Dartmouth Health

Project ECHO®

WELCOME to
Palliative Care ECHO 4.0

Improving Care for those with Serious Illness

October 2024 – June 2025

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Trauma-Informed Approach to Serious Illness

Sarah E. Guarda, MSW, LICSW

Palliative Care Echo Session #1 October 1, 2024

Learning Objectives

By the end of this session, ECHO participants will be able to:

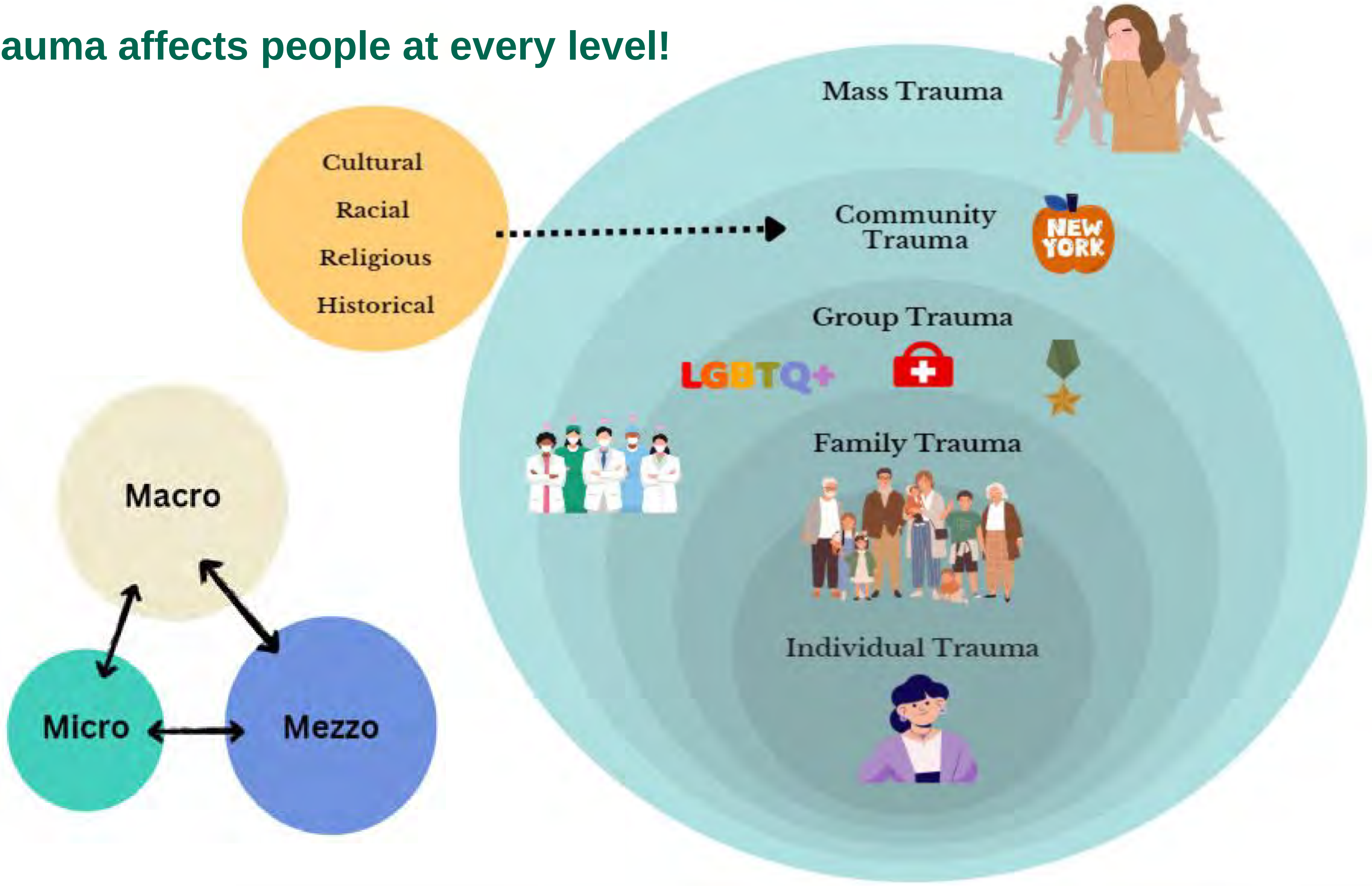
- Define trauma and identify trauma responses in our patients
- Demonstrate a trauma-informed approach to assessment, communication, and interaction with our patients
- Reflect on strategies to be a more trauma-informed provider

The "3 E's" of trauma: **event(s)** that someone **experiences** as harmful and have adverse **effects** on wellbeing.

Physical
Interpersonal
Psychological
Social
Wellbeing
Developmental
Spiritual
Economic
Environment

EVENTS → EXPERIENCES → EFFECTS

Trauma affects people at every level!



Cultural

Racial

Religious

Historical

Mass Trauma

Community Trauma

Group Trauma

Family Trauma

Individual Trauma

Macro

Micro

Mezzo

TRAUMA CAUSES PHYSICAL AND MENTAL ILLNESS.

