



WELCOME to *Palliative Care ECHO 5.0*

October 2025 –
June 2026

Schedule

10/7/2025	Moral Distress/Injury
11/4/2025	VSED-MCF
12/2/2025	Creating a Legacy
	Complicated Bereavement?
1/6/2026	
	Goals of Care for People with Disabilities
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

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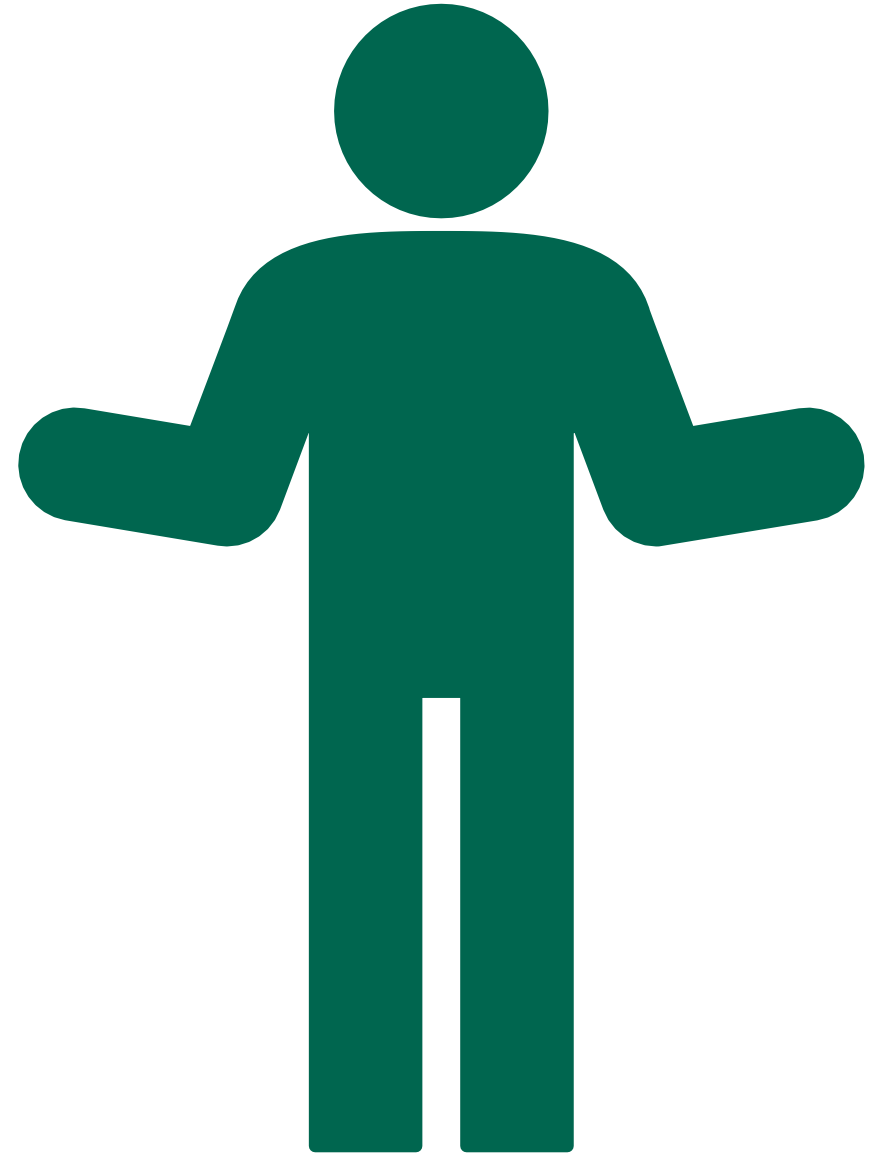
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Doctor of Nursing Practice Candidate – Boston College



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?



