WELCOME to
Palliative Care ECHO 5.0

October 2025 –
June 2026

Dartmouth Health

Schedule

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

Moral Distress and Moral Injury

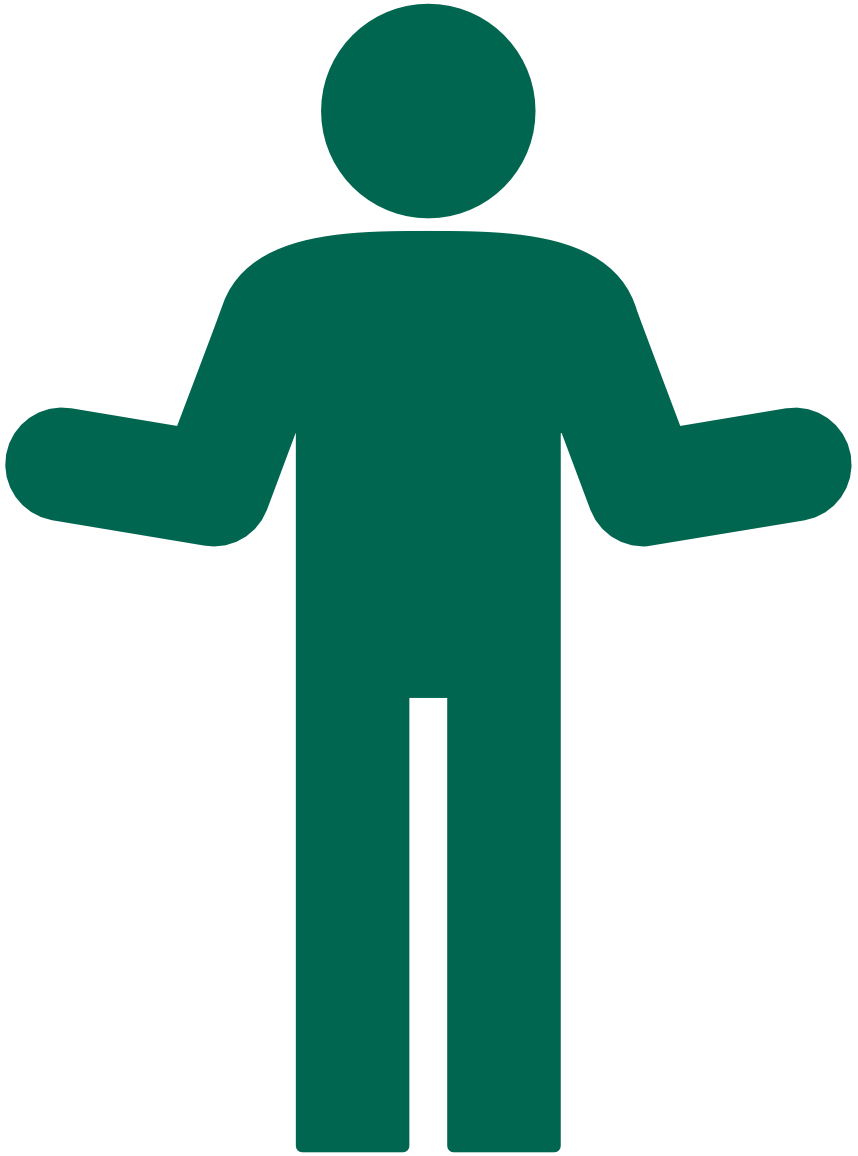
Christopher Charles, MSN, RN, CCRN

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?

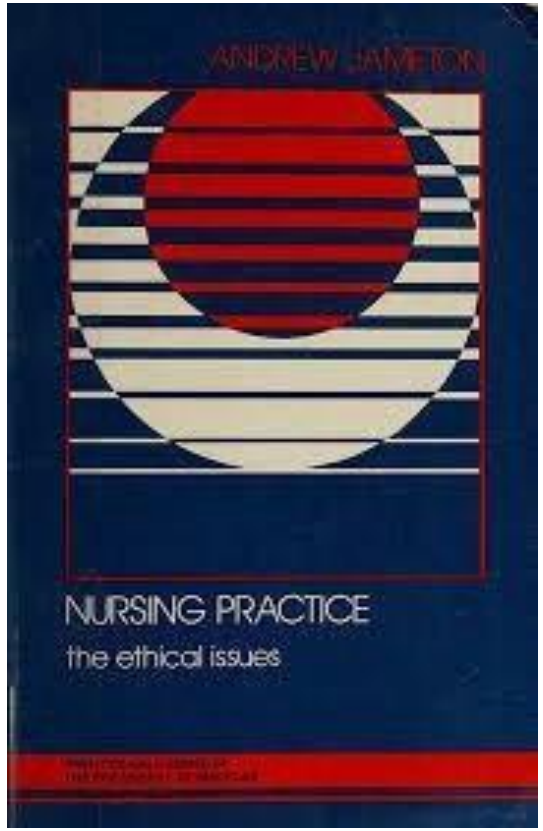


Moral Distress & Injury

- 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).

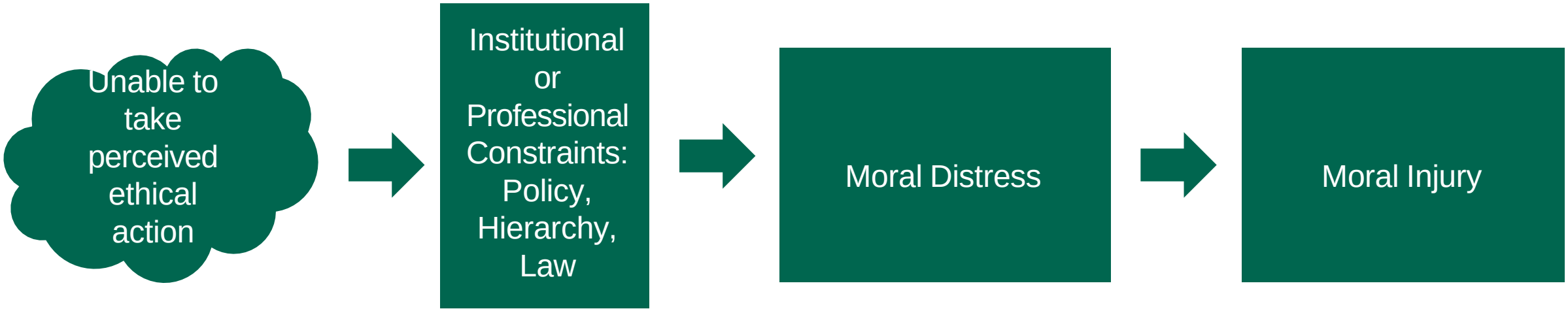
- Moral distress may result in:
  - Migration from clinical areas of high stress
  - Emotional distancing from patients, compassion fatigue, and poor outcomes.
  - Attrition from the profession (Allen & Butler, 2016; Robinson et al., 2014).
    - Large financial costs associated with attrition of trained 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).


Unable to take perceived ethical action
Institutional or Professional Constraints: Policy, Hierarchy, Law
Moral Distress
Moral Injury

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

References

- DeMeyer, E. S. (2022). *Moral distress in cancer care*. *Cancer Nursing Today*. https://www.cancernursingtoday.com/post/moral-distress-in-cancer-care
- Epstein, E. G., & Delgado, S. (2010). Understanding and addressing moral distress. OJIN, 15(3).
- Jameton, A. (1984). Nursing practice: The ethical issues. Prentice-Hall)
- Koenig, H. G., & Al Zaben, F. (2021). Moral Injury: An Increasingly Recognized and Widespread Syndrome. *Journal of religion and health*, *60*(5), 2989–3011. https://doi.org/10.1007/s10943-021-01328-0
- Litz BT, Stein N, Delaney E, Lebowitz L, Nash WP, Silva C, Maguen S. Moral injury and moral repair in war veterans: A preliminary model and intervention strategy. Clinical Psychology Review. 2009;29(8):695–706. doi: 10.1016/j.cpr.2009.07.003
- Nash, W. P. (2012, November 21). *Moral injury: The psychological wounds of war*. NPR. https://www.npr.org/2012/11/21/165663154/moral-injury-the-psychological-wounds-of-war
- Robinson, E. M., Lee, S. M., Zollfrank, A., Jurchak, M., Frost, D., & Grace, P. (2014). Enhancing moral agency: clinical ethics residency for nurses. *The Hastings Center report*, *44*(5), 12–20. https://doi.org/10.1002/hast.353

References

- Rushton, C. R. (2006). Defining and Addressing Moral Distress: Tools for Critical Care Nursing Leaders. AACN Adv Crit Care, 17 (2): 161–168
- Williamson V, Murphy D, Phelps A, Forbes D, Greenberg N. Moral injury: the effect on mental health and implications for treatment. Lancet Psychiatry. 2021 Jun;8(6):453-455. doi: 10.1016/S2215-0366(21)00113-9. Epub 2021 Mar 17. PMID: 33743196.
- Weiss Goitiandia, S., Axelrod, J. K., Brender, T. D., Batten, J. N., & Dzeng, E. W. (2024). Recognizing the Systemic Root Causes of Moral Distress. *The American Journal of Bioethics*, *24*(12), 29–32. https://doi.org/10.1080/15265161.2024.2416137
- Williamson V, Stevelink SAM, Greenberg N. Occupational moral injury and mental health: systematic review and meta-analysis. Br J Psychiatry. 2018 Jun;212(6):339-346. doi: 10.1192/bjp.2018.55. PMID: 29786495.
- “4As to Rise Above Moral Distress” (n.d.). Emerging RN Leader. Retrieved from https://www.emergingrnleader.com/wp-content/uploads/2012/06/4As_to_Rise_Above_Moral_Distress.pdf

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Section of Palliative Care
DARTMOUTH HITCHCOCK
MEDICAL CENTER

VSED: A Primer

Bradley Eckert, MD, MS, HMDC
Section of Palliative Care, Dartmouth Hitchcock Medical Center

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Dartmouth Cancer Center Southern Region Clinics

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

J Am Geriatr Soc 2018 Mar; (693):441-445

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

Source: Center to Advance Palliative Care

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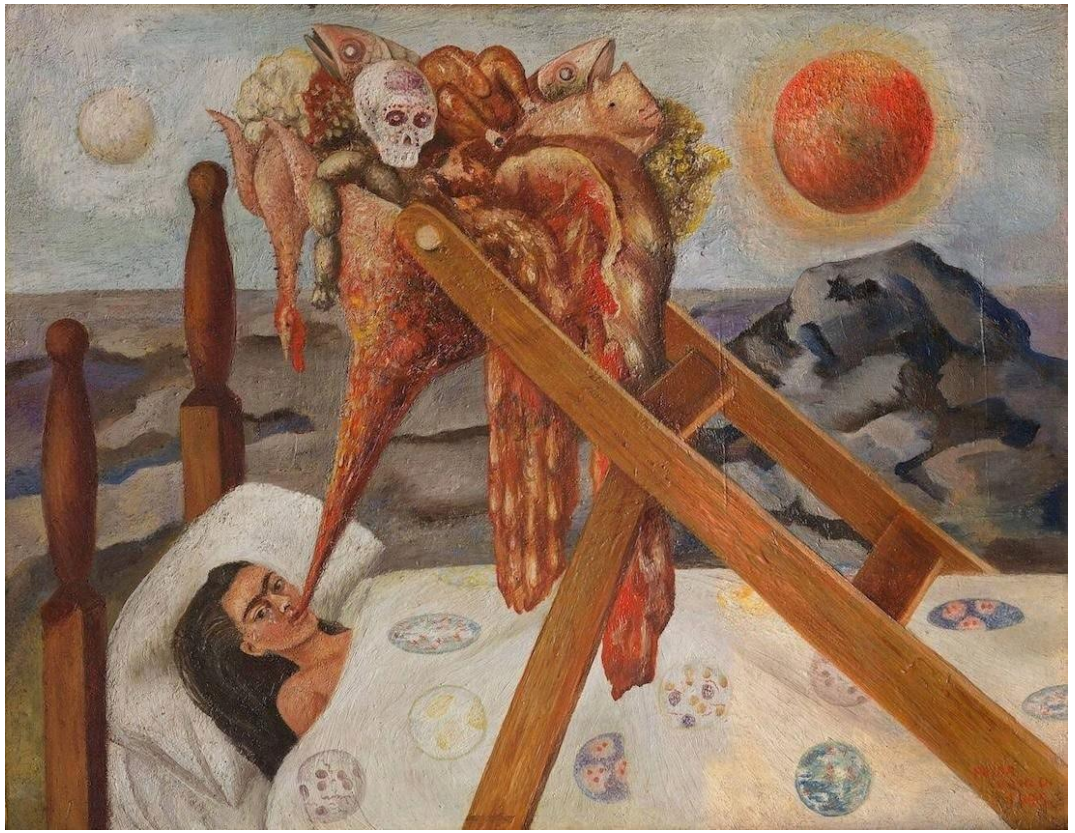
Motivations for VSED:

- 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)

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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

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Ethical and legal protections

J. W. Waterhouse, "Ulysses and the Sirens," 1891, Oil on canvas, National Gallery of Victoria

- 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.

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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

Common Phases of VSED

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

J Pain Symp Mgmt 2023 Nov; 66(5):625-631

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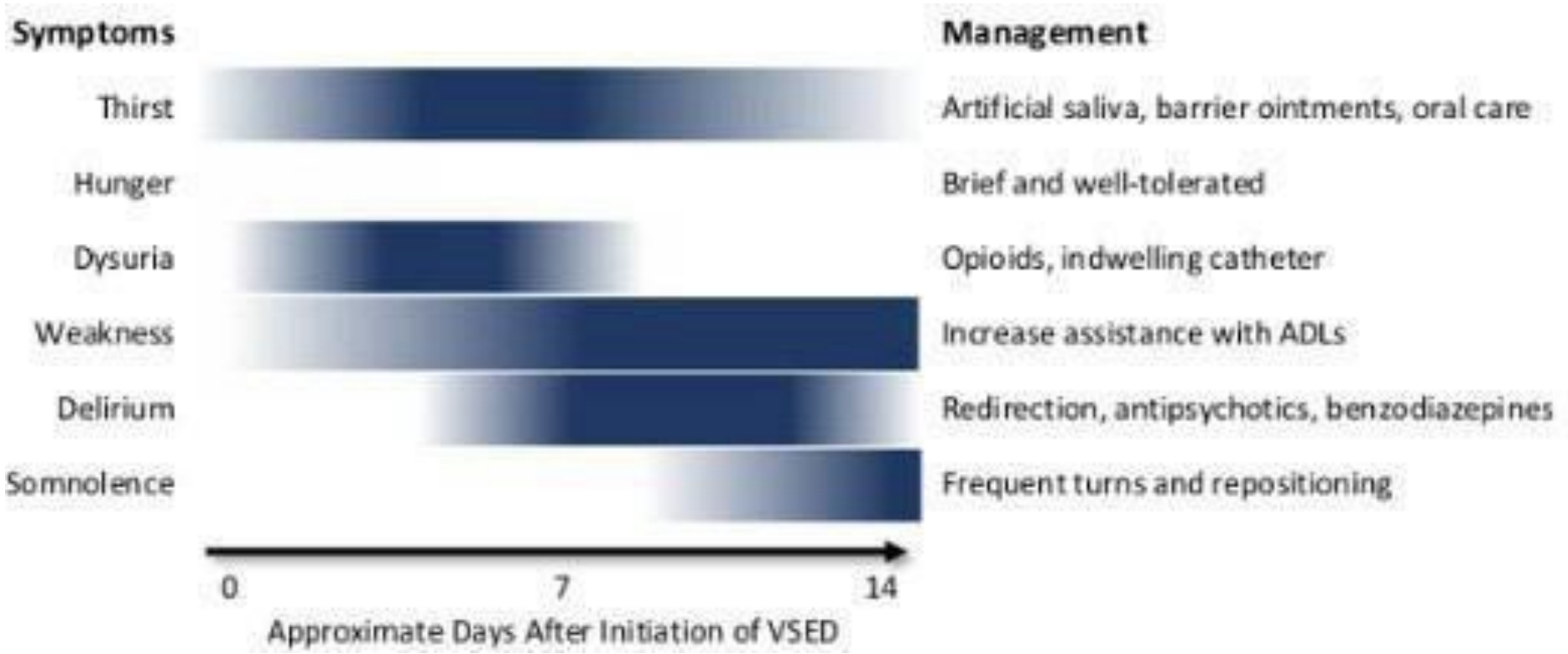
Symptom Management



Source: Wax JW, An AW, Kosier N, Quill TE. 2018

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Symptom Managem

Thirst & Dry Mouth

- Moist swabs,
- Lip balm
- Oral spray/rinse
- Humidification

Dry Skin

- Lotion
- Cooling cloths

Pain

- Frequent repositioning
- Personal care
- Opioids

Anxiety & Delirium

- Psychosocial Support
- Benzodiazepines ie. lorazepam
- Antipsychotics ie. haloperidol

Constipation & Cramping

- Recommend cleanse prior to starting
- Bowel regimen: Senna/Colace

Hunger

- Distraction
- Time with loved ones
- Music/Movies,
- Memento making
- Reiki,
- Massage

Safety

- Hospital bed
- Bedside commode
- Urinal
- Indwelling catheter
- Walker/cane/lift assist

Psychosocial & Spiritual

- Anticipatory Guidance
- Clear plan for requests for food or fluid prior to initiation

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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

Gruenewald DA. Voluntarily Stopping Eating and Drinking: A Practical Approach for Long-Term Care Facilities. J Palliat Med. 2018;21(9):1214-1220. doi:10.1089/jpm.2018.0100

Lowers J, Hughes S, Preston N. Experience of Caregivers Supporting a Patient through Voluntarily Stopping Eating and Drinking. J Palliat Med. 2021;24(3):376-381. doi:10.1089/jpm.2020.0223

Quill TE, Menzel PT, Pope TM, Nurse JS. Voluntarily Stopping Eating and Drinking. Oxford University Press; 2021.

Wax JW, An AW, Kosier N, Quill TE. Voluntary Stopping Eating and Drinking. J Am Geriatr Soc. 2018;66(3):441-445. doi:10.1111/jgs.15200

Wechkin H, Macauley R, Menzel PT, Reagan PL, Simmers N, Quill TE. Clinical Guidelines for Voluntarily Stopping Eating and Drinking (VSED). J Pain Symptom Manage. 2023;66(5):e625-e631. doi:10.1016/j.jpainsymman.2023.06.016

Wechkin HA, Menzel PT, Loggers ET, et al. "Mr. Smith Has No Mealtimes": Minimal Comfort Feeding for Patients with Advanced Dementia. J Pain Symptom Manage. 2025;69(2):216-222. doi:10.1016/j.jpainsymman.2024.11.001

How to Create a Legacy

Connolly Huddleston, MAPS, BCC

ECHO 5.0

December 2, 2025

Bon Secours

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?