EMOTIONAL & INTERPERSONAL

- **Depression & anxiety**
- Difficulty trusting others
- Difficulty regulating emotions
- Withdrawal from family, friends, & community

BEHAVIORAL

- **Substance use & abuse**
- Self-destructive behaviors
- Impulsivity
- Avoidance of situations, people, & places

PHYSICAL

- **Hyperarousal (muscle tension and insomnia)**
- Headaches, high blood pressure, fatigue
- Increased risk of cardiovascular issues, diabetes, cancers

COGNITIVE

- **Decreased concentration**
- Changes in brain development
- Impaired speech & language
- Impaired memory
- Dissociation

SPIRITUAL

- **Feelings of abandonment, betrayal, & loss of faith**
- Existential distress
- Can also result in renewed faith or spirituality

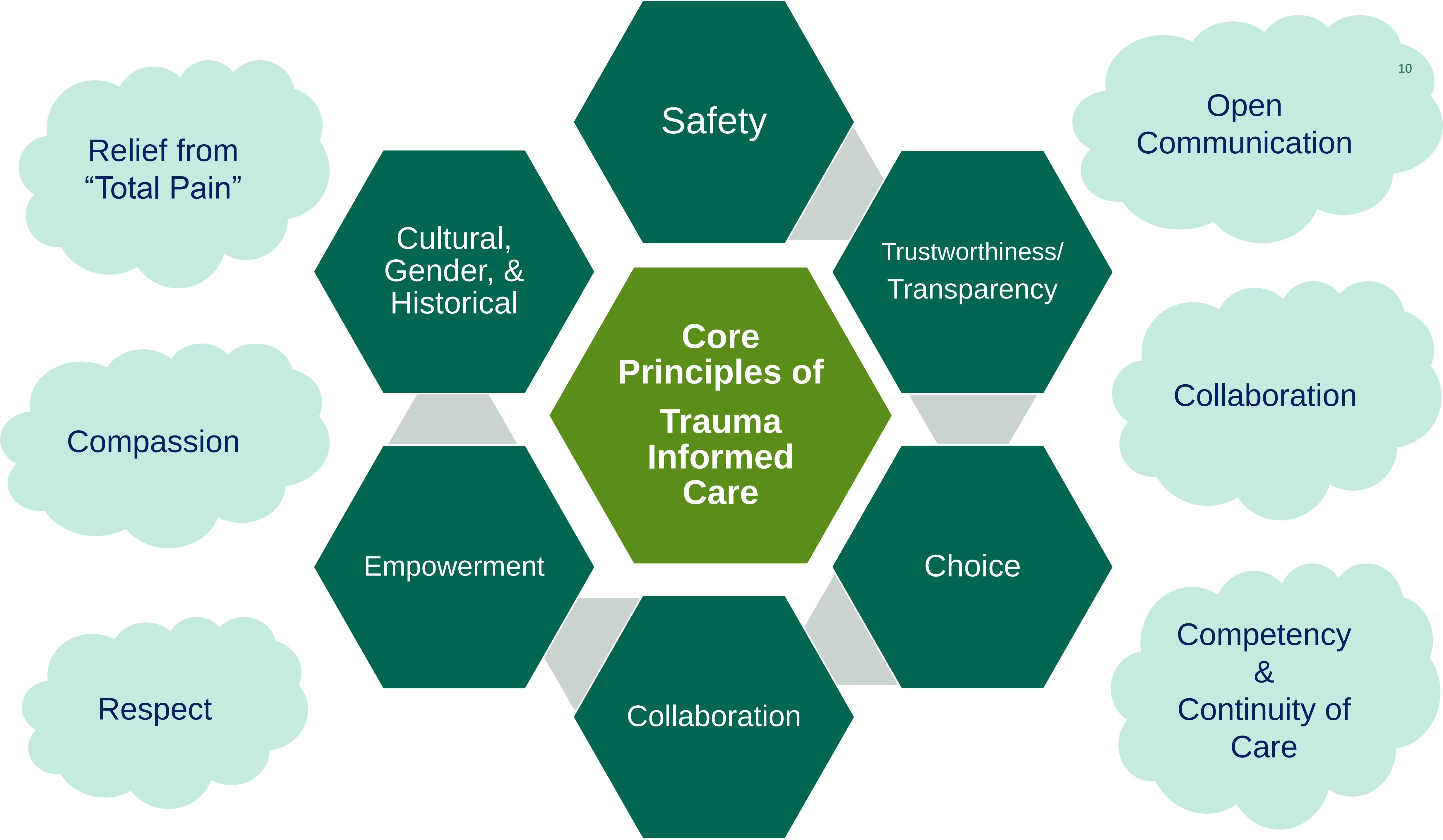
Trauma-informed approach is defined as:

"a strengths based service delivery approach that is grounded in an understanding of and responsiveness to the impact of trauma, that emphasizes **physical, psychological, and emotional safety** for both providers and survivors to rebuild a sense of control and empowerment."

SAMHSA
Substance Abuse and Mental Health Services Administration

Trauma informed care **empowers** palliative providers to be their most effective.

- Trauma informed care is accessible
- Palliative philosophy aligns with trauma informed care
- Holistic and person-centered
- Improves positive patient and provider outcomes
- Fosters connection through individualized approach
- Prevents re-traumatization
- Supports pain management



Core Principles of Trauma Informed Care

Safety

Trustworthiness/ Transparency

Choice

Collaboration

Empowerment

Cultural, Gender, & Historical

Relief from "Total Pain"

Compassion

Respect

Open Communication

Collaboration

Competency & Continuity of Care

Ask questions to assess an individual’s trauma history.

- Childhood and Family experiences
- Distressing Events
- Triggers and Unsafe Situations
- Losses and Bereavements
- Coping & Resilience
- Privacy and Confidentiality

“What can our team do today to help you feel safe?”

Use **empathy**, **reassurance**, and **sensitivity** when responding to disclosures of trauma.

- “I appreciate the courage it took to share that with me.”
- “Thank you for trusting me enough to share these experiences today.”
- “I wish that you had not been harmed/betrayed/hurt.”
- “Please know that you deserve support.”
- “You deserve to be safe.”
- “I will keep these details private unless you tell me otherwise.”
- “What can we do to help you feel safe while receiving care?”
- “How would you like me to document this information?”

Establish **physical**, **psychological**, and **emotional safety** first.