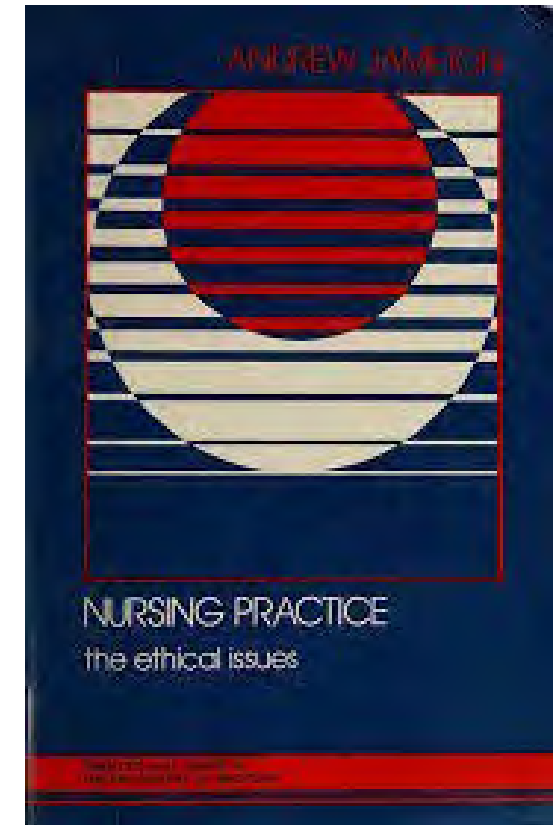
Moral Distress & Injury

- **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

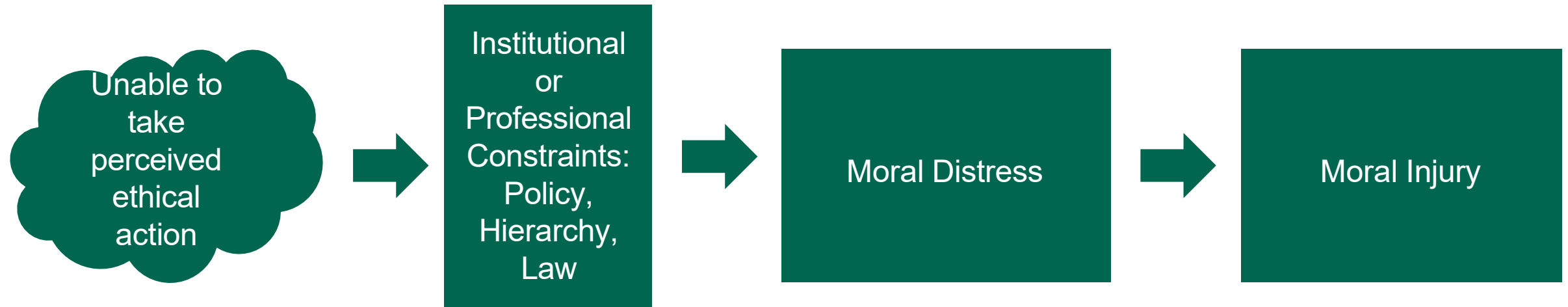
Moral Injury – Historical Context

- 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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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 & drinking
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 Waterhouse, "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