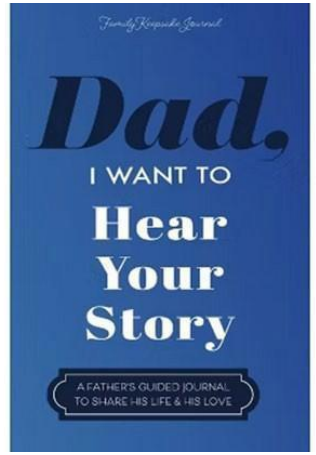
- Emotional benefits
- Symptom management
- Spiritual well-being (existential distress)
- Promotes self-awareness
- Brings comfort

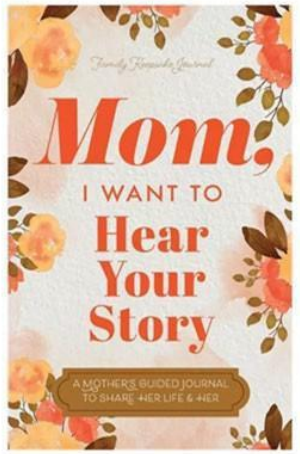
Benefits cont.

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

Legacy Builders

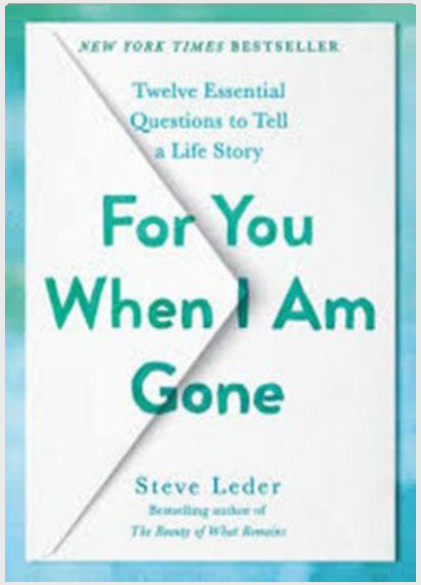
- Talk about it
- Age-appropriate items
- Cards for milestone events
- Family heirlooms
- Journaling





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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Bon Secours

References

- Getting Your Affairs in Order Checklist: Documents to Prepare for the Future; Feb. 1, 2023; https://www.nia.nih.gov/health/advance-care-planning/getting-your-affairs-order-checklist-documents-prepare-future#
- Neller SA, Cloyes KG, Edelman LS, Wong B, Baines B, Towsley GL. Preparing for the Future While Living in the Present: Older Adults' Experiences Creating a Legacy of Values. Gerontologist. 2023 Oct 17;63(9):1488-1496. doi: 10.1093/geront/gnad019. PMID: 36842069; PMCID: PMC10581374.
- Timóteo C, Vitorino J, Ali AM, Laranjeira C. Legacy in End-of-Life Care: A Concept Analysis. Nursing Reports. 2024; 14(3):2385-2397. https://doi.org/10.3390/nursrep14030177
- 7 Legacy Project Ideas to Honor Your Loved One- Eterneva https://www.eterneva.com/resources/legacy-project-ideas
- Hunter, Elizabeth G., PhD, Beyond Death: Inheriting the past and giving to the future, transmitting the legacy of one's self; OMEGA, Vol. 56(4) 313-329, 2007-2008; https://journals.sagepub.com/doi/epdf/10.2190/OM.56.4.a

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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…

GRIEF IS A SPECTRUM…

Anticipatory Grief < > Acute Grief < > Integrated Grief

…experienced in a NONLINEAR path

nonlinear

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."

nonlinear

GRIEF IS A SPECTRUM:

Dual Process Model

Stroebe & Schut, 2010

Labels Matter:

Outdated terms:

Complicated grief

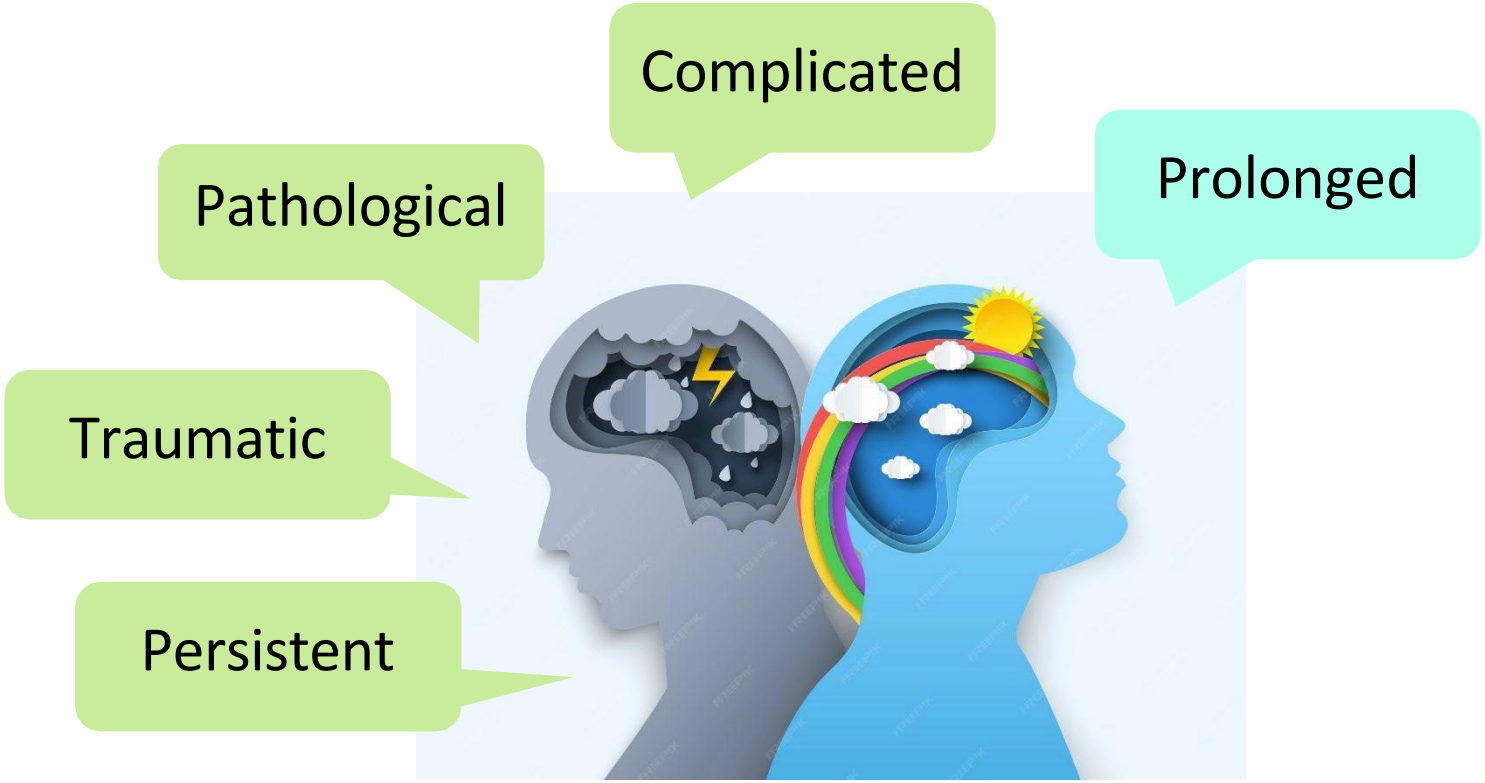
Pathological grief

Traumatic grief

Persistent complex bereavement disorder

Preferred term: Prolonged grief disorder

(after *at least* 12 months post loss with persistent pervasive yearning and longing)



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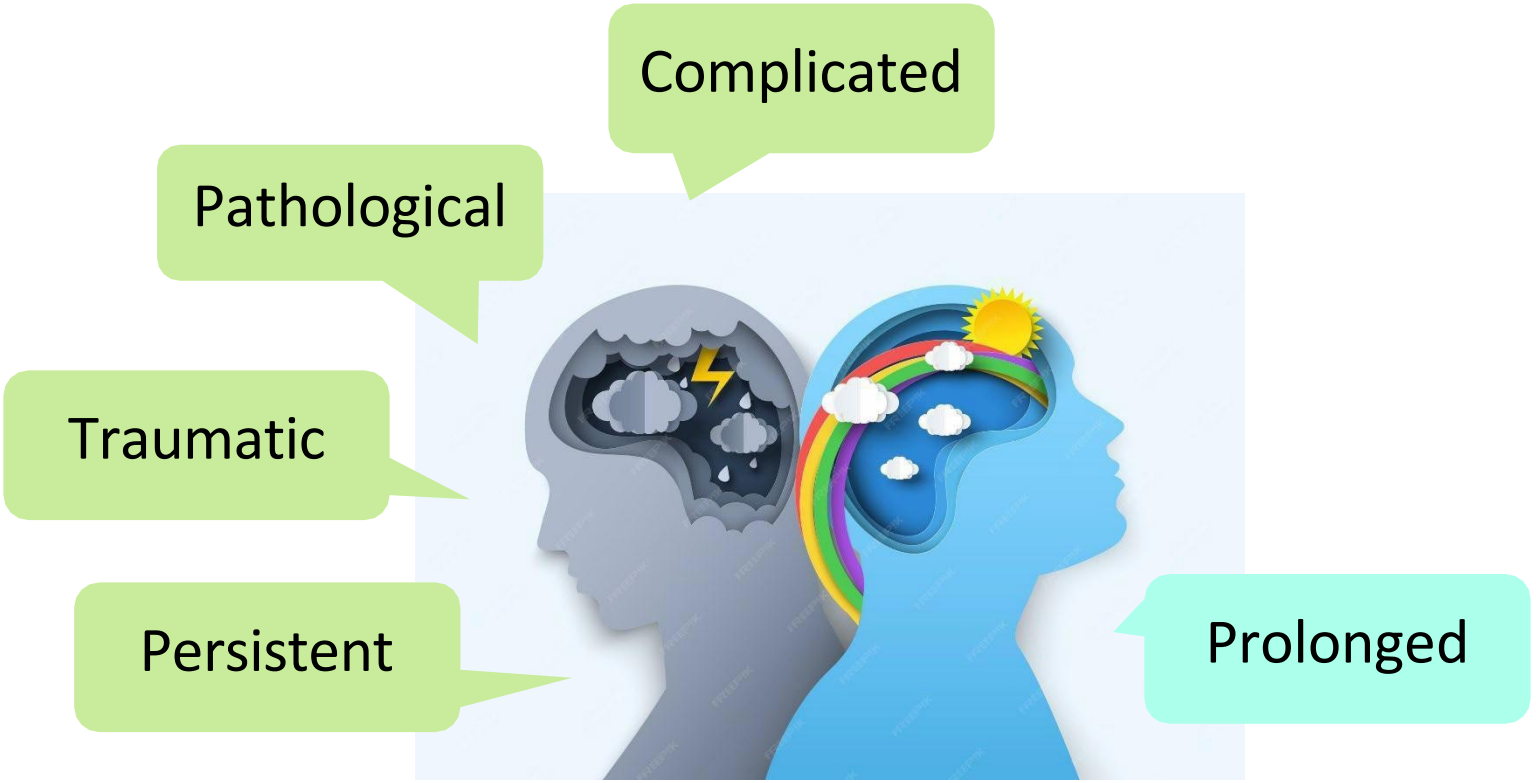
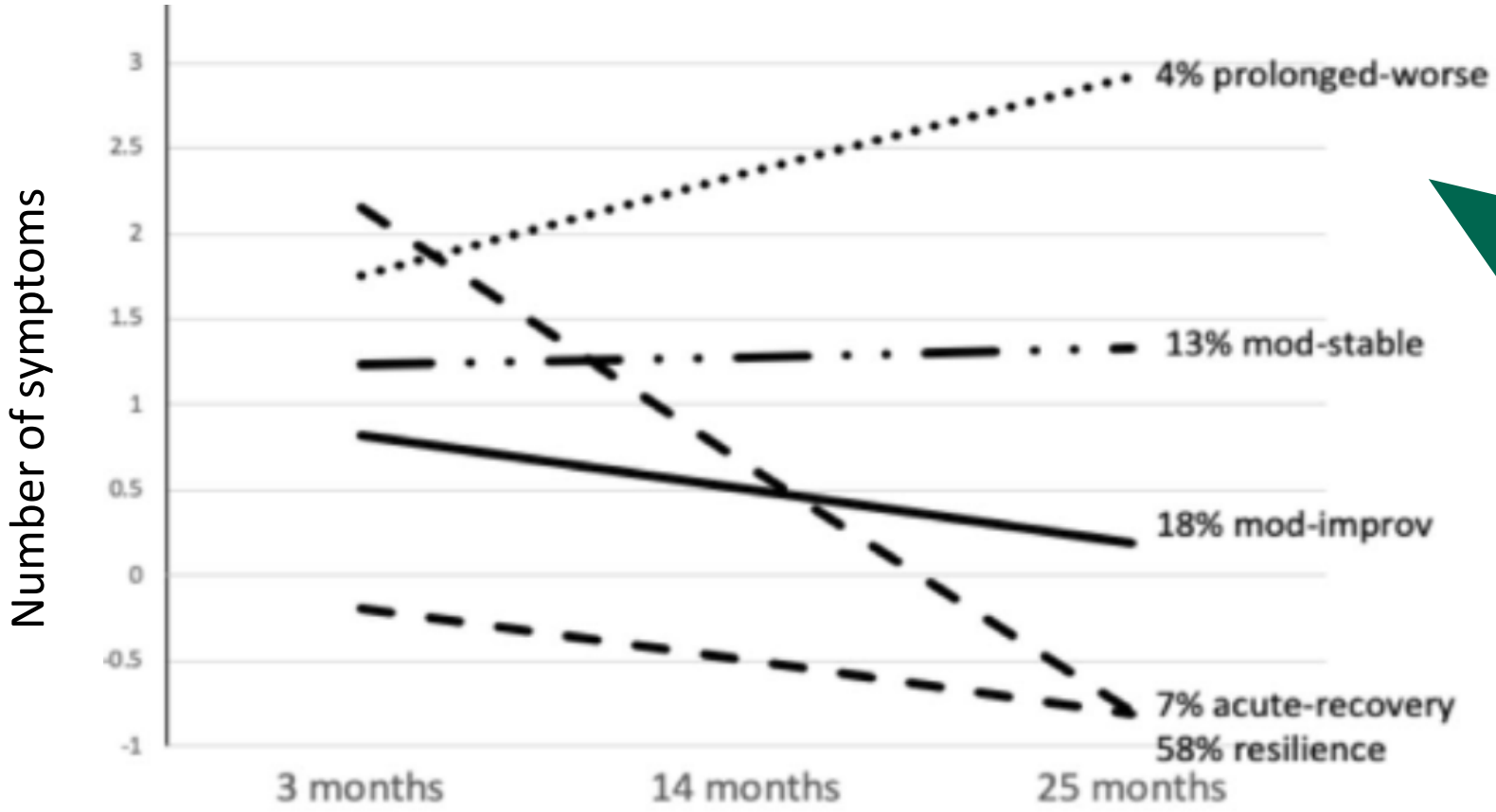


Preferred term: Prolonged grief

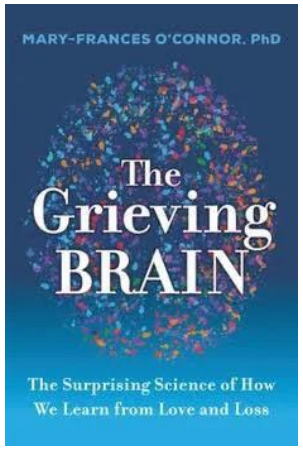
Trajectories of grief, by DSM-5 and ICD 11 diagnosis

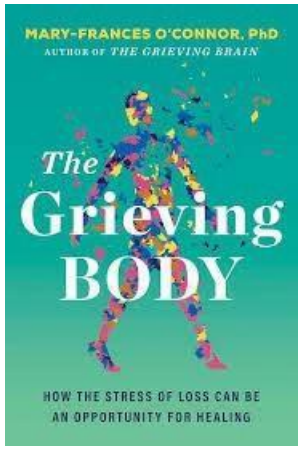


Difficult/disordered grief is a **SMALL SUBSET–** affects ~4-10% of bereaved, yet takes up to 90% of the literature and most of the clinical attention

George A. Bonanno, Matteo Malgaroli; First published: 22 April 2019 https://doi.org/10.1002/da.22902

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

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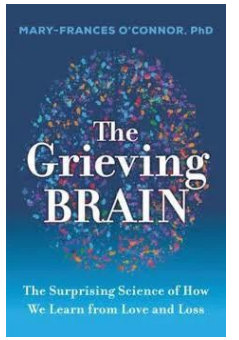
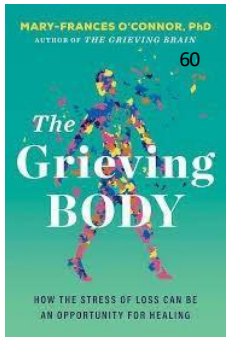
BIOPSYCHOSOCIAL RESPONSE TO LOSS