- Share preferred name and pronouns
- Determine how individuals prefer to receive medical information
- Limit jargon and avoid the “righting reflex”
- Be curious, ask clarifying questions, ask for feedback
- Mirror affect and match your patient’s energy
- Respect boundaries and preferences, be mindful of known triggers
- Offer genuine validation and affirm patient experiences
- Be mindful of touch and personal space (don’t block the door!)
- Watch for discomfort or distress- have tissues handy!

Self-care is essential to being a resilient and empathic provider.

Closing Reflections:

What is **one** thing you will do differently to incorporate a **trauma-informed approach** while caring for people living with serious illness?

Please type your answers in the chat!

Dartmouth
Health

Thank you!

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- Van Der Kolk, B. (2014). ***The body keeps the score: Brain, mind, and body in the healing of trauma***. New York: Viking.

Palliative Medicine
in the
Emergency Department

Phil Lawson MD
November, 2024

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Objectives

1. Recognize challenges of care in Emergency Departments (ED)
2. List ways to adjust and apply palliative interventions to the ED setting
3. Cite tools to assist ED providers in improving palliative care in the ED

Case:

- 84 yo comatose female brought to Critical Access Hospital GCS = 3
- AD's, POLST, P-DNR not with patient on arrival
- Intubated in ED with lines and tubes….
- Bilateral cerebral hemorrhage (brain bleed) -> call to neurosurgery -> helicopter on the way
- Friend arrives horrified stating she would never want this

GCS = Glascow Coma Scale; AD = Advance Directive; POLST = Portable Medical Order; DPOAH = Durable Power of Attorney for Healthcare

Best Practice Goals ED providers

Best Practice palliative care per ACEP includes:

1. Screening and assessing patients for palliative care needs
2. Managing patients with palliative care needs in the Emergency Department (ED)
3. Consulting palliative care specialists in/from the ED
4. Transitioning palliative care or hospice eligible patients from the ED

ACEP: American College of Emergency Physicians

Loffredo A et al. ***United States Best Practice Guidelines for Primary Palliative Care in the Emergency Department.*** Annals of Emergency Medicine Vol 78(5), Nov 2021, 658-669

Realities of the Venue

- Rapid Triage
- Variable wait times for care
- Focus is on the presenting complaint
  - Rule out what is life/limb threatening
  - Make a tentative diagnosis based on limited available information
  - Achieve disposition rapidly*

Realities of the Venue

- Loud, limited privacy, limited comfort
- Frequently interrupted patient/provider time
- Limited (sometimes no) available medical information
- Extensive testing (for the "rule out")
- A culture of "If in doubt, intervene…"

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Conclusions from recent research

CPR on cancer patients in the ED

- Advance Directives (AD’s) associated with:
  - Quicker adjustment to DNR status
  - Shorter ICU stay
  - Shorter hospital stay
  - No difference in mortality

Wechsler AH et al. Prior Advanced Care Planning and Outcomes of CPR in the ED of a Comprehensive Cancer Center. *Cancers* **2024**, *16*(16), 2835; https://doi.org/10.3390/cancers16162835

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Recent Research


Advance Care Planning Guide

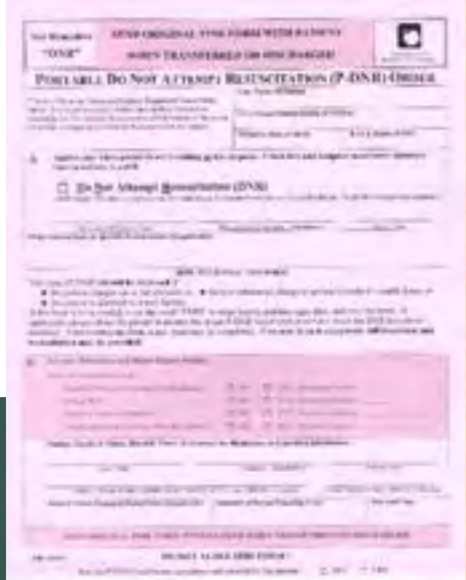

New Hampshire Advance Directive Form

Advance Directives (AD’s) are not available

- 20-25% reported having AD’s; 7% available
- High variance amongst ED’s: 1 - 48% had any form of AD’s available

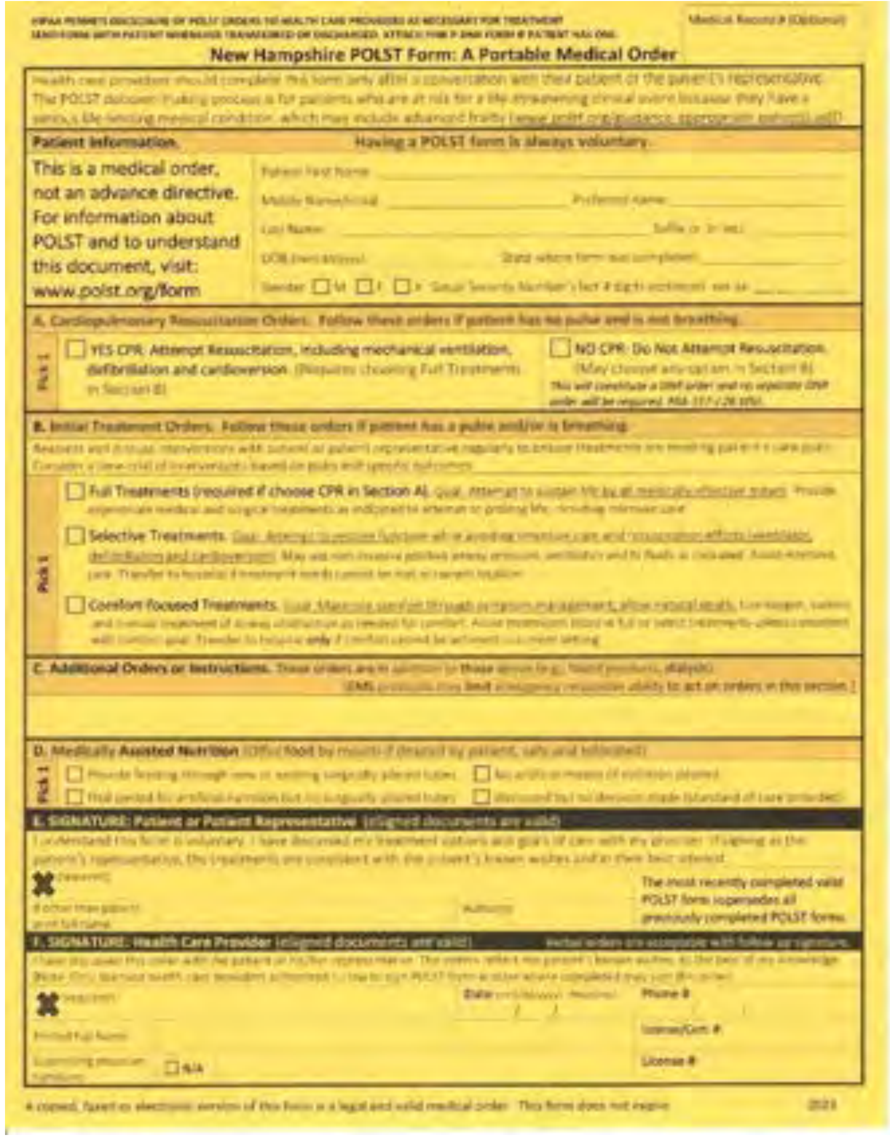
Patients and providers don’t talk about AD’s/goals of care in the ED

