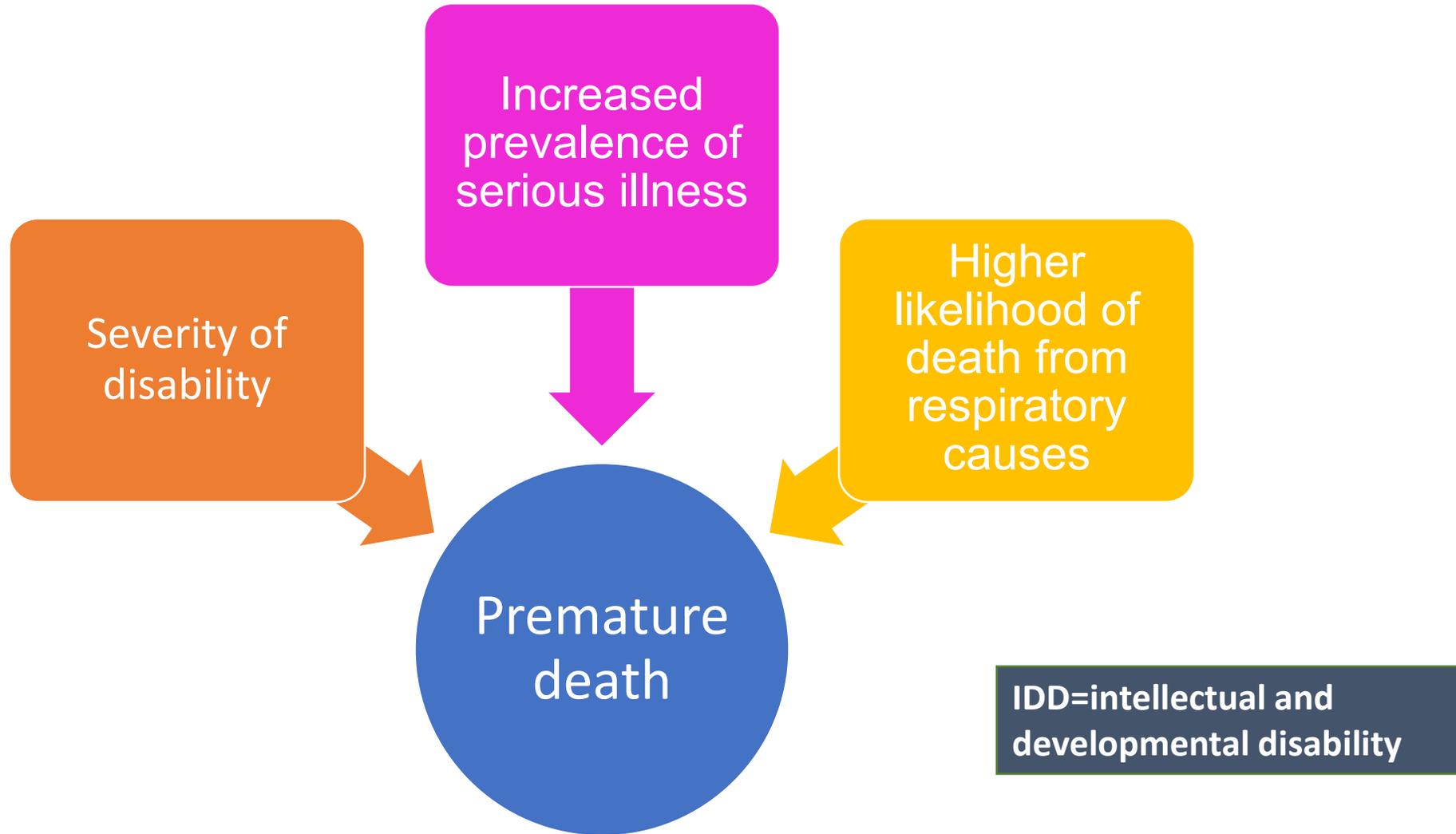
‘I Am Not The Doctor For You’: Physicians’ Attitudes About Caring For People With Disabilities

[Tara Lagu](#), [Carol Haywood](#), [Kimberly Reimold](#), [Christene DeJong](#), [Robin Walker Sterling](#), and
[Lisa I. Iezzoni](#)

People with intellectual and developmental disabilities (IDD) face unique challenges

- Lack of awareness of IDD among healthcare providers and organizations
- Communication barriers
- Social and physical isolation
- Medical complexity
- Trauma history

Individuals with IDD die sooner than those without IDD



Landes SD, Stevens JD, Turk MA. Heterogeneity in age at death for adults with developmental disability. *J Intellect Disabil Res.* 2019;63(12):1482-1487.

Landes SD, Stevens JD, Turk MA. Cause of death in adults with intellectual disability in the United States. *J Intellect Disabil Res.* 2021;65(1):47-59.

Disability bias exists in clinical practice

Ineffectual bias

- Clinicians assume patients with disabilities possess lower levels of agency and competence than non-disabled patients.

Fragility bias

- Clinicians perceive that patients with disabilities suffer more than non-disabled patients.