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

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Feelings

- Dysregulated
- Intensely negative
- Low positive

GRIEF DERAILERS

Thoughts

- Second guessing
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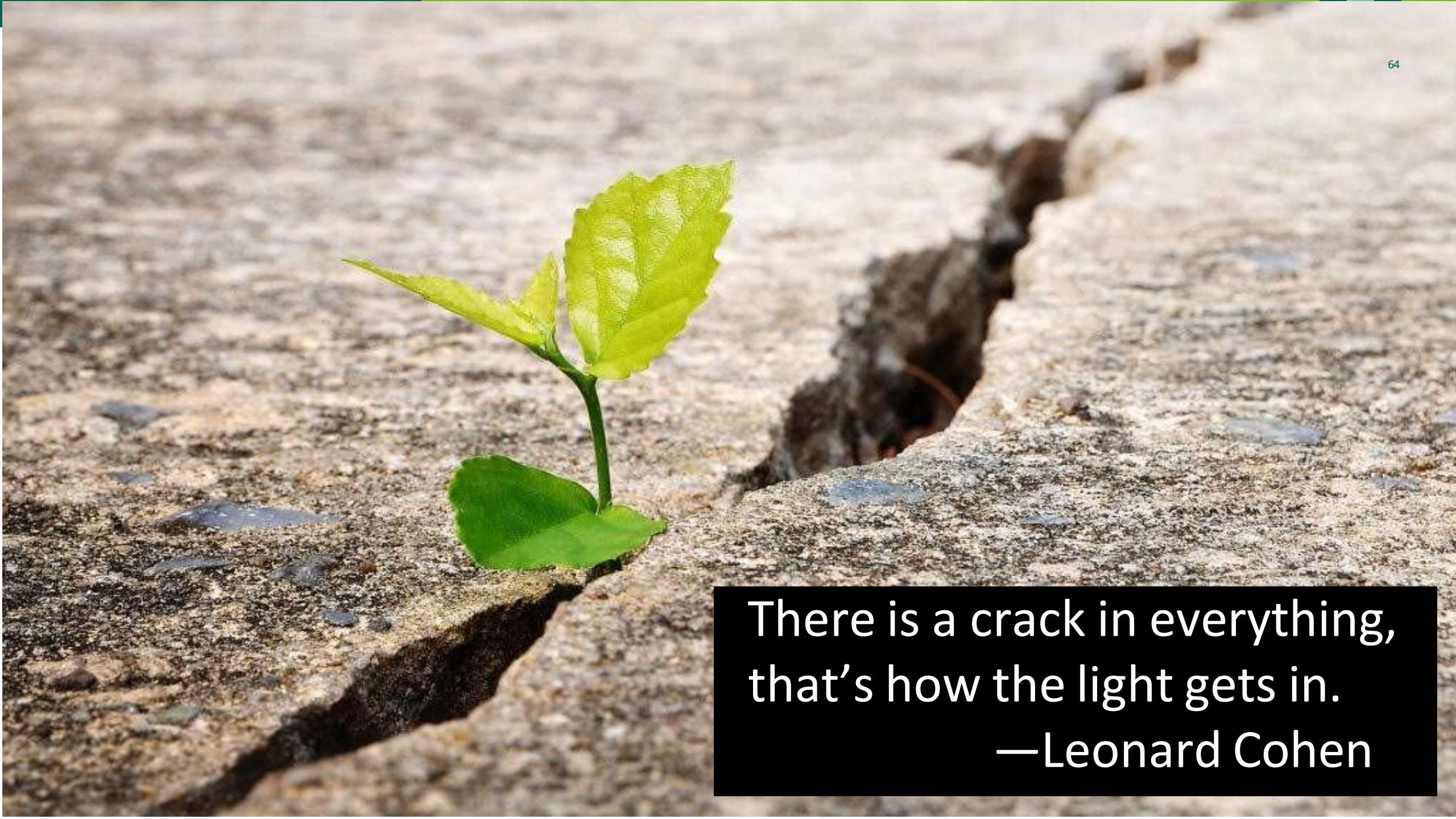
Behaviors

- 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**

Prigerson H et al. JAMA Psychiatry 2022; Simon N and Shear MK. N Engl J Med 2024; Killikelly C et al. Lancet 2025

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 --Bipolar disorder
  - Substance use disorder --Imminent suicidal risk

Reference: Center for Prolonged Grief
https://prolongedgrief.columbia.edu/

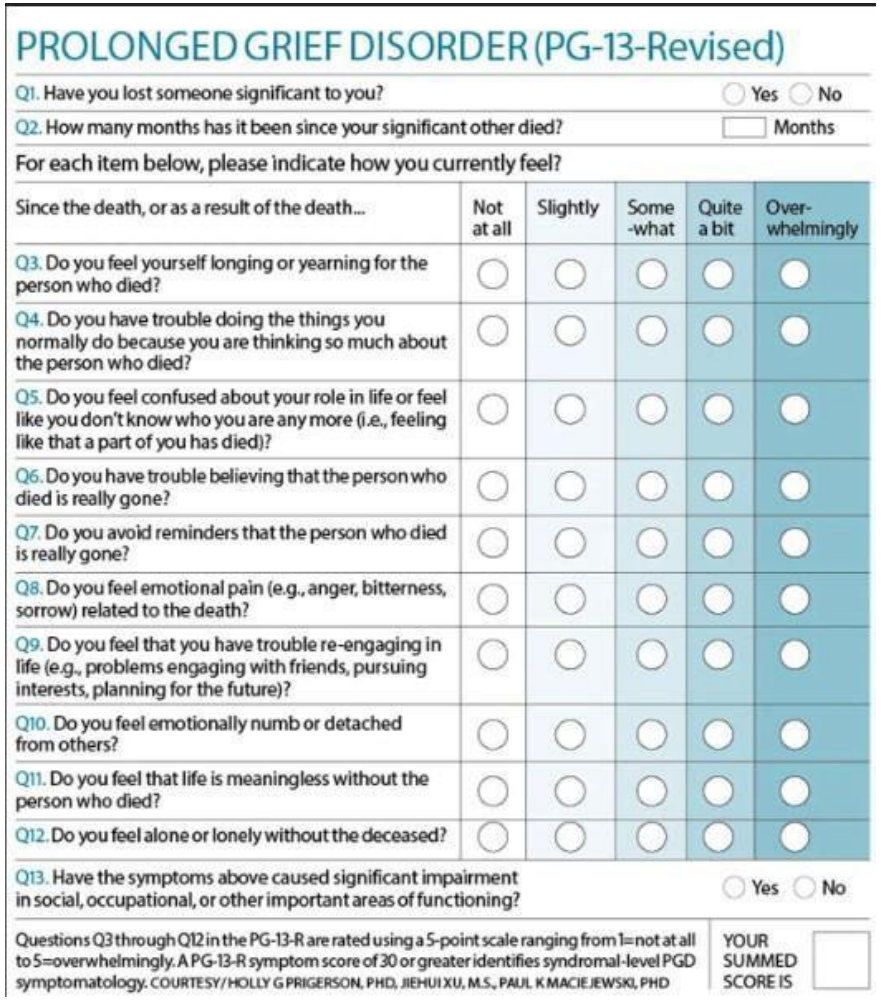
SCREENING & ASSESSING Prolonged Grief Disorder (PSD)

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	Over-whelmingly
Q3. Do you feel yourself longing or yearning for the person who died?	○	○	○	○	○
Q4. Do you have trouble doing the things you normally do because you are thinking so much about the person who died?	○	○	○	○	○
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)?	○	○	○	○	○
Q6. Do you have trouble believing that the person who died is really gone?	○	○	○	○	○
Q7. Do you avoid reminders that the person who died is really gone?	○	○	○	○	○
Q8. Do you feel emotional pain (e.g., anger, bitterness, sorrow) related to the death?	○	○	○	○	○
Q9. Do you feel that you have trouble re-engaging in life (e.g., problems engaging with friends, pursuing interests, planning for the future)?	○	○	○	○	○
Q10. Do you feel emotionally numb or detached from others?	○	○	○	○	○
Q11. Do you feel that life is meaningless without the person who died?	○	○	○	○	○
Q12. Do you feel alone or lonely without the deceased?	○	○	○	○	○

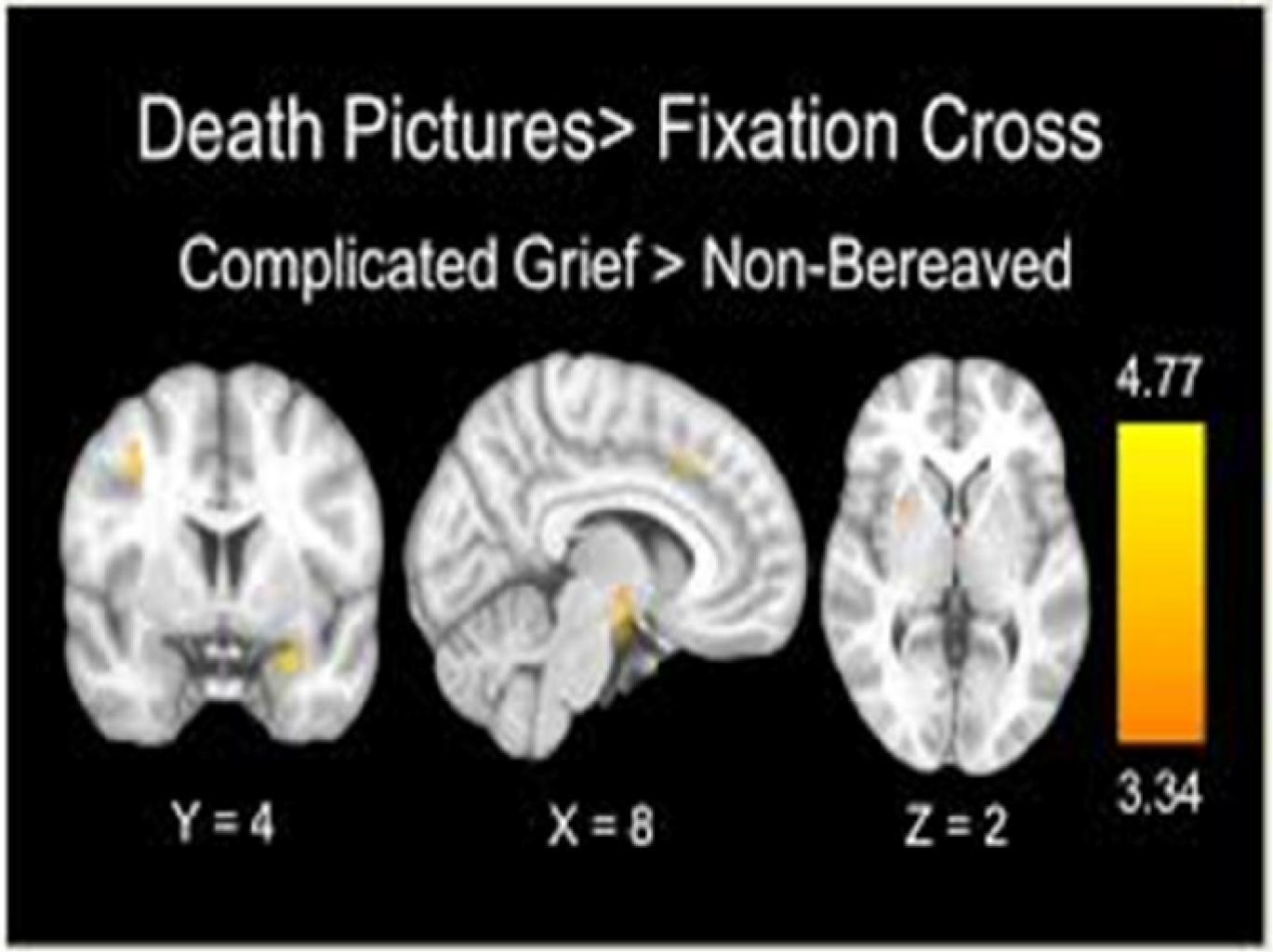
Q13. Have the symptoms above caused significant impairment in social, occupational, or other important areas of functioning? ○ Yes ○ No

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)

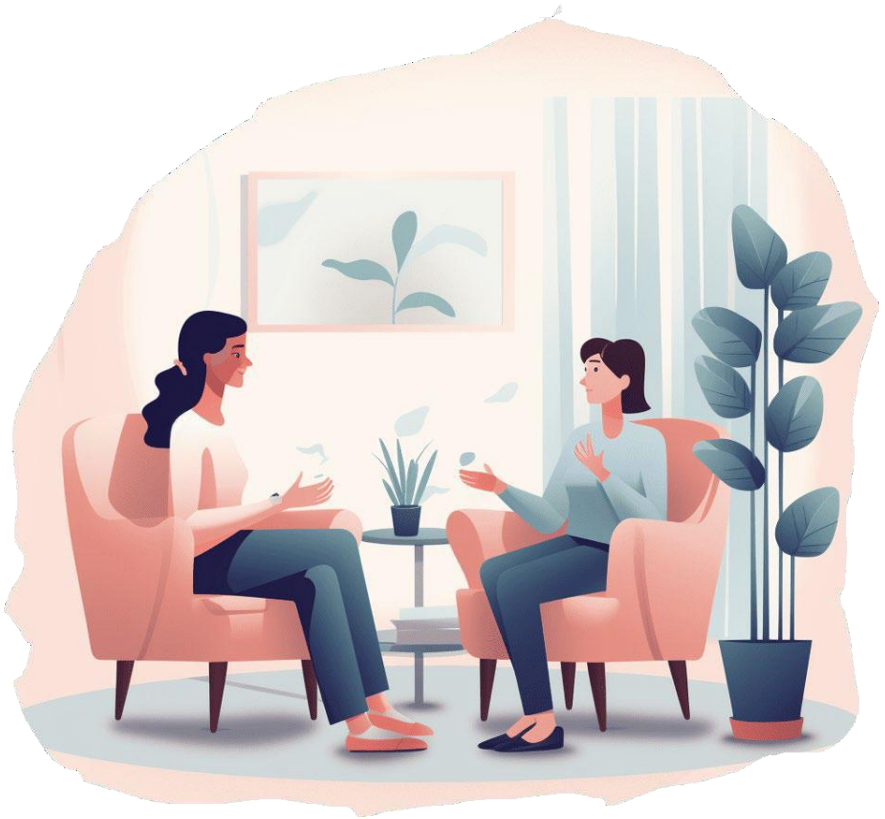
Accelerated Resolution Therapy (ART)

Exposure Therapy

Cognitive Narrative Therapy

Music Therapy

Multimedia Therapy



Treatment for Prolonged Grief Disorder: A Systematic Review and Network Meta-Analysis Pleshka et. al 2025, Vol. 0(0) 1-30 OMEGA-Journal of Death and Dying

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

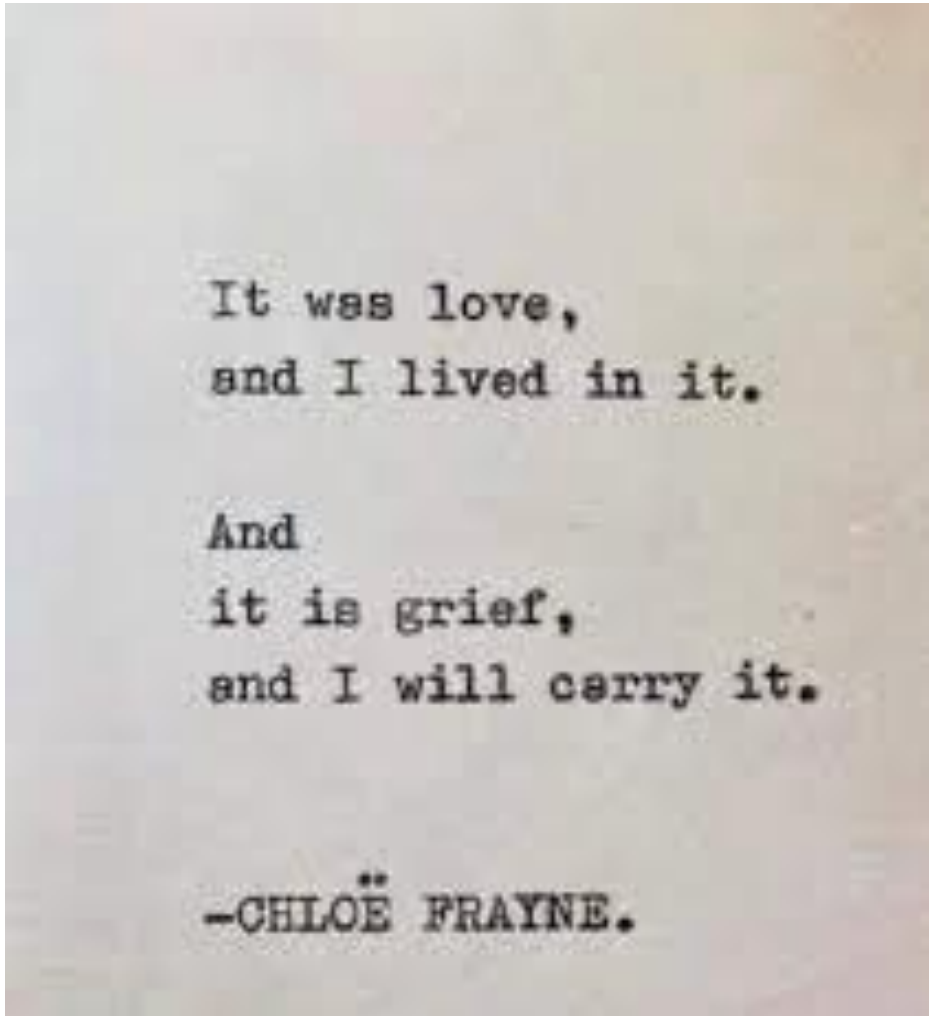
How Long Should It Take to Grieve? Psychiatry Has Come Up With an Answer.

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.



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Palliative Care
DARTMOUTH HITCHCOCK MEDICAL CENTER

Thank you.

Kristen.R.Johnson@hitchcock.org

603-308-2447

Dartmouth Health

Department of Medicine /
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

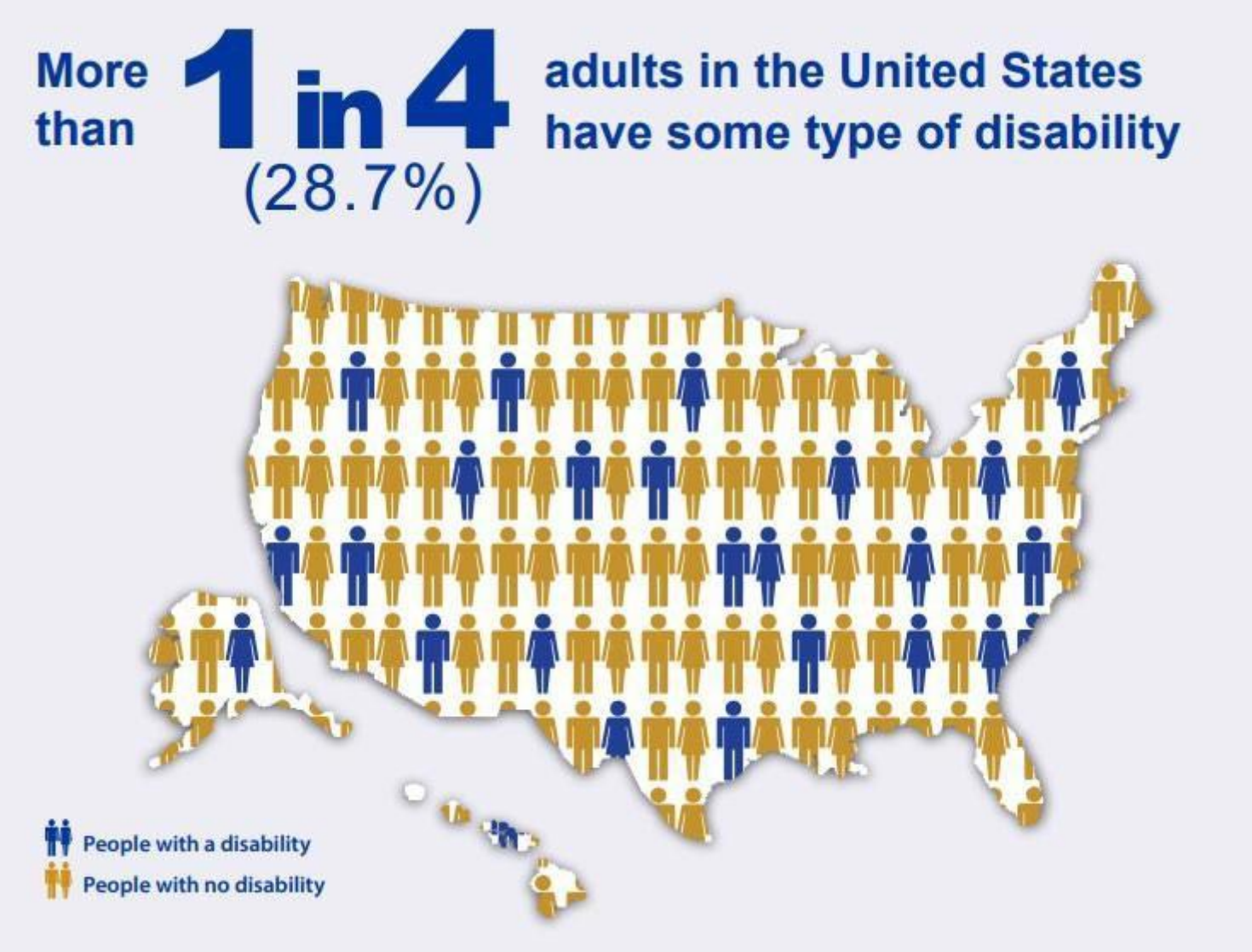
Photo credit: Lisa Jamieson, disabiltyisbeautiful.com

HOW WE ADDRESS DISABILITY MATTERS.