- @10% of elderly ill patients in ED are asked about AD’s
- @80% thought ED providers should be aware
- <40% expressed desire to discuss goals of care


Portable Do Not Attempt Resuscitation (P-DNR) Order

*References in chat

What PC Providers can offer the ED



New Hampshire POLST Form: A Portable Medical Order

Patient Information. Having a POLST form is always voluntary.

This is a medical order, not an advance directive. For information about POLST and to understand this document, visit: www.polst.org/form

A. Cardiopulmonary Resuscitation Orders. Follow these orders if patient has no pulse and is not breathing.

Pick 1

☐ **YES CPR: Attempt Resuscitation, including mechanical ventilation, defibrillation and cardioversion.** (Requires choosing Full Treatments in Section B)

☐ **NO CPR: Do Not Attempt Resuscitation.** (May choose any option in Section B)

B. Initial Treatment Orders. Follow these orders if patient has a pulse and/or is breathing.

Pick 1

☐ **Full Treatments (required if choose CPR in Section A).**

☐ **Selective Treatments.**

☐ **Comfort-focused Treatments.**

C. Additional Orders or Instructions.

D. Medically Assisted Nutrition

Pick 1

☐

☐

☐

☐

E. SIGNATURE: Patient or Patient Representative (eSigned documents are valid)

The most recently completed valid POLST form supersedes all previously completed POLST forms.

F. SIGNATURE: Health Care Provider (eSigned documents are valid)

Date

Phone #

License/Cert #

License #

☐ N/A

- Out of hospital arrest
- Goal concordant vs goal discordant care
- POLST as a starting place in the ED

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What PC Providers can offer the ED

New Hampshire Forms

Advance Care Planning Guide

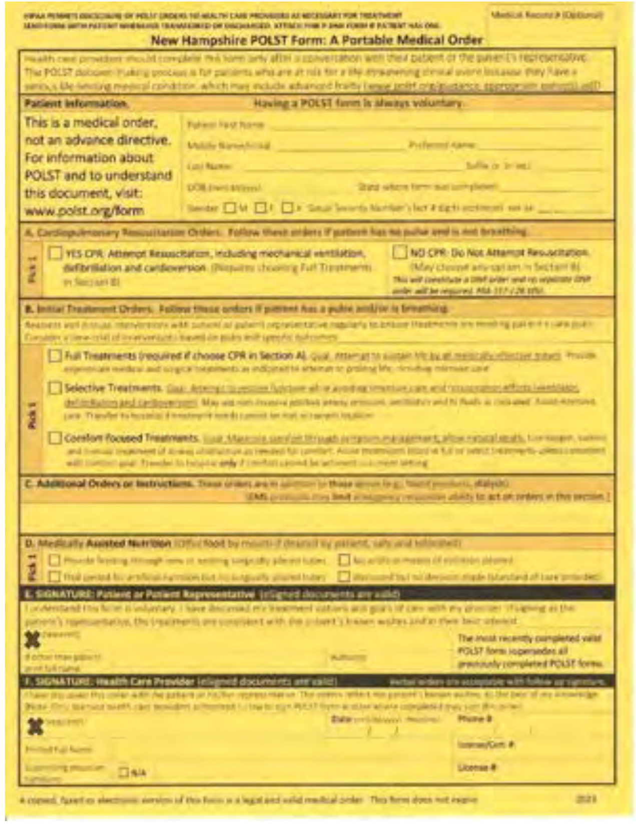
Foundation for Healthy Communities

New Hampshire Advance Directive Form

DOB:

I. DURABLE POWER OF ATTORNEY FOR HEALTH CARE

A. Choosing Your Agent:



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B. Initial Treatment Orders. Follow these orders if patient has a pulse and/or is breathing.

☐ Full Treatments (required if choose CPR in Section A).

☐ Selective Treatments.

☐ Comfort-focused Treatments.