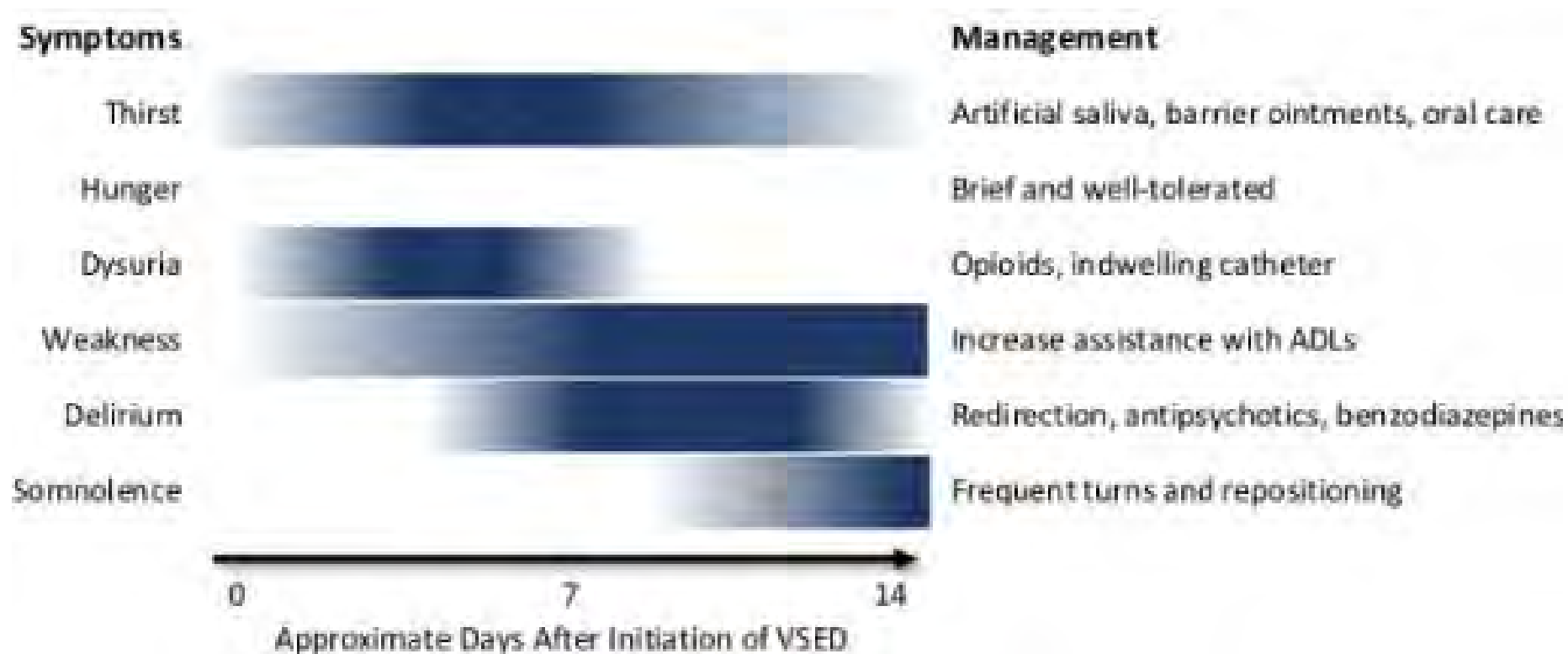
- Most difficult phase
- Symptoms: thirst, some delusions, often lack of capacity, potential agitation, weakness
- Important phase for symptom management to ensure comfort