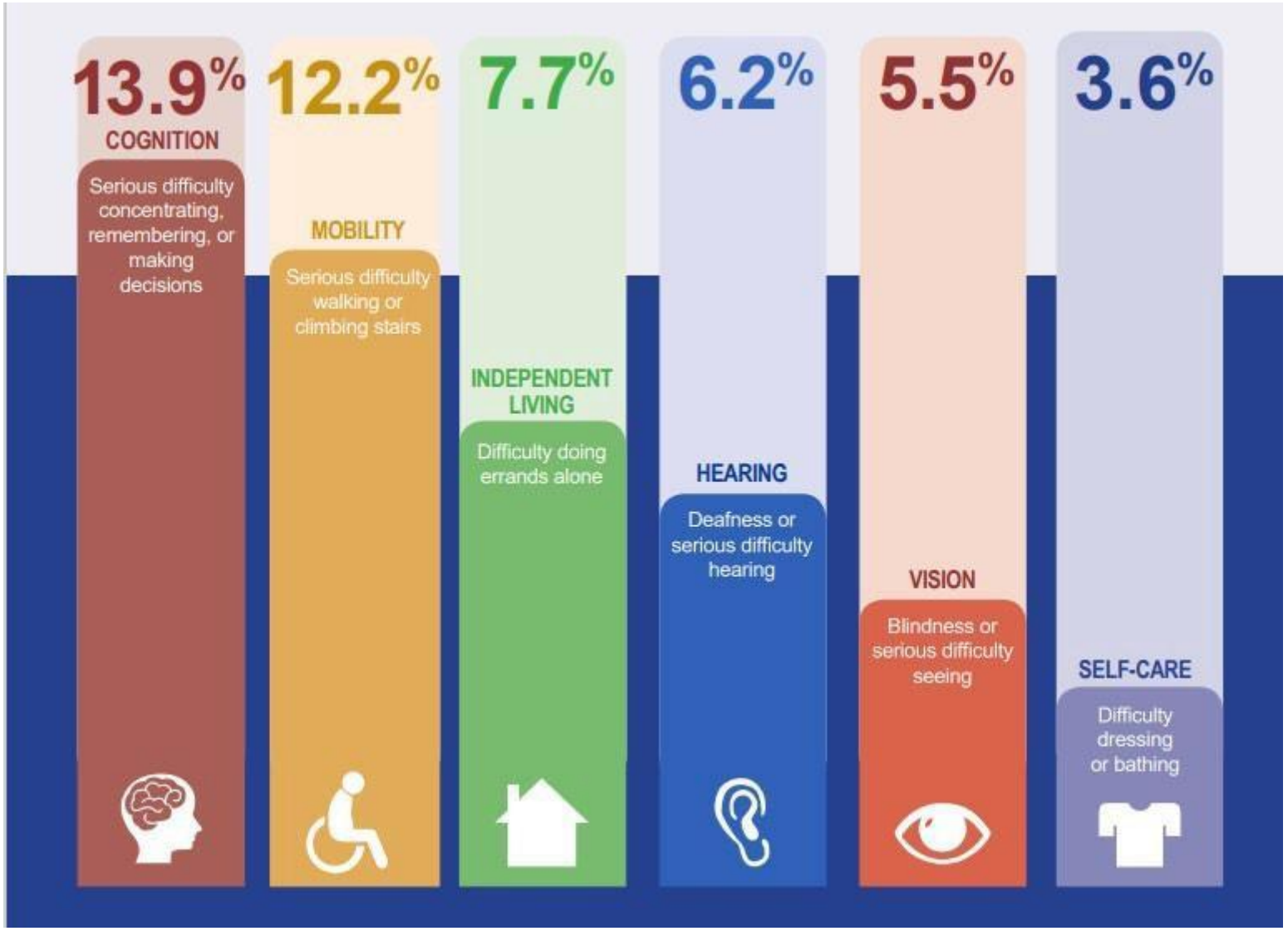
Photo credit: Angie Morin, disabiltyisbeautiful.com

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



Source: https://www.cdc.gov/disability-and-health/articles-documents/disability-impacts-all-of-us-infographic.html#:~:text=This%20infographic%20shows%20healthcare%20access%20barriers%20for%20adults,the%20United%20States%20have%20some%20type%20of%20disability. Accessed 5/27/2025.



Source: https://www.cdc.gov/disability-and-health/articles-documents/disability-impacts-all-of-us-infographic.html#:~:text=This%20infographic%20shows%20healthcare%20access%20barriers%20for%20adults,the%20United%20States%20have%20some%20type%20of%20disability. Accessed 5/27/2025.

DISABLED INDIVIDUALS FACE SIGNIFICANT HEALTH DISPARITIES.

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

Source: https://www.cdc.gov/disability-and-health/articles-documents/disability-impacts-all-of-us-infographic.html#:~:text=This%20infographic%20shows%20healthcare%20access%20barriers%20for%20adults,the%20United%20States%20have%20some%20type%20of%20disability. Accessed 5/27/2025.

DISABILITY

By Lisa I. Iezzoni, Sowmya R. Rao, Julie Ressalam, 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

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

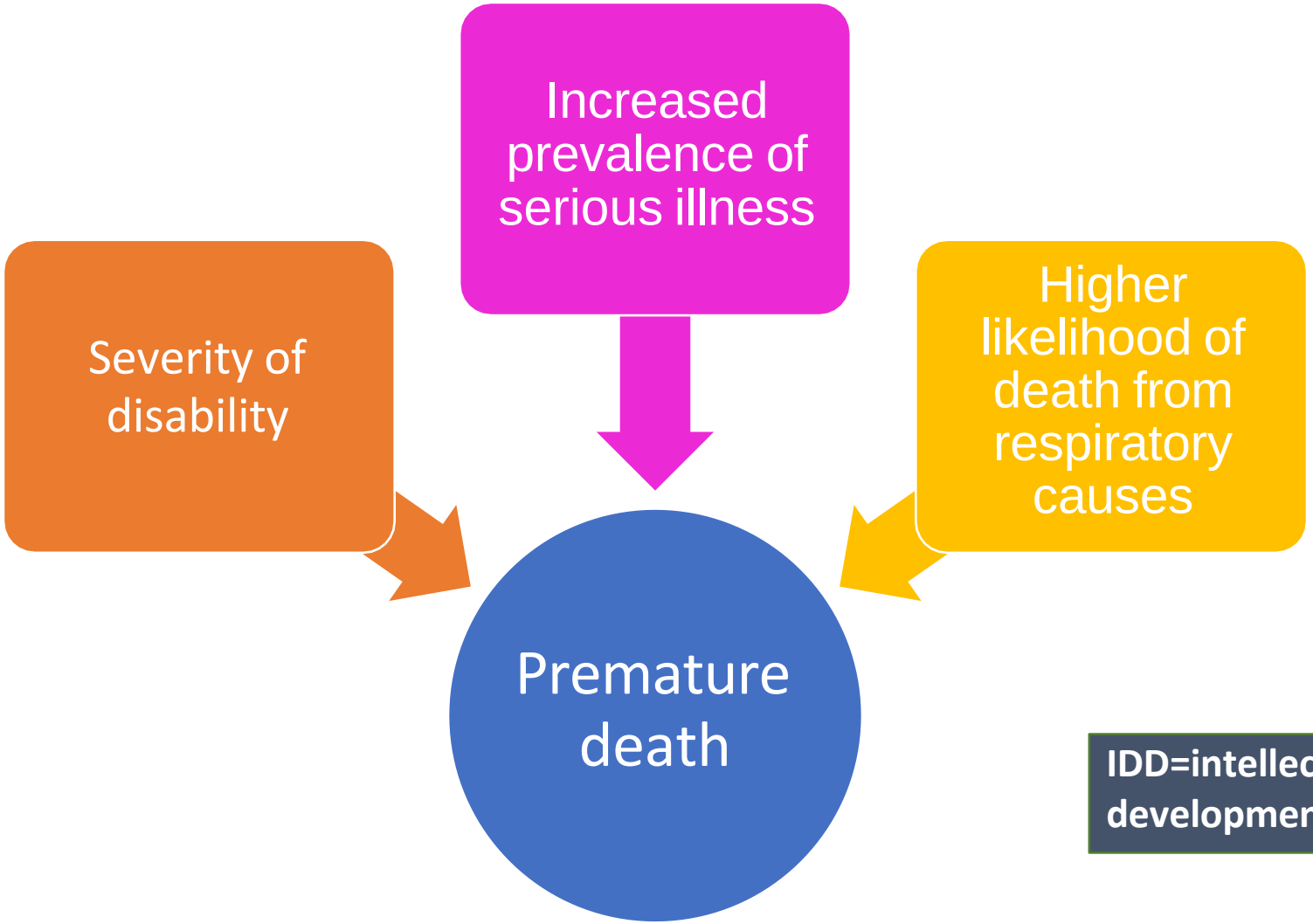
'I Am Not The Doctor For You': Physicians' Attitudes About Caring For People With Disabilities

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



IDD=intellectual and developmental disability

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

Disability Bias in Health Care. Harvard Law School Project on Disability. Oct 20, 2021. https://hpod.law.harvard.edu/news/entry/disability-bias-in-health-care. Accessed 5/27/2025.

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.

Gary L. Albrecht, Patrick J. Devlieger,
The disability paradox: high quality of life against all odds, Social Science & Medicine,Volume 48, Issue 8,1999, Pages 977-988, ISSN 0277-9536,
https://doi.org/10.1016/S0277-9536(98)00411-0.

AWARENESS LEADS TO MORE MEANINGFUL CONVERSATIONS.

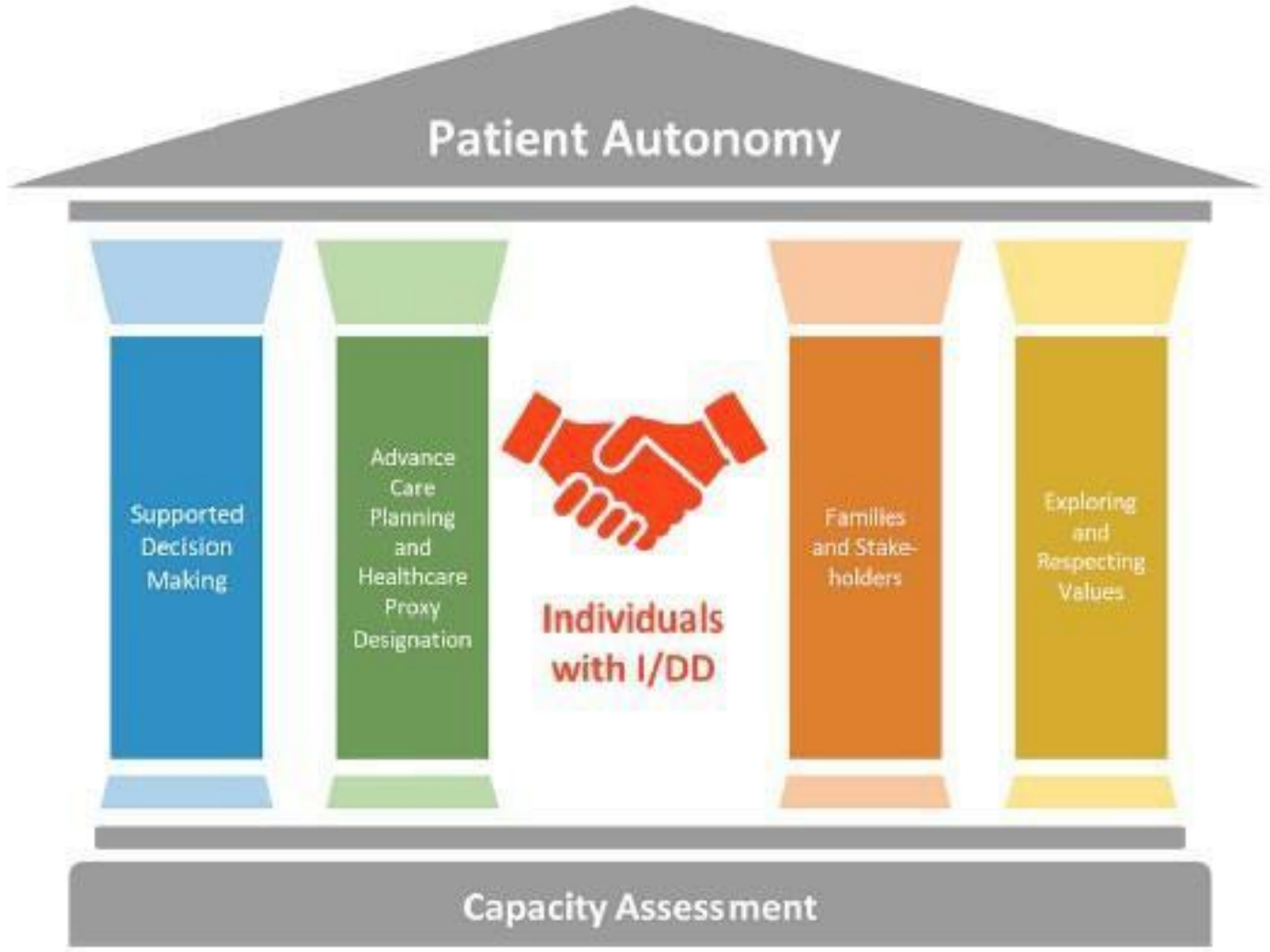


Fig. 1. Pillars of autonomy for patients with intellectual/developmental disabilities (I/DD) adapted from the World Health Organization's framework for palliative care.[9]

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.

Photo credit: Gritchell Fallesgon, affecttheverb.com/disabledandhere

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, disabiltyisbeautiful.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

Photo credit: Gritchell Fallesgon, affecttheverb.com/disabledandhere

SARAH.R.DURANTE@HITCHCOCK.ORG

References

1. CDC infographic
2. Iezzoni LI et al. Physicians' Perceptions of People With Disability and their Health Care, Health Affairs 40, No. 2 (2021): 297–306.
3. Lagu T et al. 'I Am Not The Doctor For You': Physicians' Attitudes About Caring For People With Disabilities. Health Aff (Millwood). 2022 Oct;41(10):1387-1395
4. Disability Bias in Health Care. Harvard Law School Project on Disability. Oct 20, 2021. https://hpod.law.harvard.edu/news/entry/disability-bias-in-health-care.
5. Albrecht GL, Devlieger PJ, The disability paradox: high quality of life against all odds, Social Science & Medicine, Volume 48, Issue 8,1999, Pages 977-988.
6. Institute on Disability
7. Center for Inclusive Health
8. Inclusive Health Principles and Strategies
9. https://www.aapd.com/recent-immigration-policies-impacts-disabled-people-and-long-term-care/
10. Disability Bias in Health Care. Harvard Law School Project on Disability. Oct 20, 2021. https://hpod.law.harvard.edu/news/entry/disability-bias-in-health-care.
11. Castillo, M et al. State Decision-Making Approaches in Seriously Ill People With Intellectual/Developmental Disability. Journal of Pain and Symptom Management, Vol. 70 No. 5 (2025): 337-342.