C. Additional Orders or Instructions.

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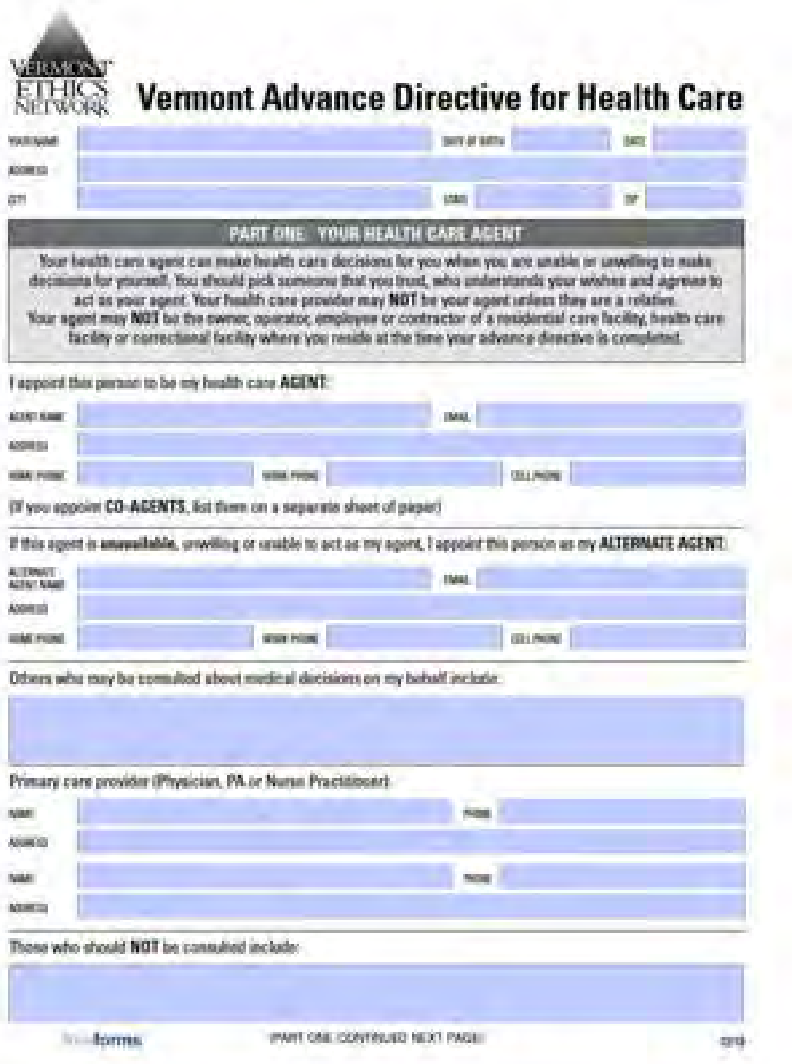
What PC Providers can offer the ED



Vermont Advance Directive for Health Care

PART ONE YOUR HEALTH CARE AGENT

Your health care agent can make health care decisions for you when you are unable or unwilling to make decisions for yourself. You should pick someone that you trust, who understands your wishes and agrees to act as your agent. Your health care provider may **NOT** be your agent unless they are a relative. Your agent may **NOT** be the owner, operator, employee or contractor of a residential care facility, health care facility or correctional facility where you reside at the time your advance directive is completed.

I appoint this person to be my health care **AGENT**:

(If you appoint **CO-AGENTS**, list them on a separate sheet of paper)

If this agent is **unavailable**, unwilling or unable to act as my agent, I appoint this person as my **ALTERNATE AGENT**:

Others who may be consulted about medical decisions on my behalf include:

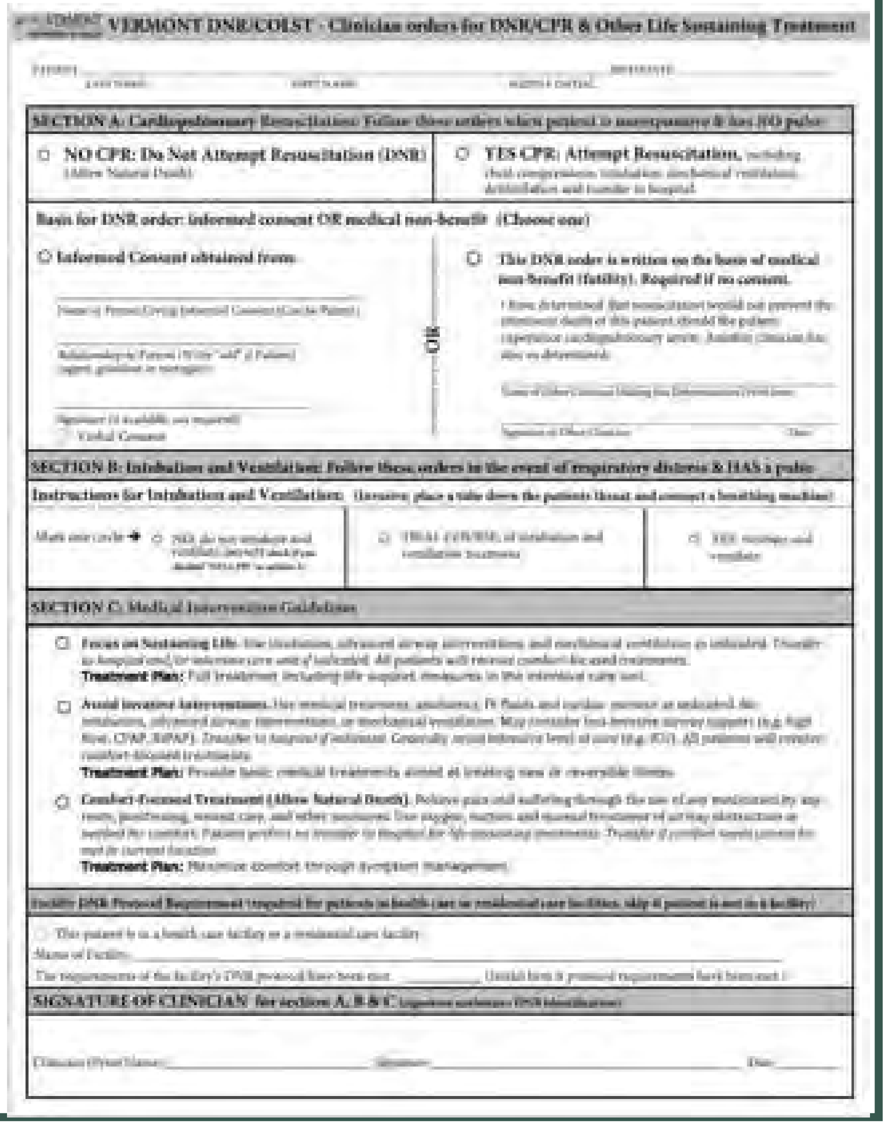
Primary care provider (Physician, PA or Nurse Practitioner):