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

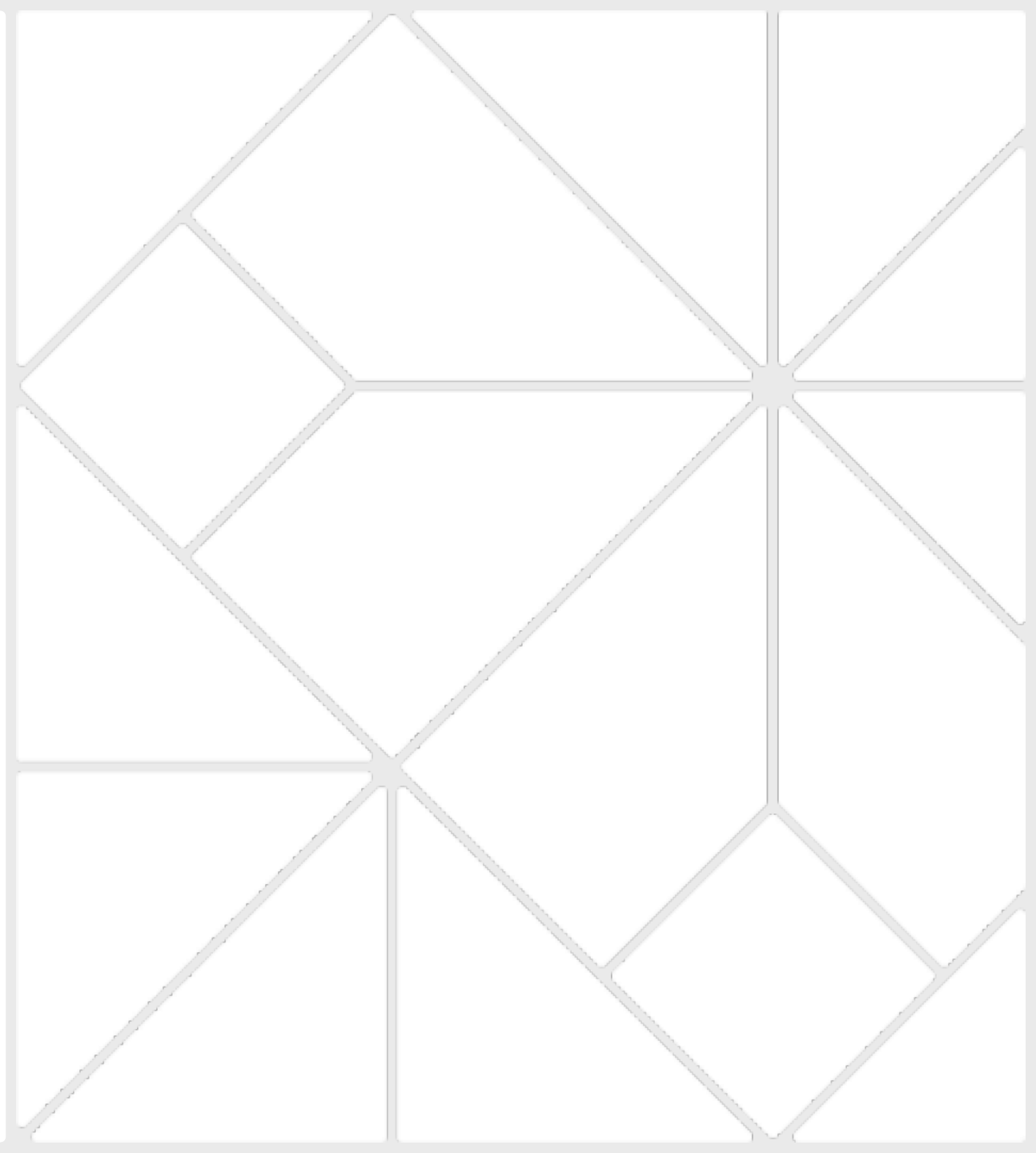
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How to Create a Legacy

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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**



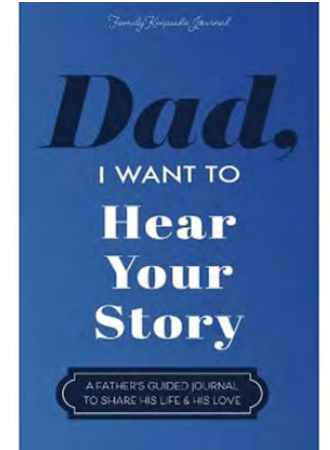
Benefits cont.

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



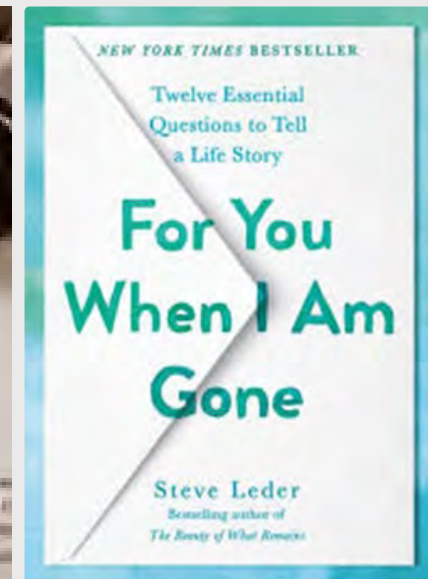
Legacy Builders

- 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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