Cannabis Use:
What You Need to Know
About Potential Benefits versus Risks

Kathleen Broglio, DNP, ANP-BC, ACHPN, CARN-AP, FPCN, FAANP, FAAHPM
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3-2026

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Disclosures and Acknowledgments

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Gratitude to Dr. Robin Larson for her review and editing of the slides

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Objectives

- Review prevalence and commonly reported reasons for cannabis use
- Describe cannabis pharmacology and routes of administration
- Discuss potential benefits and harms of cannabis use

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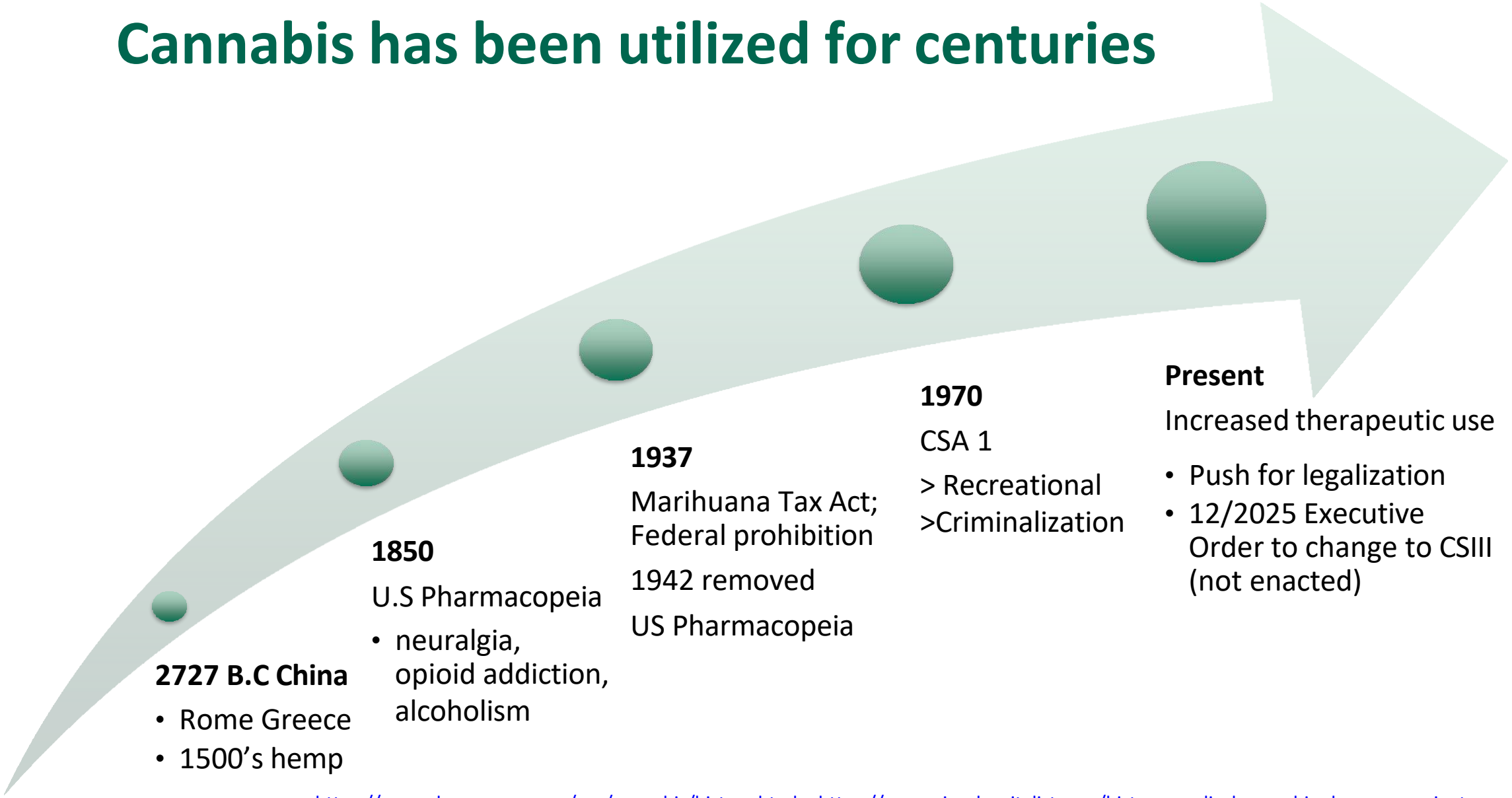
Cannabis has been utilized for centuries



2727 B.C China

- Rome Greece
- 1500's hemp

1850

U.S Pharmacopeia

- neuralgia, opioid addiction, alcoholism

1937

Marihuana Tax Act; Federal prohibition

1942 removed

US Pharmacopeia

1970

CSA 1

> Recreational

>Criminalization

Present

Increased therapeutic use

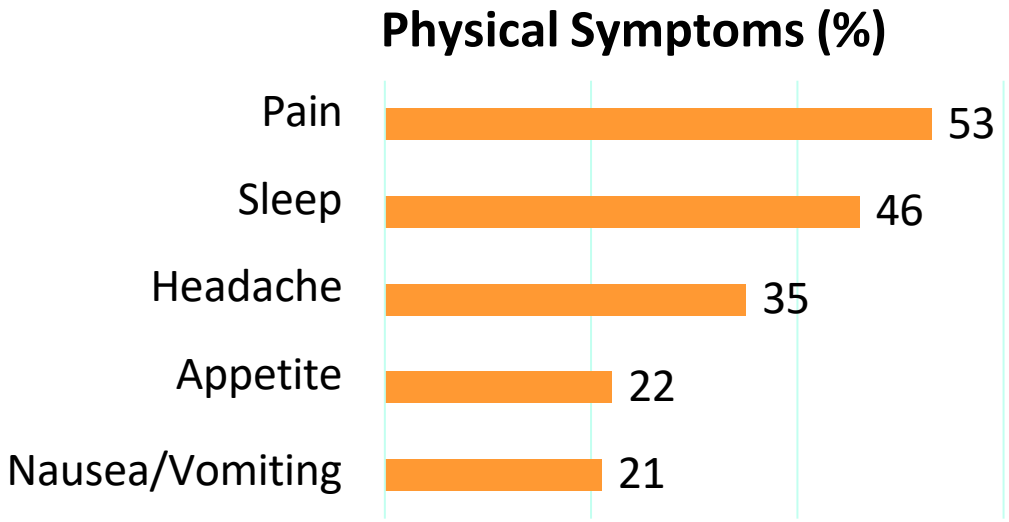
- Push for legalization
- 12/2025 Executive Order to change to CSIII (not enacted)

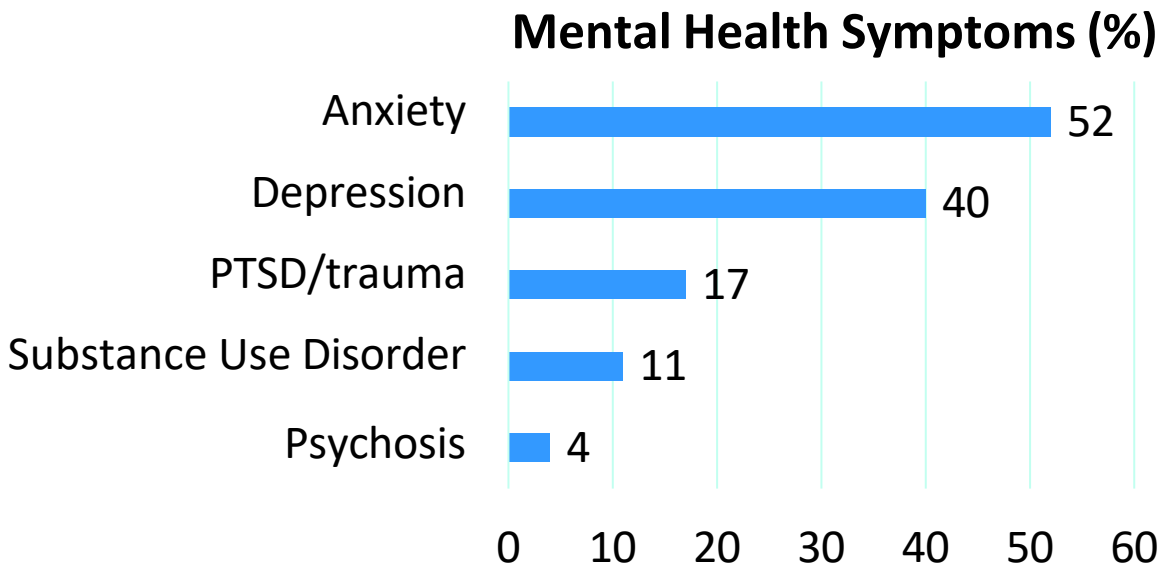
https://www.deamuseum.org/ccp/cannabis/history.html; https://www.visualcapitalist.com/history-medical-cannabis-shown-one-giant-map/

People use cannabis to self-treat symptoms

27,169 respondents to 2018 online survey in U.S and Canada

- **27% self-reported ever use for symptom management**
- Higher in states with legal use (34%) versus no legal use (23%)
- Among reported reasons for symptom management:





Leung et al Psychopharmacology (Berl). 2022https://pmc.ncbi.nlm.nih.gov/articles/PMC9110511/

Individuals with CANCER use cannabis … AND may not tell their clinicians

- Prevalence use from national samples 4-22%[1]
- 42% reported use at one cancer center; up to 50% believed it was treating cancer[2]
- 27% reported use for multiple symptoms at a rural academic medical center[3]

Amin et al Cancer Spectr. 2024 Jan 4;8(1):pkae004. doi: 10.1093/jncics/pkae004;[1]Weiss et al, *Cancer* 2022;128:160-168;[2] Wilson et al. *J Palliat Med;* 2019;,1224-1226[3]

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Cannabis Pharmacology – What do we know?

Endogenous cannabinoid system

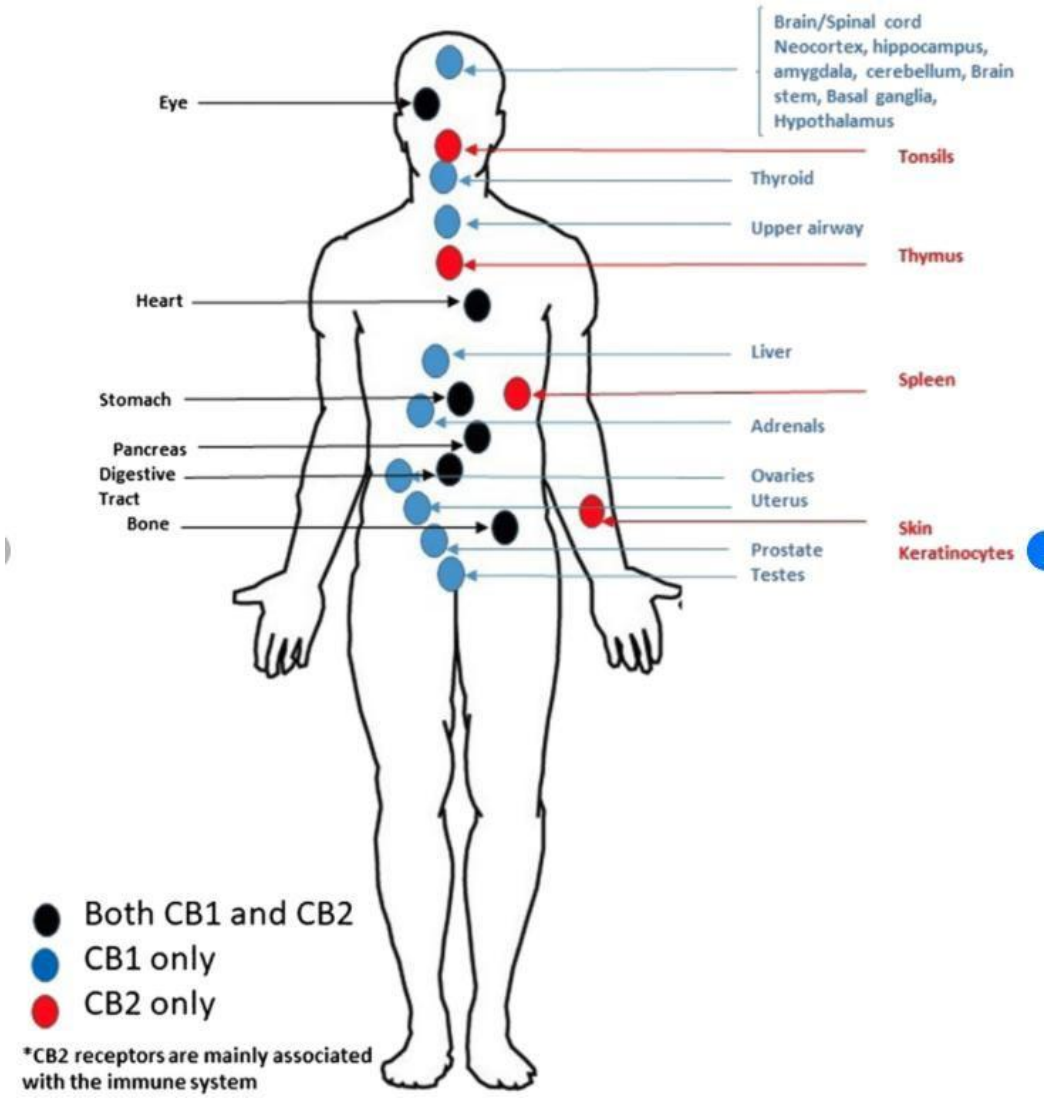
Endocannabinoids bind to cannabinoid receptors

- CB1 (primarily in nervous system)
- CB2 (primarily in immune system)

Physiologic roles

- Pain regulation
- Mood modulation including reward
- Cognition, learning & memory
- Energy balance, appetite

Implications: Limited understanding of the effects of exogenous (external) cannabinoids on endogenous (internal) cannabinoid system



Volkow et al. *Annu Rev Pharmacol Toxicol,* 2017;57:285-308;

Cannabis contains > 100 phytocannabinoids and > 500 chemical constituents

- Two most prevalent cannabinoids
  - **Δ^9-tetrahydrocannabinol (THC)**
    psychoactive; anti-emetic, analgesia, appetite stimulation (discovered 1964)
  - **Cannabidiol (CBD)**
    not psychoactive; anti-convulsant, anxiolysis, anti-inflammatory (discovered 1988)
- Less studied cannabinoids & terpenes may contribute to cannabis effects
- NO standardization—diverse strains bred and available
  - Very high THC concentrations are available (SOME up to 94% THC)

https://cannabis.semel.ucla.edu/compunds/

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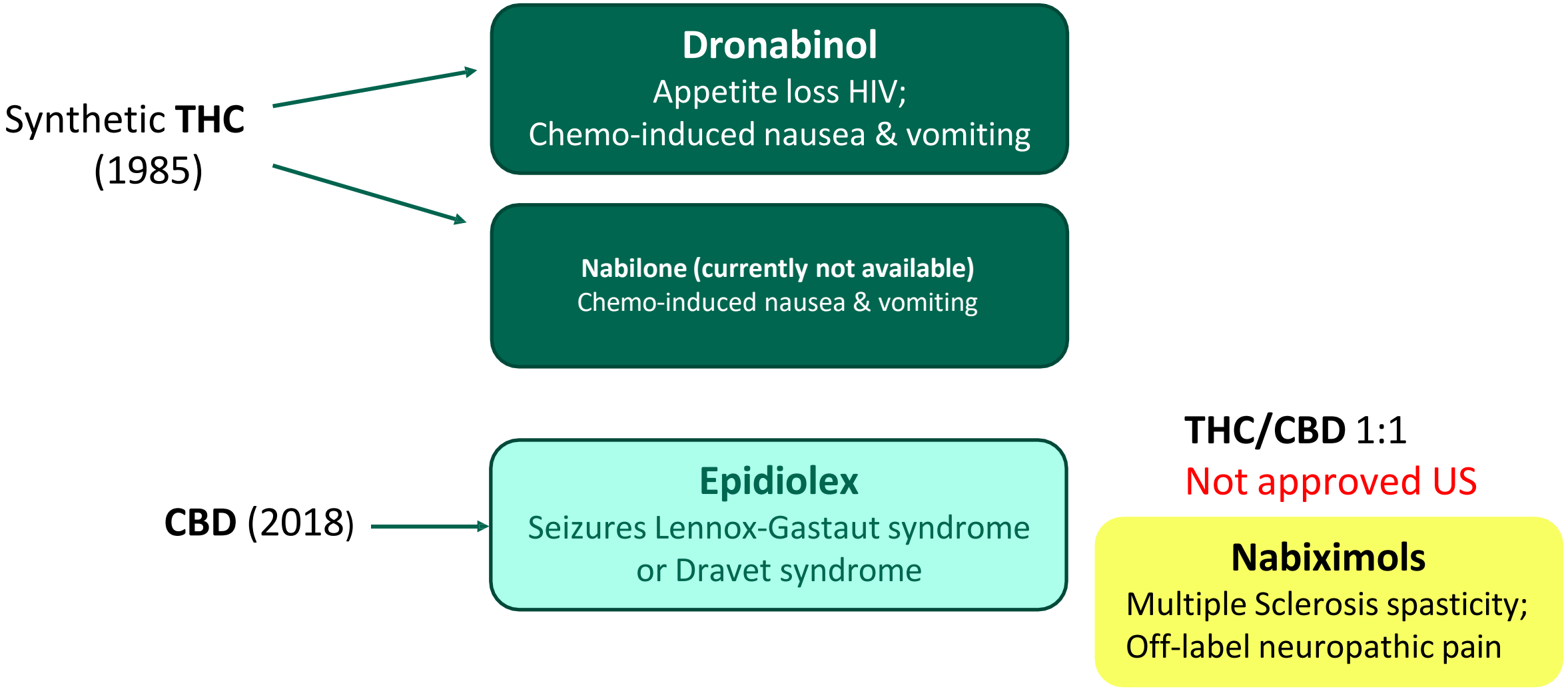
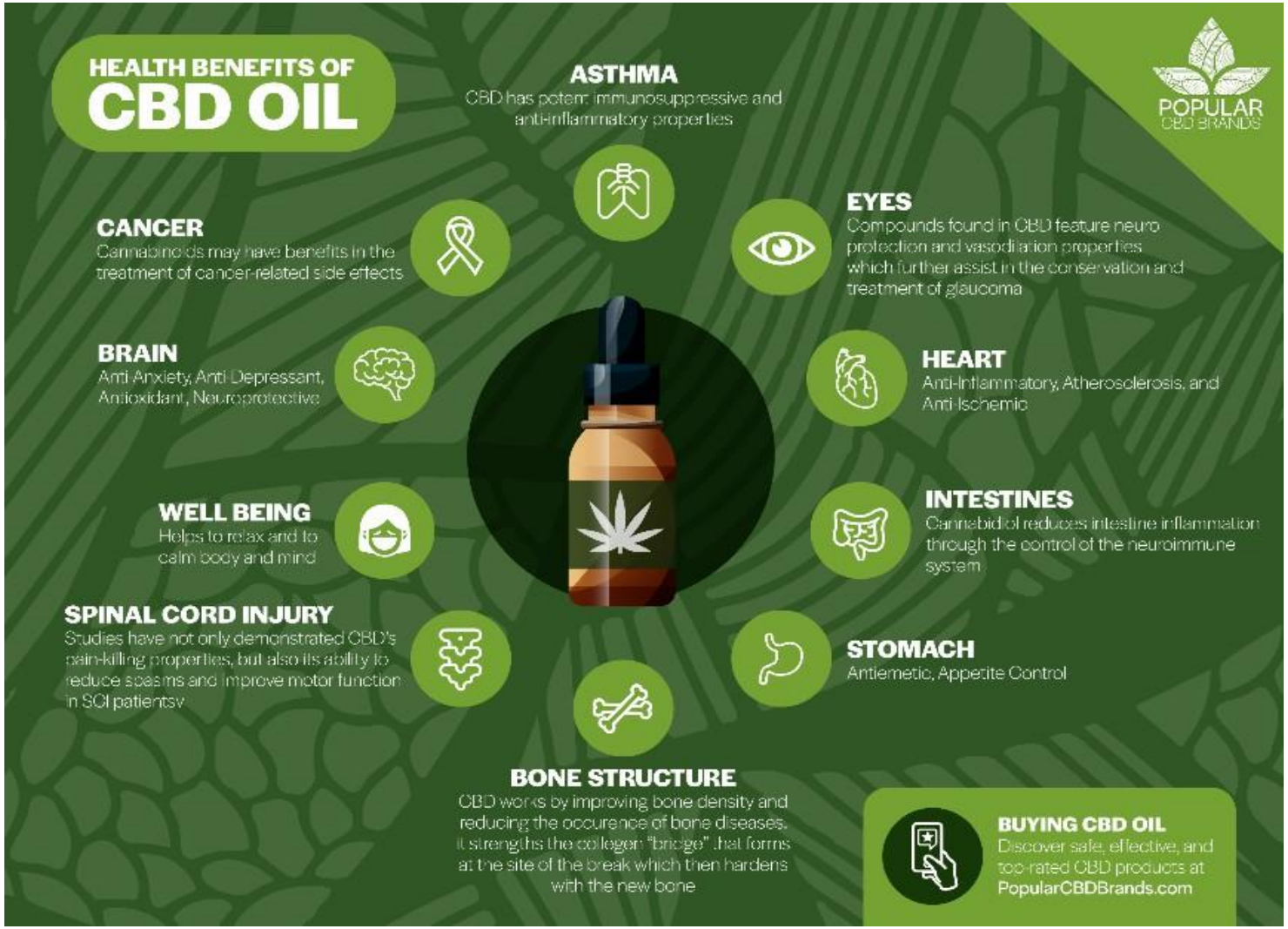
What formulations of cannabis are utilized?