Those who should **NOT** be consulted include:

(PART ONE CONTINUED NEXT PAGE)

Vermont Forms

- Short Form
- Long Form
- Registry
- COLST



VERMONT DNR/COLST - Clinician orders for DNR/CPR & Other Life Sustaining Treatment

SECTION A: Cardiopulmonary Resuscitation: Follow these orders when patient is unresponsive & has NO pulse

○ **NO CPR: Do Not Attempt Resuscitation (DNR)** (Allow Natural Death)

○ **YES CPR: Attempt Resuscitation,**

Basis for DNR order: informed consent OR medical non-benefit (Choose one)

○ **Informed Consent obtained from:**

OR

○ **This DNR order is written on the basis of medical non-benefit (futility). Required if no consent.**

SECTION B: Intubation and Ventilation: Follow these orders in the event of respiratory distress & HAS a pulse

Instructions for Intubation and Ventilation:

SECTION C: Medical Intervention Guidelines

☐ **Focus on Sustaining Life:**

Treatment Plan:

☐ **Avoid Invasive Interventions.**

Treatment Plan:

○ **Comfort-Focused Treatment (Allow Natural Death).**

Treatment Plan:

SIGNATURE OF CLINICIAN for sections A, B & C

What ED Providers need

- Respond immediately to requests for help
- Focus response with information that is:
  - “Need to know”
  - “Immediately actionable”
- Give very specific, focused recommendations
- Assure appropriate follow up

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Tools and Scripts

- **Opioid Equivalence Tools**
- **Early Hospice Referral**
  - Tools to address hospice qualifiers: LCD’s
- **Transferable Medical Orders**
  - POLST: NH form
  - P-DNR form (Pink Portable) + card
- **Communication Skills Training**
  - Serious Illness Conversation Trainings, VITALtalk
- **System based and Quality Tools**
  - Center for Advancement of Palliative Care
  - American College of Emergency Physicians Toolkit

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Scripts: Our "surgical" Skills

What not to say	What might be more appropriate
"Do you want everything done?"	"This is a medical procedure that has risks and benefits. Let me briefly go through them with you"
"Do you want me to try to keep you alive?"	Review best possible, worst possible and expected outcomes
"You are not getting enough oxygen; do you want me to put a tube down to help you breath?"	"We are considering putting you on a breathing machine, but I am worried about what might happen to you if we do; and we have options to help your breathing…"
"Do you want us to try to revive you if your heart stops?"	"I want to make sure we treat you the way you want to be treated if your condition gets worse. CPR is an option that has risks for you….."

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Communication Tools

Best Possible

- "Alive hooked up to machines for at least a few days, and then a long rehabilitation likely in a nursing home; best possible outcome being a condition not as good as you have recently been"

Worst Possible

- "A prolonged dying process with suffering on machines"

Expected Outcomes

- "I think there is a chance you might survive, but I am worried that if you do, you will have to spend the rest of your life receiving extensive care from others, maybe in a nursing home"

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What PC Providers can offer the ED

Approaches to talk about CPR, intubation and life-sustaining care

- *“Miracles*… can occur no matter what type of medical care you choose”

- *Wish/ Worry/ Wonder*
    - “I wish we could get you *…. back home and independent*”
    - “I worry this could lead to … *a prolonged time of suffering on machines until your death*”
    - “I wonder if you might prefer… *a focus on comfort; allowing your natural death when it occurs?*”

- *Time Limited Trials*
    - If we choose to intervene what will success look like?
    - When should we reassess to see if we have reached that goal?

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Reasonable CPR outcome data

Location and Original setting/function	Survival to Discharge from Hospital	Survival with ‘good’ neurologic outcome
Hospital Monitored, High Functional Status	50-60% (1 in 2)	30-50% (1 in 2-3)
Hospital overall	15-25% (1 in 4-5)	10-15% (1 in 10-15)
Outpatient/ In hospital with cancer	10-15% (1 in 7-10)	5-8% (1 in 15-20)
Nursing Home	2-4% (1 in 25-50)	1-2% (1 in 50-100)
Frailty	1-4% (1 in 25-100)	< 1-2% (< 1 in 50-100)