Catastrophe bias

- Clinicians project more suffering onto patients with disabilities than patients actually experience

THE “DISABILITY PARADOX”

- Many people with serious and persistent disability report experiencing a good or excellent quality of life.
- They view their lives as rich and full.
- They value their lives.

**AWARENESS LEADS TO MORE
MEANINGFUL CONVERSATIONS.**

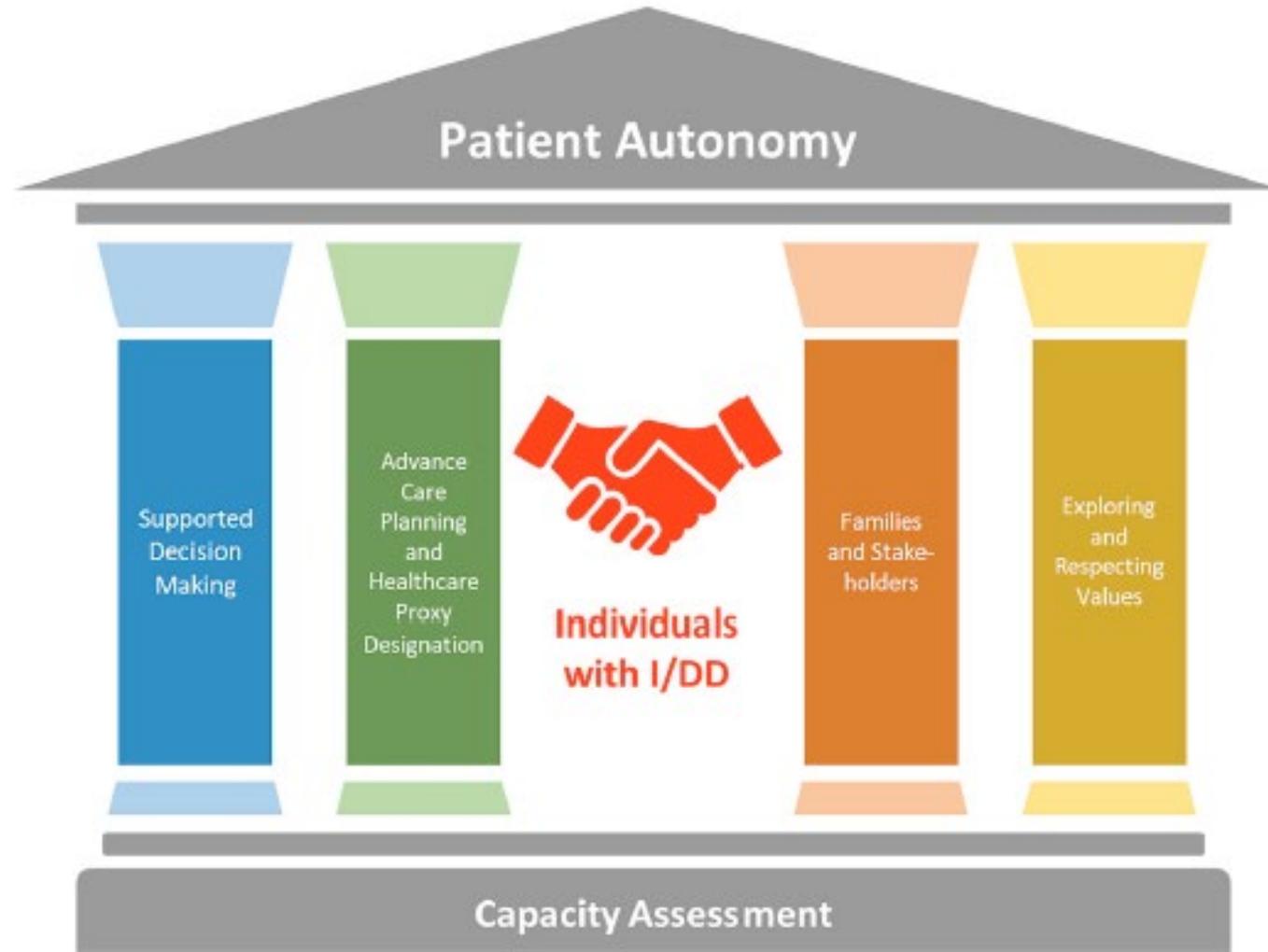


Fig. 1. Pillars of autonomy for patients with intellectual/developmental disabilities (I/DD) adapted from the World Health Organization's framework for palliative care.⁹

Quality goals of care conversations...



- Explore preferences re: person-first vs identity-first language.
- Adapt to communication differences in order to center a person's voice and autonomy.
- Involve collaboration on meaningful goals.

Quality goals of care conversations...

- Are trauma-informed and non-judgmental.
- Involve multidisciplinary support.
- Require awareness of bias and power dynamics.



Photo credit: Angie Morin, disabilityisbeautiful.com

Resources for healthcare professionals

**University of New Hampshire
Institute on Disability:**

[Institute on Disability](#)

Special Olympics:

[Center for Inclusive Health](#)

[Inclusive Health Principles and
Strategies](#)





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