Three pharmaceutical cannabis products available in U.S.



Cannabidiol (CBD) is widely available, but is not highly regulated



Cannabidiol (CBD) is widely available, but is not highly regulated

Enthusiasm for use is not supported by the current evidence for efficacy

58 of 84 samples of CBD purchased online had mislabeled CBD content Bonn-Miller et al. *JAMA*. 2017;318 (17):1708-1709

Cannabis product formulations

Smoked

- Rapid onset of action 5-10 min
- Duration 2-4 hrs.
- Bioavailability 10-30%

Vaporization

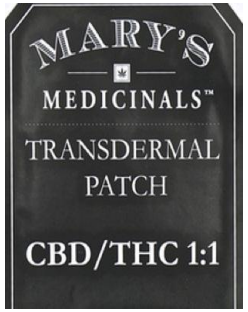
- Rapid onset of action 5-10 min
- Metered dosing devices
- Risk of EVALI (e-cig/vaping associated lung injury)

Transmucosal, Sublingual

- Onset of action 15-45 minutes
- Duration 6-8 hours
- Pharmaceutical form (nabiximols) available

Edible

- Onset of action 60-180 min
- Duration 6-8 hours
- Bioavailability 6% extensive first pass effects



Transdermal Topical

- Variable onset - duration
- Highly lipophilic
- Slow onset, stable blood levels

https://cms.trekk.ca/wp-content/uploads/2023/11/2025_01_31-Cannabis-Methods-of-Delivery-and-Formulations-v2.0-Final.pdf

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What does the evidence show about cannabis therapeutic effects?

Evidence of effects is difficult to accurately determine

Heterogeneity of studies

Opinion bias; **industry** influence

THC content in studies is **lower** than patients utilizing

Changing evidence over time

Research & clinical challenges

NASEM; 2017https://www.nap.edu/catalog/24625/the-health-effects-of-cannabis-and-cannabinoids-the-current-state; Abrams, *Eu J Int Med,* 2018, 49, 7-11

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Cannabis: Evidence of Effects

Substantial
or conclusive evidence for efficacy

- Chronic pain in adults, particularly neuropathic pain[1,2]
- Chemotherapy-induced nausea & vomiting[1,3]
- Subjective spasticity multiple sclerosis[1]
- Epilepsy (Dravet and Lennox-Gastaut) CBD Epidiolex[4]

Moderate

- Short-term sleep[1,5]

[1] NASEM; 2017https://www.nap.edu/catalog/24625/the-health-effects-of-cannabis-and-cannabinoids-the-current-state; [2]Nugent et al. 2017;*167*(5):319-331. [3]Lichtman et al JPSM 2018 https://doi.org/10.1016/j.jpainsymman.2017.09.001
[4]Chow et al. Support Care in Cancer. 2020;28:2095–2103 https://doi.org/10.1007/s00520-019-05280-4 ; MacCallum & Russo. *Eur J Int Med.* 2018;49:12-19; [4] Privitera et al. *Epilepsia.* 2021;62(5):1130-1140 [5]Bonaccorso. *Neurotoxicol.* https://doi.org/10.1016/j.neuro.2019.08.002

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Cannabis: Evidence of Effects

Limited

- Appetite & weight loss in HIV/AIDS[1]
- Tourette symptoms[1]
- Anxiety symptoms in social anxiety disorders (CBD)[1,2]
- Post traumatic stress disorder symptoms[1]
- Dementia[1]

Insufficient evidence

- Cancer cachexia >appetite, > side effects
- Cancer – most literature preclinical[4,5]
- Neurodegenerative disorders[1]
- Irritable bowel syndrome[1]
- Addiction abstinence[6]

[1] NASEM. 2017;https://www.nap.edu/catalog/24625/the-health-effects-of-cannabis-and-cannabinoids-the-current-state; [2]Wright. *Cannabis Cannabinoid Res* 2020. https://pubmed.ncbi.nlm.nih.gov/32923656/ [3]Wang et al. *Biomed Res Int.* 2019; https://doi.org/10.1155/2019/2864384; [4]Abu-Amna et al. *Curr. Treat. Options in Oncol*. 2021;22:16 doi: 10.1007/s11864-020-00811; [5]Goyal et al. *Comp Ther Med.* 2020; https://doi.org/10.1016/j.ctim.2020.102336; [6]Bonaccorso. *Neurotoxicol.* https://doi.org/10.1016/j.neuro.2019.08.002

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What are the adverse effects or potential harms of cannabis?

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Commonly reported adverse effects of THC

- **Central Nervous System**
  - Drowsiness
  - Dizziness
  - Confusion
  - Mental Clouding
  - Slurred speech
- **Physical**
  - Rapid heart beat
  - High or low blood pressure
  - Nausea
  - Fatigue
  - Dry mouth
  - Cannabis hyperemesis syndrome

National Institute of Drug Abuse – Cannabis https://nida.nih.gov/research-topics/cannabis-marijuana#short-term-health-cannabis

Reported CBD adverse effects

- Drowsiness/sedation
- Mood changes
- Interactions with prescription medications that may affect actions/toxicity
- Liver toxicity
- Reproductive and developmental effects

TAKE HOME: People are using CBD and may not be cognizant of potential adverse effects

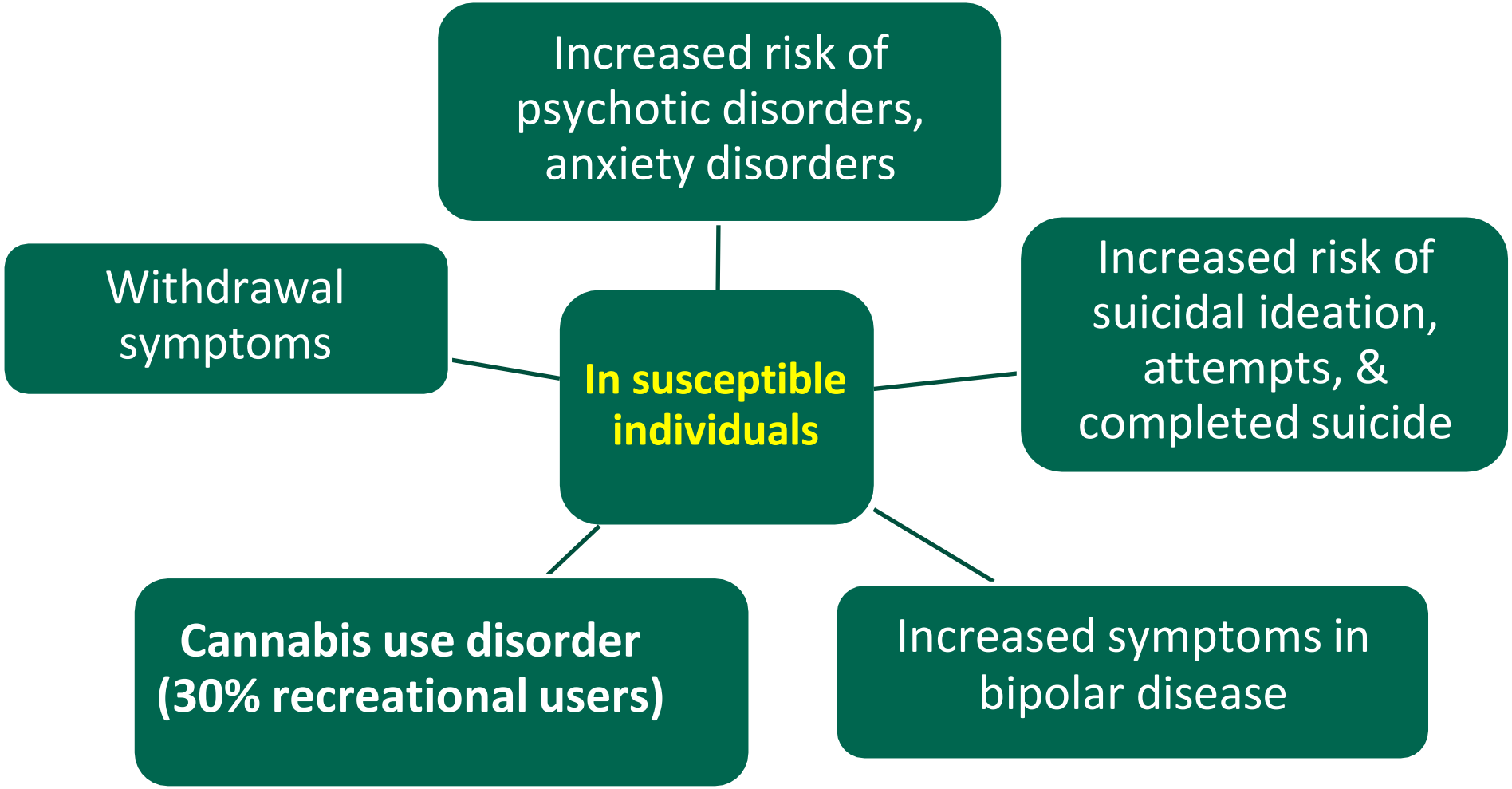
. Cannabidiol (CBD) – Potential Harms, https://library.samhsa.gov/sites/default/files/pep22-06-04-003.pdf

Some Harms of Cannabis Use

Cardiac	• Associations between cannabis use and heart attack, stroke and atrial arrhythmias
Drug-Drug Interactions	• Greater than 100 known drug interactions • May affect action of other medications • May affect efficacy of immunotherapy
Motor vehicle accidents	• Some studies show a significant correlation between high THC (affects central nervous system) blood concentrations and car crash risk

NIDA– Cannabis https://nida.nih.gov/research-topics/cannabis-marijuana#short-term-health-cannabis; Jeffers et al *Journal of the American Heart Association*. 2024;13(5). doi:10.1161/JAHA.123.030178;Chye et al *Heart rhythm*. doi:10.1016/j.hrthm.2025.05.062; Bal et al, 2020 https://pmc.ncbi.nlm.nih.gov/articles/PMC7563978/pdf/cancers-12-02447.pdf

Potential Mental Health Harms of Cannabis



National Academies of Science, Engineering & Medicine, 2017 Report; Substance Abuse and Mental Health Services Administration- https://www.samhsa.gov/substance-use/learn/marijuana/risks

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Ask ALL patients about cannabis use

"Many patients use marijuana to treat symptoms. I wonder if you do?"

OR "I always ask patients about marijuana use as I want to make sure if you are using it that I can provide some guidance about use"

OR "Since I am prescribing opioids for your pain, I ask you to do a urine test to make sure I am practicing safely. Will there be anything else in your urine such as THC which is in marijuana?"

Some Take Away Considerations

- Cannabis use is common in individuals with serious illness
- Information about cannabis pharmacology is evolving and current research does not indicate very effective for many conditions
- Cannabis is not ‘benign’ & may carry more risks than currently known
- Clinicians should routinely ask patients about cannabis use and when appropriate should counsel about potential harms

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Selected References

- Amin S, Chae SW, Kawamoto CT, Phillips KT, Pokhrel P. Cannabis use among cancer patients and survivors in the United States: a systematic review. JNCI Cancer Spectr. 2024 Jan 4;8(1):pkae004. doi: 10.1093/jncics/pkae004. PMID: 38291891; PMCID: PMC10868394.
- Balachandran P, Elsohly M, Hill KP. Cannabidiol Interactions with Medications, Illicit Substances, and Alcohol: a Comprehensive Review. J Gen Intern Med. 2021 Jul;36(7):2074-2084. doi: 10.1007/s11606-020-06504-8. Epub 2021 Jan 29. PMID: 33515191; PMCID: PMC8298645.
- Bar-Sela, G., Cohen, I., Campisi-Pinto, S., Lewitus, G. M., Oz-Ari, L., Jehassi, A., Peer, A., Turgeman, I., Vernicova, O., Berman, P., Wollner, M., Moskovitz, M., & Meiri, D. (2020). Cannabis Consumption Used by Cancer Patients during Immunotherapy Correlates with Poor Clinical Outcome. *Cancers*, *12*(9), 2447. https://doi.org/10.3390/cancers12092447
- Bonn-Miller MO, Loflin MJE, Thomas BF, Marcu JP, Hyke T, Vandrey R. Labeling Accuracy of Cannabidiol Extracts Sold Online. JAMA. 2017 Nov 7;318(17):1708-1709. doi: 10.1001/jama.2017.11909. PMID: 29114823; PMCID: PMC5818782.
- Chye DM, Sampaio Rodrigues T, Quarto LJG, et al. Cannabis use and atrial arrhythmias: A systematic review and meta-analysis of large populational studies. *Heart rhythm*. Published online 2025. doi:10.1016/j.hrthm.2025.05.062
- Jeffers AM, Glantz S, Byers AL, Keyhani S. Association of Cannabis Use With Cardiovascular Outcomes Among US Adults. *Journal of the American Heart Association*. 2024;13(5). doi:10.1161/JAHA.123.030178
- Leung J, Chan G, Stjepanović D, Chung JYC, Hall W, Hammond D. Prevalence and self-reported reasons of cannabis use for medical purposes in USA and Canada. Psychopharmacology (Berl). 2022https://pmc.ncbi.nlm.nih.gov/articles/PMC9110511
- National Institute of Drug Abuse. Cannabisl. Updated September 2024. https://nida.nih.gov/research-topics/cannabis-marijuana#long-term-health-cannabis
- National Academies of Sciences, Engineering, and Medicine; Health and Medicine Division; Board on Population Health and Public Health Practice; Committee on the Health Effects of Marijuana: An Evidence Review and Research Agenda. The Health Effects of Cannabis and Cannabinoids: The Current State of Evidence and Recommendations for Research. Washington (DC): National Academies Press (US); 2017 Jan 12. Available from: https://www.ncbi.nlm.nih.gov/books/NBK423845/ doi: 10.17226/24625
- Preuss UW, Huestis MA, Schneider M, Hermann D, Lutz B, Hasan A, Kambeitz J, Wong JWM, Hoch E. Cannabis Use and Car Crashes: A Review. Front Psychiatry. 2021 May 28;12:643315. doi: 10.3389/fpsyt.2021.643315. PMID: 34122176; PMCID: PMC8195290.

Selected References, continued

- Storck W, Elbaz M, Vindis C*, et al.* Cardiovascular risk associated with the use of cannabis and cannabinoids: a systematic review and meta-analysis. *Heart* Published Online First: 17 June 2025. doi: 10.1136/heartjnl-2024-325429
- Substance Abuse and Mental Health Services Administration. (2024). Key substance use and mental health indicators in the United States: Results from the 2023 National Survey on Drug Use and Health (HHS Publication No. PEP24-07-021, NSDUH Series H-59). Center for Behavioral Health Statistics and Quality, Substance Abuse and Mental Health Services Administration. https://www.samhsa.gov/data/report/2023-nsduh-annual-national-report
- Substance Abuse and Mental Health Services Administration. Know the risks, effects and side effects of marijuana. https://www.samhsa.gov/substance-use/learn/marijuana/risks (updated 11/2024)
- Substance Abuse and Mental Health Services Administration. Cannabidiol (CBD) – Potential harms, side effects and unknowns. Cannabidiol (CBD) – Potential Harms, Side Effects, and Unknowns (updated 2/2023)
- Translating Emergency Knowledge for Kids (TREKK) 2025. Cannabis Methods of Delivery and Formulations. Updated 2025. https://cms.trekk.ca/wp-content/uploads/2023/11/2025_01_31-Cannabis-Methods-of-Delivery-and-Formulations-v2.0-Final.pdf
- UCLA Semel Institute. Center for Cannabis and Cannabinoids. https://cannabis.semel.ucla.edu/compunds/

Palliative Medicine ECHO:
Agitation in Serious Illness and at the End of Life

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Conflicts of Interest/Disclosures

- No disclosures or conflicts of interest
- All content/data presented reflects my own viewpoints, not those of Dartmouth Health or the Geisel School of Medicine at Dartmouth

Learning Objectives

- **Define** terminal agitation and **distinguish** it from other forms of distress at end of life
- Recognize the **prevalence** and **clinical burden** of agitation in serious illness and at the end of life
- Articulate the **impact** of agitation on patients, families, and care partners including burden and bereavement
- Identify **evidence-based** pharmacologic and non-pharmacologic **management** strategies

Sources of Distress in Serious Illness and at the End of Life

Existential & Spiritual
Fear, meaning, dignity
Unfinished business

Psychological
Anxiety, depression, adjustment disorder

Delirium (hypoactive)
Withdrawal, somnolence
Reduced interaction
Often missed

Terminal Agitation
Refractory
+/- psychotic symptoms
Suggests proximity to death

Delirium (hyperactive)
Agitation, calling out
Combativeness
Distressing to witness

Terminal Agitation

- A neuropsychiatric syndrome in the final hours to days of life
- Characterized by:
  - Motor restlessness and purposeless movements
  - Cognitive impairment and disorientation
  - Emotional distress (fear, moaning, grimacing)
  - Agitation and combativeness
  - Psychotic symptoms (hallucinations, paranoia)
  - Inability to communicate meaningfully or be consoled

- Also called:
  - Agitated delirium, terminal restlessness, refractory distress at end of life

Prevalence and Clinical Burden

42–88% of dying patients experience **delirium** in their final days

~25% of terminal delirium cases are **hyperactive** or **agitated**
which is often refractory to treatment

78% of hospice nurses report witnessing **severe agitation** in the last 24 hours of life

- Terminal agitation can be the most distressing symptom witnessed by families and staff at the end of life
- Prevalence rises sharply in the final 24 to 48 hours
- Under recognition is common as hypoactive delirium can be mistaken for sedation and hyperactive delirium for pain

Hosie et al., Palliat Med, 2013; Moyer et al., Am J Hosp Palliat Care, 2011; Brajtman, Palliat Med, 2003

Pathophysiology and Contributing Factors

PHYSIOLOGIC

- Hypoxia / metabolic dysregulation
- Urinary retention, constipation, pain
- Drug toxicity / withdrawal
- Organ failure

NEUROLOGIC

- Central nervous system tumors / metastases
- Cerebrovascular disease
- Neurodegenerative disease
- High anticholinergic burden

PSYCHOLOGICAL

- Unresolved fear / existential distress
- Anxiety / trauma reactivation
- Depression with anxious distress
- Unfinished business

IATROGENIC & SOCIAL

- Opioid neuroexcitation / myoclonus
- Benzodiazepine paradox
- ICU environment / restraints
- Caregiver distress amplifying patient's

Impacts on **Patients**

- Cognitive Impairment
  - Unable to recognize loved ones, express needs, or engage in the psychological tasks of dying
  - Relational and meaning-making work of a good death is disrupted
- Loss of Agency/Dignity
  - Deprives patients of dying on their own terms
  - Restraints, rushed decisions, and environmental chaos can further erode dignity at life's end
- Geriatric Vulnerability
  - Older adults with cognitive impairment are at dramatically higher risk for terminal agitation
  - Anticholinergic burden, polypharmacy, and sensory deficits compound challenges
  - Delirium superimposed on dementia is especially refractory