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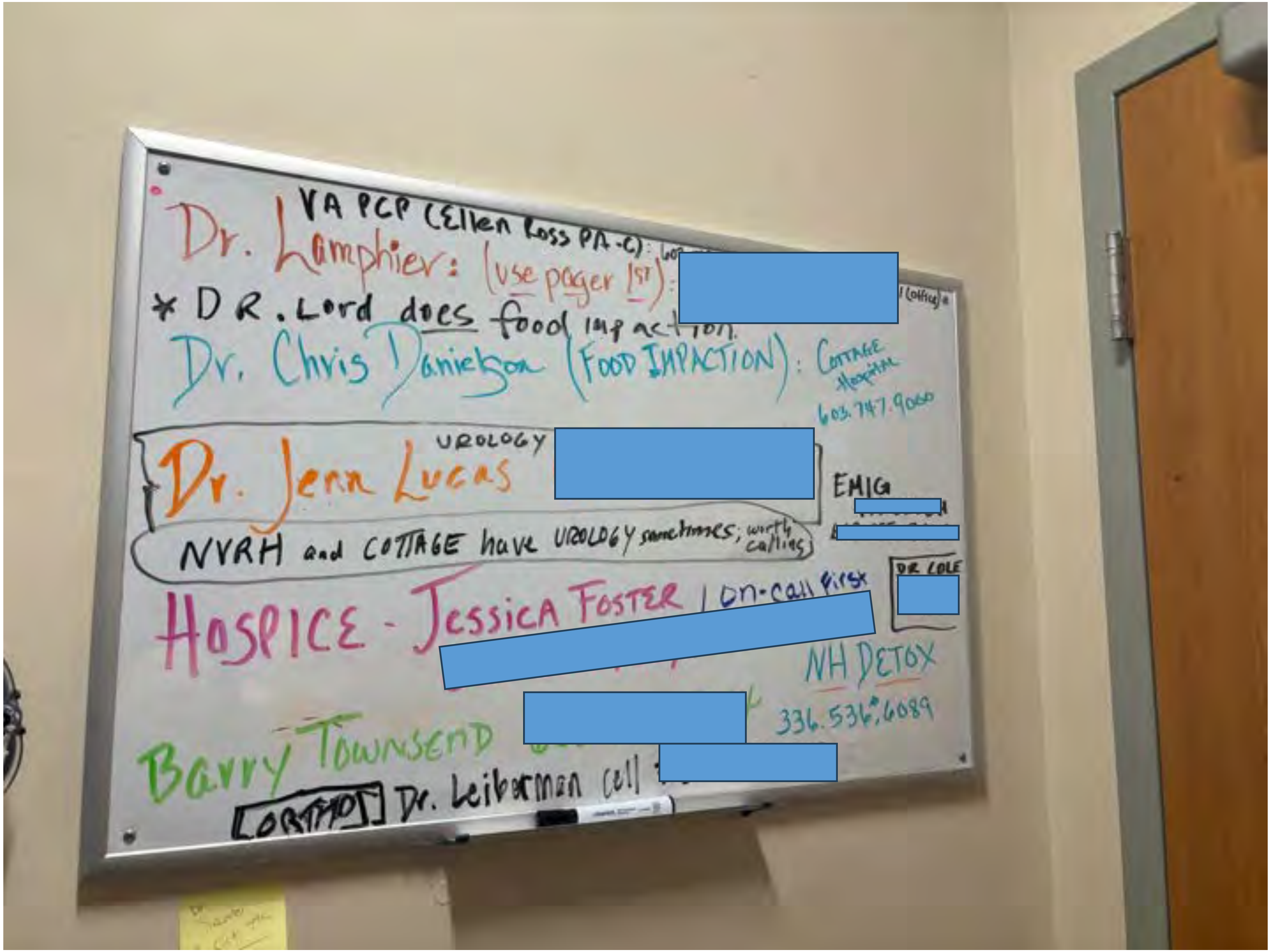
What PC Providers can offer the ED

Scripts to assist in demystifying hospice

- “Focused on bringing the care to your home and avoiding the ED”
- “Reduce the burdens of medical management for family”
- “Covered at 100% under Medicare” (for those without supplemental insurance)
- *“Would you like to meet with the someone from the hospice team to discuss what it would mean for your care?”*



VA PCP (Ellen Ross PA-C): [redacted] (office)

Dr. Lamphier: (use pager 1st):

* DR. Lord does food impaction.

Dr. Chris Danielson (FOOD IMPACTION): Cottage Hospital 603.747.9000

Dr. Jenn Lucas UROLOGY [redacted]

NVRH and COTTAGE have UROLOGY sometimes; worth calling

EMIG
[redacted]
[redacted]

HOSPICE - Jessica Foster | on-call first [redacted]

DR COLE
[redacted]

NH DETOX
336.536.6089

Barry Townsend [redacted]

[ORTHO] Dr. Leiberman cell [redacted]

What PC Providers can offer the ED

ED care of hospice patients:

1. Call hospice team immediately
2. Explore what triggered the decision to attend the ED/ call 911
3. Treat distressing symptoms
4. Avoid diagnostic interventions until coordinating with hospice or goals of care discussion
5. Urgent Palliative Care assistance @ any life-sustaining interventions
   - rapid goals of care discussion (ie hospice team or in-hospital palliative medicine assistance)

Adapted from Fast Fact #246. PCNOW. Palliative Care Network of Wisconsin

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Models of Palliative Care in the ED

ED Nurse driven Goals of Care (GOC) discussions

- 50% (who did not have one) completed a POLST
- 95% rated 4-5/5 satisfaction after; and 100% at 6 months
- No change in hospitalization, length of stay, or ICU stay

- Bigelow S et al. Difficult conversation: Outcomes of Emergency Department Nurse-Directed Goals of Care Discussions. Journal of Palliative Care. Volume 39, Issue 1; https://doi.org/10.1177/08258597221149402 2024

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Models of Palliative Care in the ED

Quality Improvement strategies for early hospice referral

- Multi-pronged quality improvement training in ED
- Prior MOLST was associated with much higher rates of hospice referral (OR 5.02)
- Pre: 22.6% Hospice referral < 96 hr vs Post: 54.1%

Baugh C et al. A hospice transitions program for Patients in the Emergency Department. JAMA.
JAMA Netw Open. 2024;7(7):e2420695. doi:10.1001/jamanetworkopen.2024.20695

- Brigham and Womens, Boston

Models of Palliative Care in the ED

Embed Palliative Care Provider Services in ED

- 10X increase in ED palliative consultation
- 49% changed code status in ED
- 11% admitted to lower level of care than planned
- 17% immediate hospice referral
- No change in ED length of stay
- Compared to inpatient consults: 8.1 day shorter length of stay (3.0 vs 11.1 days)
- 6.7X ROI ($)

Wang D and Heidt R. Emergency Department Embedded Palliative Care Service Creates Value for Health Systems. J Palliat Med 2023; May 26(5): 646-652. doi: 10.1089/jpm.2022.0245. Epub 2022 Nov 11.