Impacts on **Patients**

- Symptom Misattribution
  - Can impair efforts to correctly identify and treat contributing symptoms
- Physical Suffering
  - Can cause elevated heart rate, sweating, labored breathing, muscle twitching
  - Suffering may persist without ability to communicate it
- Undertreated Suffering
  - Clinician hesitation to use appropriate and proportional treatments due to concerns about hastening death or family misunderstanding
  - Can result in prolonged, preventable distress

Impact on **Care Partners & Families**

- Acute Distress
  - Witnessing agitation, combativeness, grimacing, or moaning activates threat responses, including trauma-like symptoms in observers
  - **83% of families report terminal agitation as the most distressing end of life event they witnessed**
- Care Partner Burden
  - Prolonged agitation correlates with care partner exhaustion, helplessness, and moral distress
  - Home hospice care partners bear a particularly high burden, managing agitation with support that may be limited and often without adequate preparation or education
- Grief
  - Traumatic end of life experiences, especially witnessing agitation and aggression, independently predict prolonged grief disorder and post-traumatic stress disorder (PTSD) in bereaved family members

Morita et al., J Pain Symptom Manage, 2004; Gagnon et al., Palliat Med, 2002; Brajtman, Palliat Med, 2003; Schulz et al., Gerontologist, 2007; Kissane et al., JCO, 2016

Assessment of Agitation & Confusion in the Seriously Ill

- **Richmond Agitation-Sedation Scale (RASS)**
  - **Bedside sedation/agitation level**
  - Widely validated in **ICU** settings
  - RASS-PAL for **palliative** settings
- **Confusion Assessment Method (CAM)**
  - **Delirium** screening tool
  - 94% sensitivity
  - CAM-ICU for **non-verbal** patients
- **Memorial Delirium Assessment Scale (MDAS)**
  - 10-item scale
  - Validated in **palliative** populations
  - Quantifies severity for titration

Example

A. Richmond Agitation-Sedation Scale, range -5 to +4

Scale	Label	Description	
+4	Combative	Violent, immediate danger to staff	OBSERVATION
+3	Very agitated	Pulls or removes tube(s) or catheter(s); aggressive	
+2	Agitated	Frequent non-purposeful movement, fights ventilator	
+1	Restless	Anxious but movements not aggressive, vigorous	
0	Alert and calm	Spontaneously pays attention to care giver	
-1	Drowsy	Not fully alert, but has sustained awakening (eye-opening/eye contact) to voice (>10 seconds)	VOICE
-2	Light sedation	Briefly awakens with eye contact to voice (<10 seconds)	
-3	Moderate sedation	Movement or eye opening to voice (but no eye contact)	
-4	Deep sedation	No response to voice, but movement or eye opening to physical stimulation	TOUCH
-5	Unarousable	No response to voice or physical stimulation	

Assessment of Agitation & Confusion in the Seriously Ill

- **Pain Assessment in Advanced Dementia (PAINAD)**
  - Useful for **pain** assessment in **non-verbal** or severely cognitively impaired patients
  - ***Critical to exclude pain as agitation driver***
- **Edmonton Symptom Assessment System (ESAS-r)**
  - **Patient-reported**
  - Captures agitation, anxiety, and **distress burden holistically**
- **Palliative Prognostic Index (PPI)**
  - Predicts **survival** in terminally ill patients based on five criteria
  - If the PPI is greater than 6.0, survival is less than three weeks (Sensitivity - 80%; Specificity - 85%)

Five behaviors are rated 0, 1 or 2 for score 0-10

PAINAD domains & 2-point examples

Behavior	2
Breathing independent of vocalization	• Noisy labored breathing • Long period of hyperventilation • Cheyne-Stokes respirations
Negative vocalization	• Repeated troubled calling out • Loud moaning or groaning • Crying
Facial expression	• Facial grimacing
Body language	• Rigid • Fists clenched • Knees pulled up
Consolability	• Unable to console, distract or reassure

Management: Engage & Assess

- Define Goals of Care
  - Is patient in final hours or days?
  - Are priorities comfort-focused vs continued disease-directed care?
- Identify Reversible Causes
  - Urinary retention, fecal impaction, drug toxicity/interactions, hypoglycemia, paradoxical disinhibition, uncontrolled pain
  - Treat first!
- Assess Suffering and Severity
  - Use RASS or MDAS
  - Involve nursing and care partners
  - Is patient visibly distressed?
  - Does agitation persist despite comfort measures?
- Engage Family and Team
  - Explain what agitation means and what it does not mean
  - Establish shared goals
  - Prepare for palliative sedation discussion if needed

Management: Non-Pharmacologic

FIRST-LINE for mild agitation and essential adjuncts at all stages…
…though frequently **underutilized**

ENVIRONMENTAL

- Quiet, familiar, dimly lit environment
- Consistent presences
- Avoid physical restraints
- Soft music, familiar voices, touch if tolerated

COMMUNICATION

- Calm, orienting statements
- Validate
- Reinforce that presence is therapeutic
- Limit number of people in room

SPIRITUAL/EXISTENTIAL

- Early chaplaincy involvement
- Life review and forgiveness facilitation
- Support meaningful rituals and practices
- Address unfinished business if patient able

CARE PARTNER SUPPORT

- Educate family/care partners
- Prepare for what dying looks & sounds like
- Give family a meaningful role
- Debrief care team after difficult deaths

Management: Pharmacologic

Agent	Class	Typical Dose / Route	Key Considerations
Haloperidol	Antipsychotic (typical)	0.5–2 mg IV/SC/PO q4–6h; PRN dosing	First-line for delirium-associated agitation at EOL; minimal anticholinergic; risk of QTc prolongation; low dose target in elderly
Chlorpromazine	Antipsychotic (typical)	12.5–50 mg IV/SC/PO q4–6h	More sedating than haloperidol; useful for severe refractory agitation; included in palliative sedation protocols
Olanzapine	Antipsychotic (atypical)	2.5–5 mg SL/PO/IM q6–8h	Useful for agitation + nausea; avoid in severe hepatic impairment; sublingual route ideal for imminently dying
Lorazepam	Benzodiazepine	0.5–2 mg IV/SC q2–4h PRN	Adjunct to antipsychotic; can cause paradoxical agitation in elderly/dementia; useful for alcohol/BZD withdrawal or refractory cases
Midazolam	Benzodiazepine	2.5–5 mg SC/IV; continuous infusion 1–5 mg/hr	Preferred agent for palliative sedation; short-acting but accumulates; titrate to RASS/comfort target
Phenobarbital	Barbiturate	60–200 mg SC/IV; continuous infusion	Refractory terminal agitation unresponsive to BZD; deepest level of sedation available in hospice setting

Agar et al., JAMA IM, 2017; Hui et al., Lancet Oncol, 2020

Palliative Sedation for Refractory Agitation

- Intentional reduction of consciousness to relieve refractory suffering that cannot be controlled by other means
- **Distinct from euthanasia as the intent is comfort, not death;** supported ethically by the principle of double effect and European Association of Palliative Care guidelines

INDICATIONS

- Refractory terminal agitation
- Death expected within hours to days
- Patient/surrogate consent after informed discussion
- Goals of care clearly aligned with comfort focus
- Multidisciplinary team consensus achieved

COMMUNICATION & TEAM PLAN

- Clearly distinguish from euthanasia
- Communicate that sedation alleviates suffering
- Document goals, family meeting, & clinical rationale
- Offer ethics consult for complex or contested cases
- Plan for team debriefing

TREATMENT PLAN

- Midazolam 2.5–5 mg SC/IV bolus, then infusion 1–5 mg/hr; titrate to RASS –2 to –3
- Phenobarbital 60–200 mg SC/IV if benzodiazepine refractory
- Chlorpromazine as alternative (less respiratory depression)
- **Continue opioids for pain/dyspnea** — do NOT abruptly discontinue
- Reassess q1–4 hrs; document clinical intent and response clearly

Cherny et al., Palliat Med, 2009; EAPC Guidelines; NHPCO Guidelines; Beller et al., CDSR, 2015

Conclusions

- Terminal agitation affects the **majority** of dying patients and is **profoundly distressing** for patients, families, and clinicians
- It is frequently **unrecognized** and **misdiagnosed**
- A **structured**, **multi-faceted** approach is essential
  - Ruling out reversible causes, rating severity, & engaging and educating care partners prevents both under- and over-treatment
  - Non-pharmacological treatment is first line
  - Judicious use of pharmacotherapies including palliative sedation
- **Older adults require a specialized lens** considering pre-existing dementia, polypharmacy, drug-disease interactions, and altered pharmacokinetics
  - Geriatric psychiatry is a meaningful consultative partner in these complex cases
- **Impact on families is significant** -- a key driver of prolonged grief disorder and post-traumatic stress disorder (PTSD)
  - **Our treatment of a patient's suffering simultaneously protects the bereaved**

Comments? Questions?

Thank you!

CARING FOR LEGAL SYSTEM-INVOLVED PATIENTS AT THE END OF LIFE

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University of Vermont Medical Center
Department of Palliative Medicine
Department of Emergency Medicine

Palliative ECHO - May 5, 2026

LEARNING OBJECTIVES

1. Identify the unique challenges that face people who are incarcerated at end of life
2. Consider the unique psychosocial concerns that impact legal-system involved patients
3. Reflect on what we can do in the palliative community to care for this vulnerable population

THE WORDS WE USE MATTER

HOW SHOULD WE DESCRIBE PEOPLE HELD IN CORRECTIONAL FACILITIES

Preferred:

- Legal-System Involved
- Incarcerated individual
- Person who is in prison

Mixed feelings:

- Justice Involved
- Prisoner

Avoid:

- Felon
- Convict
- Inmate
- Offender

Person first language → Defines people by their crime

"What Words We Use – and Avoid – When Covering People and Incarceration." A. Solomon. The Marshall Project.

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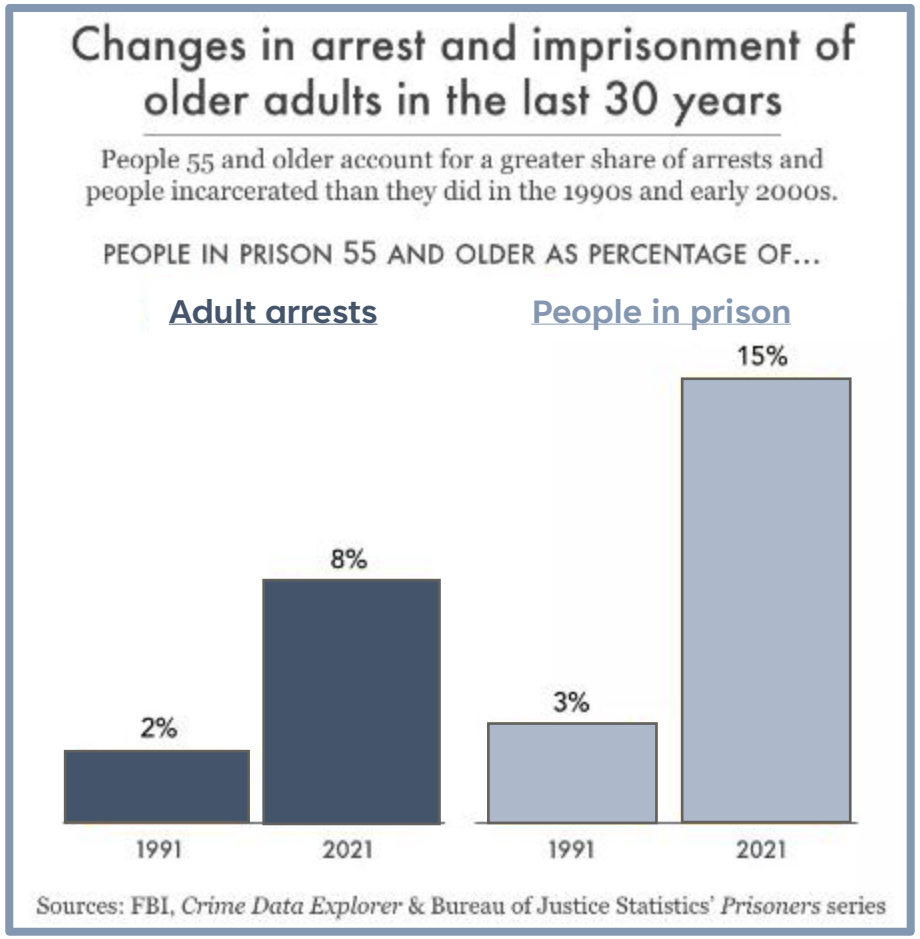
LEGAL-SYSTEM INVOLVED PATIENTS FACE UNIQUE CHALLENGES AS THEY NEAR END OF LIFE

THE U.S. PRISON POPULATION IS RAPIDLY AGING



- **By 2030 the number of incarcerated older adults will exceed 400,000**

  → Increased number serving a life sentence or life without parole

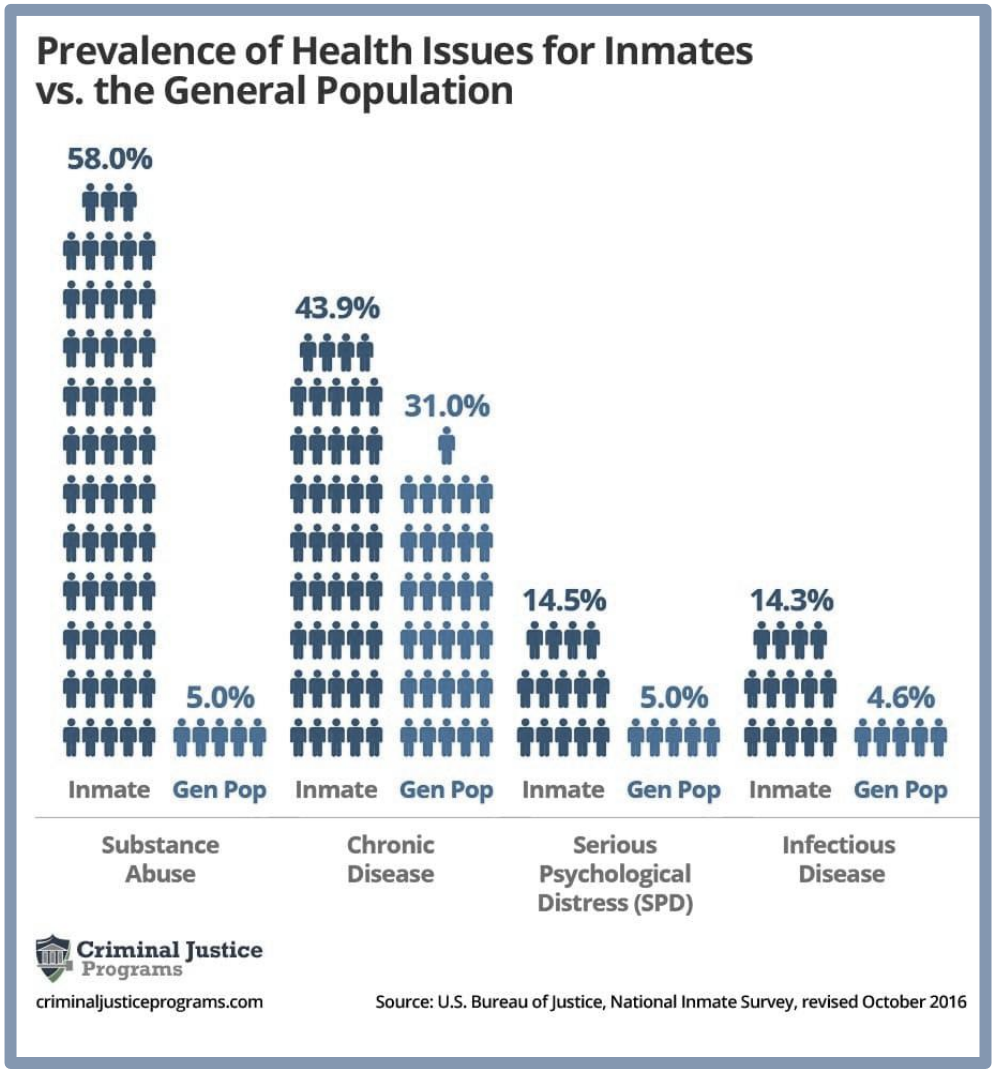
  →Less parole approval

  →Underutilization of compassionate release

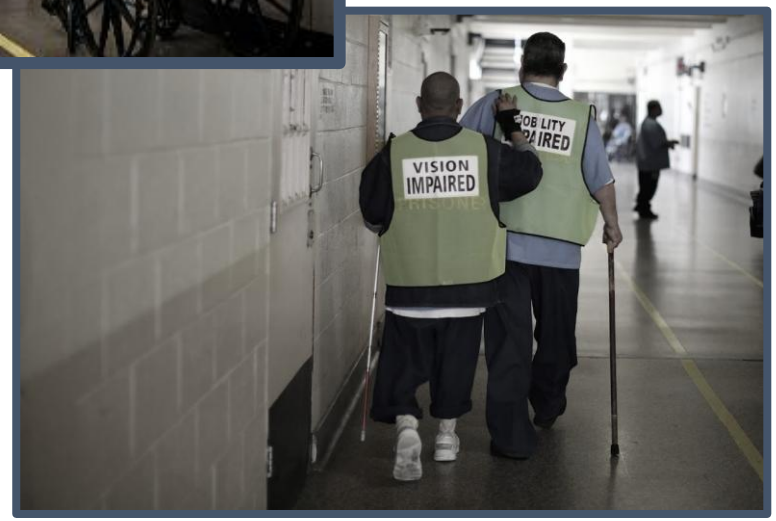
- **The system is not logistically or financially equipped to care for older adults**

UpToDate. "Palliative care for incarcerated adults" https://www.uptodate.com/

CHRONIC ILLNESS ACCOUNTS FOR 90% OF DEATHS IN PRISON



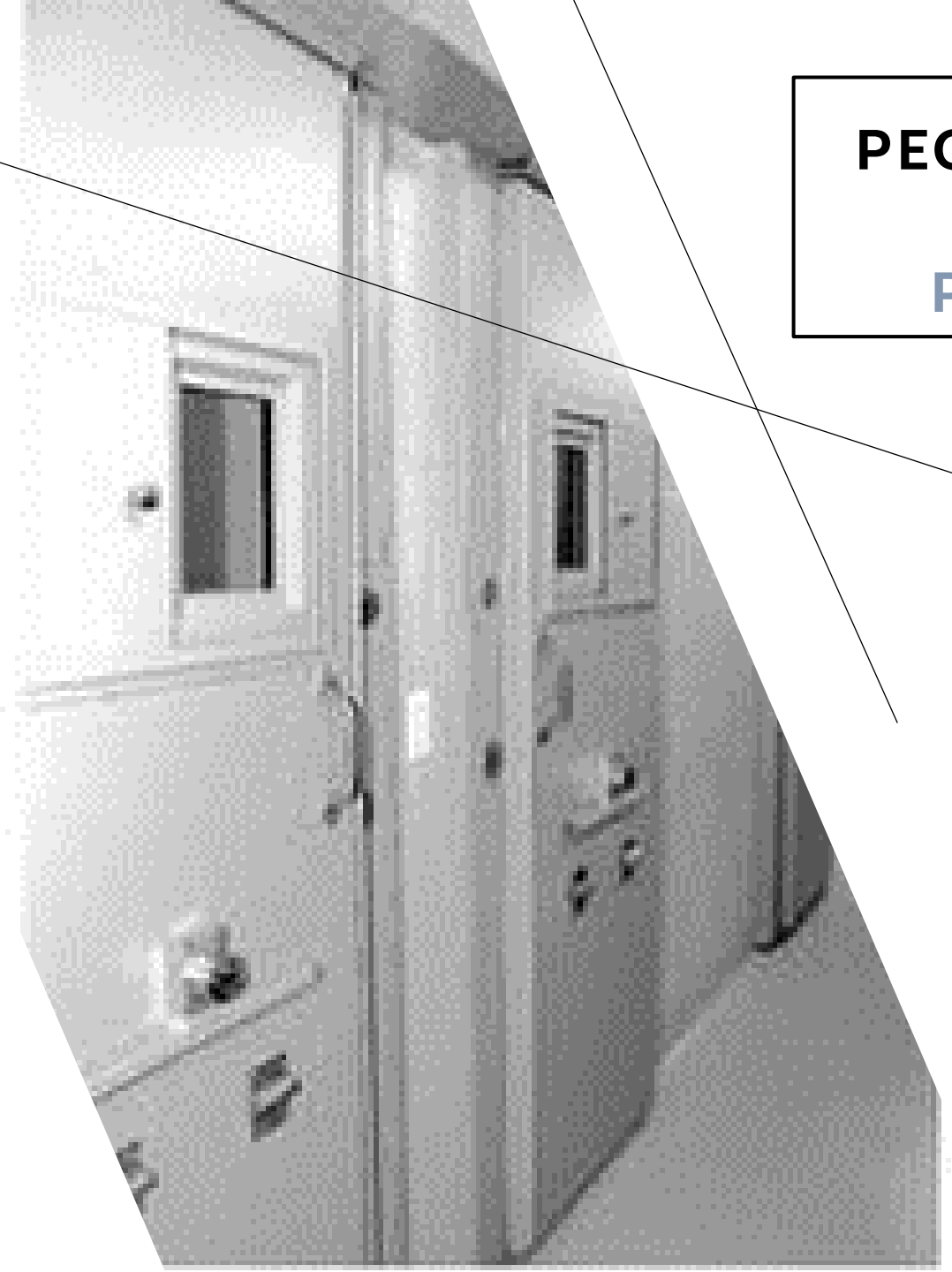
INDIVIDUALS EXPOSED TO INCARCERATION EXPERIENCE A "PHENOMENON OF ACCELERATED AGING"



- Every year an individual is incarcerated is associated with a 2-year reduction in life expectancy

- Early functional decline limits ability to participate in "Prison ADLs" (Activities of Daily Living)

UpToDate. "Palliative care for incarcerated adults" https://www.uptodate.com/.



PEOPLE WHO ARE INCARCERATED FACE INCREASED BARRIERS TO PALLIATIVE CARE AND RESOURCES

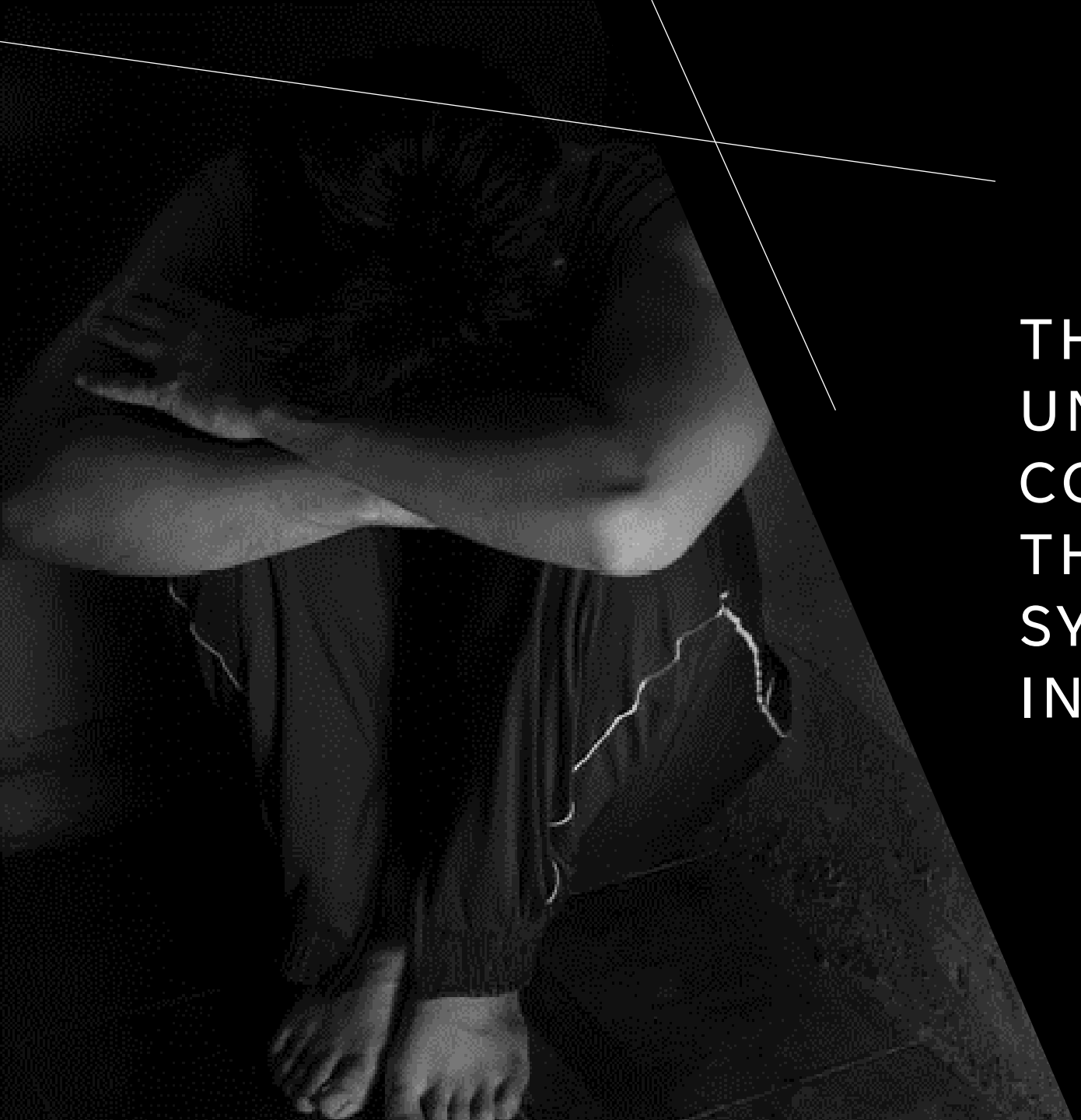
- Lack of access to **palliative care specialists**
- Lack of access to **medications**
  - Cost of medications
  - Limited use of “as needed” (PRN)
- Lack of access to **additional support**
  - Spiritual care, support groups for grief and loss, psychotherapy
- Lack of access to **basic health care**
  - Physical and emotional barriers
  - Financial barriers

THE COST OF CARE

- Copays are a significant portion of pay
  - People in prison earn on avg between $0.86 and $3.45 per day, copays can be as high as $20
- Medicare and Medicaid funds **DO NOT** pay for medical services for incarcerated patients
- “Medicaid Inmate Payment Exclusion” exists

Cost of care lies with the correctional facility

Medicaid for Incarcerated Individuals. https://www.congress.gov



THERE ARE UNIQUE PSYCHOSOCIAL CONCERNS THAT IMPACT LEGAL-SYSTEM INVOLVED INDIVIDUALS

Unique Psychosocial Concerns

Loss of Autonomy: Lack of perceived control to achieve end of life goals, or make decisions

Loss of Life and Freedom: Sense of loss due to liberty, denial of parole, family connections

Trauma-informed care: History of trauma, exposure to childhood adverse events, discrimination, violence

Lack of Trust: In correctional facility system and health care system

UpToDate. “Palliative care for incarcerated adults” https://www.uptodate.com/.

WE RECOGNIZE THAT PRISONER'S RIGHTS ARE HUMAN RIGHTS

- **<u>Prisoners have the right to:</u>**
  - **Adequate health care** while incarcerated
  - **Protect** their private health information (PHI)
  - **Make their OWN health care decisions**
  - **Surrogate decision maker,** if they cannot make their own decisions

COMMON SITUATIONS THESE RIGHTS MAY BE CHALLENGED:

- Advanced Care Planning
- Surrogate Decision Makers
- Protected Health Information (PHI)
- Decision to pursue comfort measures only (CMO)
- Code Status Discussions

Scopes and Shields.
https://www.scopesandshields.org/

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ROLE OF COMPASSIONATE RELEASE

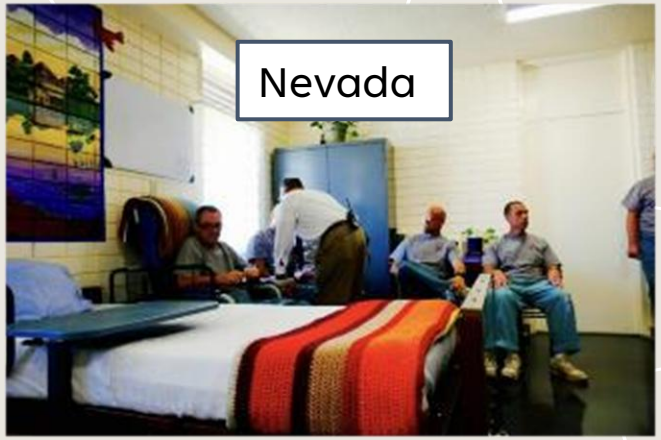
- What is it?
  - **Reduction in term or early release due to terminal illness or debilitating disease**

- Why isn't it used?
  - **Federal and State criteria are complex**
  - **Approval rate is very low (*6-14%)**

Note: Do Not Resuscitate/Do Not Intubate code status is NOT required nor is Comfort Measures Only

WHAT DOES END-OF-LIFE CARE LOOK LIKE IN A **PRISON HOSPICE PROGRAM**?

NATIONWIDE THERE ARE **ABOUT 75 HOSPICE PROGRAMS** BEHIND BARS

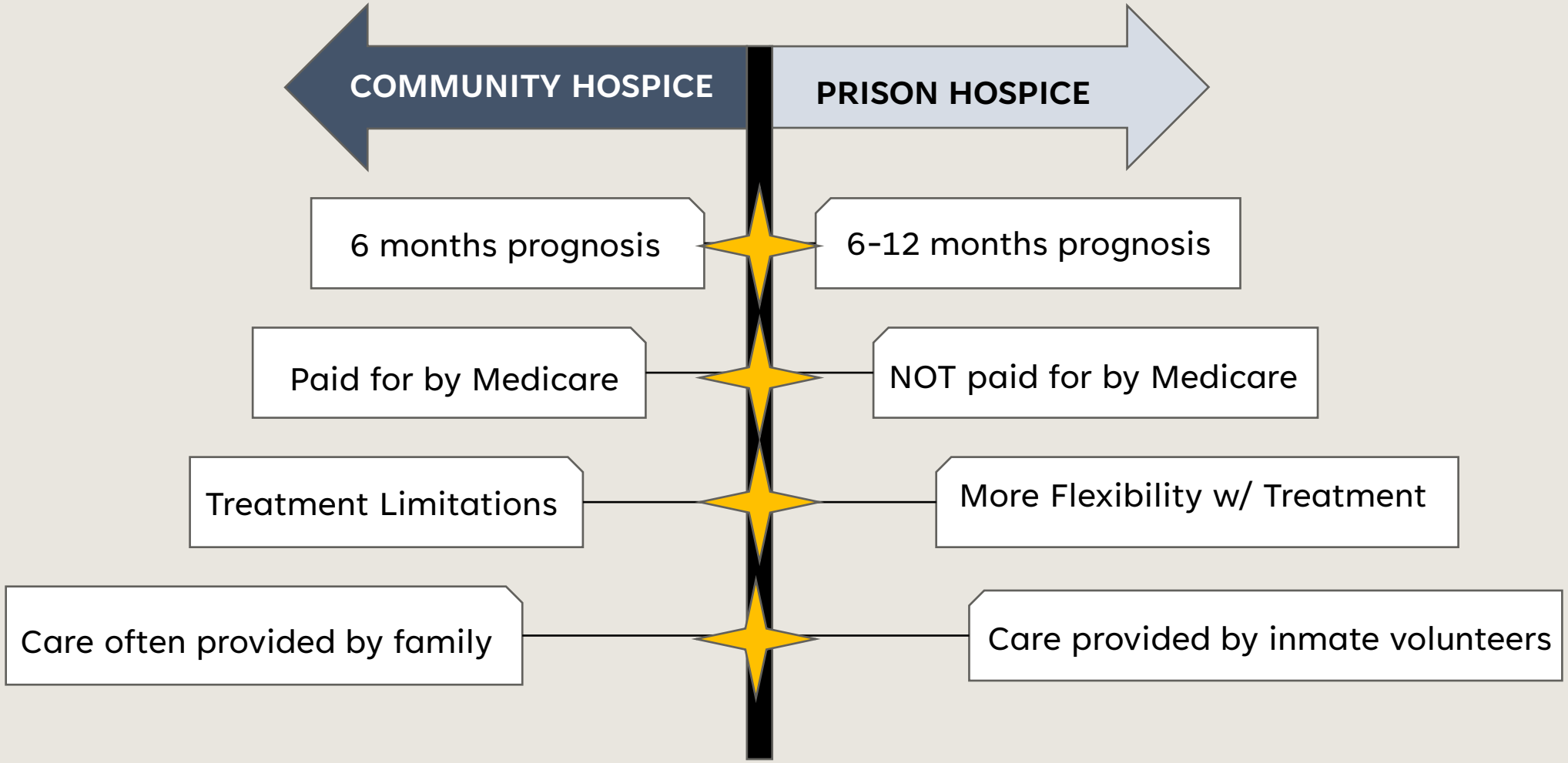


"Death and redemption in prison. " NPR Shots: health news from NPR. February 18, 2024

PRISON SYSTEMS IN NEW ENGLAND HAVE VARYING DEGREES OF HOSPICE CARE AVAILABLE

- **Maine:** state prison has a successful hospice program and drawn national attention as the U.S. prison population ages
- **New York:** Mohawk-Walsh is a regional prison facility with 21 hospice beds
- **Rhode Island:** one of the few states with effective compassionate release programs in place
- **Vermont and New Hampshire**: both offer hospice as part of the medical care afforded to prisoners

COMMUNITY HOSPICE AND PRISON HOSPICE HAVE KEY DIFFERENCES



UpToDate. "Palliative care for incarcerated adults" https://www.uptodate.com/.

GeriPal Podcast. "Hospice in Prison: Part I"

PEER VOLUNTEERS PLAY AN IMPORTANT ROLE

- Prisoners go through training to become **peer volunteers and care partners**
- Participate as part of an **interdisciplinary team**
- Training in **“therapeutic – non medical care”** at end of life, such as vigil volunteers
- Part of a growing movement to **humanize end-of-life** care behind bars

UpToDate. “Palliative care for incarcerated adults” https://www.uptodate.com/.
GeriPal podcast “Hospice in Prison: Part II”
“We carry a light”: Inmates at Shawnee Corrections Center care for the prisoners dying..
https://thesouthern.com/news/local/we-carry-a-light-inmates-at-shawnee-correctional-center-care/article_cad783ab-53b2-52cd-a5fb-c8417724e39c.html?mode=nowapp

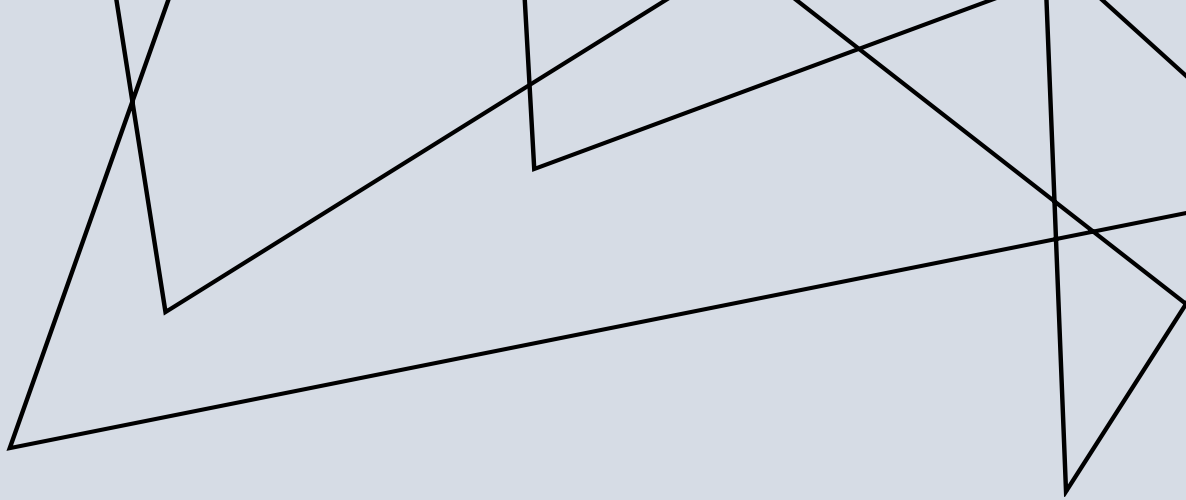
The New York Times Magazine THE HEALTH ISSUE

"The workers make a point not to find out what the patients have done. They worry that knowing too much could affect the quality of care. When a patient's past sins cross over into the realm of the horrific, it can be hard to keep creeping judgments and questions at bay. How do you reconcile the dissonance between the serial killer and the elderly patient, bedridden, incontinent and lost in the fog of dementia? The workers are also in prison for crimes, but that doesn't make them immune to judgment. "Death can be an equalizer." The past falls aside. Time is grounded in the shifting demands of the body as it begins its decay."

"The Prisoners who care for the dying and get another chance at life."
- By Suleika Jaquad. May 16, 2018

WHAT CAN WE DO
TO PROVIDE EQUITABLE AND THOUGHTFUL CARE TO LEGAL-SYSTEM INVOLVED PATIENTS?

- Use a **nonjudgemental and curious** approach to care
- Recognize the **unique psychosocial challenges** impacting this population when discussing Goals of Care
- **Advocate** for legal system involved individuals
- Be **mindful of implicit or explicit bias**



THANK YOU