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Consultation in the ED

1. What is the question? What is needed?
2. What is the urgency?
3. Who (of the team) can best address this need rapidly?
4. Get background data rapidly (chart review, corollary history, AD/POLST….)
5. Do consult and/or give specific, brief recommendations
   - Honor the reality of the ED environment
6. Offer effective tools
   - Opioid equivalence resource, Fast Facts, specific scripts/ communication skills
7. Assure follow up

Adapted from Fast Facts #298. PCNOW, Palliative Care Network of Wisconsin, June 11, 2024

Wang D et al. Top Ten Tips Palliative Care Clinicians should know about caring for Patients in the Emergency Department. 2019 Dec;22(12):1597-1602. doi: 10.1089/jpm.2019.0251. Epub 2019Jul 29

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Recommendations

1. <u>Make Directives/ Orders available to ED staff (POLST, P-DNR, AD…)</u>
   - Train ED staff to see them and use them
   - “Fix” the Electronic Medical Record barrier!
2. <u>Build, Model and Distribute Tools for ED staff to assist in</u>:
   - Scripts for rapid goals of care conversations at the bedside
   - Prognostic tools (ie PPS/ Karnovsky/ frailty indices….)
   - Prescribing tables/ tools (opioid equivalence, symptom mgt algorithms)
   - Rapid access to palliative and hospice specialty support
   - Assistance and support with debriefing strategies
3. <u>Set Quality Improvement goals for ED Palliative presence</u>
   - Start with active patients

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End of talk

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What ED Providers need

The American College of Emergency Physicians believes that:

- Emergency physicians play an important role in providing care at the end of life (EOL).
- Helping patients and their families achieve greater control over the dying process will improve EOL care.
- Advance care planning can help patients formulate and express individual wishes for EOL care and communicate those wishes to their health care providers by means of advance directives (including state approved advance directives, DNAR orders, living wills and durable powers of attorney for health care).

To enhance EOL care in the ED, the American College of Emergency Physicians believes that emergency physicians should:

- Respect the dying patient's needs for care, comfort, and compassion.
- Communicate promptly and appropriately with patients and their families about EOL care choices, avoiding medical jargon.
- Elicit the patient's goals for care before initiating treatment, recognizing that EOL care includes a broad range of therapeutic and palliative options.
- Respect the wishes of dying patients including those expressed in advance directives. Assist surrogates to make EOL care choices for patients who lack decision making capacity, based on the patient's own preferences, values, and goals.
- Encourage the presence of family and friends at the patient's bedside near the end of life, if desired by the patient.
- Protect the privacy of patients and families near the end of life.
- Promote liaisons with individuals and organizations in order to help patients and families honor EOL cultural and religious traditions.
- Develop skill at communicating sensitive information, including poor prognoses and the death of a loved one.
- Comply with institutional policies regarding recovery of organs for transplantation.
- Obtain informed consent from surrogates for postmortem procedures

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Conclusions from research

Advance Care Planning Guide

Evidence to support Advance Directives

- Sean Morrison's take: "Decades of research demonstrate advance care planning doesn't work. We need a new paradigm." Sean Morrison MD

Morrison, S.R., Meier, D.E., Arnold, R.M. (2021). What's wrong with advance care planning? *Journal of the American Medical Association* (326)16: 1575-1576. doi: 10.1001/jama.2021.16430

Jimenez G et al. Overview of systematic reviews of Advance Care Planning: Summary of Evidence and Global Lession. J Pain Sym Mgt. 56(3): 436-459 , 2018

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LGBTQIA+ Hospice and Palliative Care:

Striving for Equality in Serious Illness

Bradley Eckert, M.D., M.S.
Palliative Care, DHMC
December 3, 2024

Learning Objectives

1. Recognize the ways **historical, sociocultural, political, and institutional factors** may influence the care LGBTQIA+ individuals receive

2. Identify the **preferences, needs, and experiences** among LGBTQIA+ individuals with serious illness

3. Recommend **strategies to create a more inclusive environment** for LGBTQIA+ patients across palliative care settings

Disclosures

None

How do we define LGBTQIA+

LESBIAN	A woman who is primarily attracted to women
GAY	A man who is primarily attracted to men; sometimes a broad term for individuals attracted to the same sex
BISEXUAL	An individual attracted to people of their own and opposite gender
TRANSGENDER	An individual whose gender identity differs from their assigned sex at birth
QUEER	Often an umbrella term to be more inclusive of the many identities that make up the LGBTQIA+ community
INTERSEX	An individual whose sexual anatomy or chromosomes do not fit with the traditional markers of “female” and “male”
ASEXUAL	An individual who generally does not feel sexual desire or attraction to any group of people
+ (Plus)	To represent the many varieties that make up one’s identity

SOURCE: National Academies of Science, Engineering, and Medicine (2020). *Understanding the Well-Being of LGBTQI+ Populations*

What are **challenges** that LGBTQIA+ patients may experience related to **hospice or palliative care**?

Meet Robert

- **87-year-old male** with **metastatic prostate cancer** to the **lungs and bone**
- He is s/p radiation and chemotherapy
- Symptoms: Fatigue, anorexia, back/shoulder pain, shortness of breath, constipation
- Social: He lives in VT with his partner Scott (35 years) & cat Oliver
- He has had two recent falls at home and fears needing a long-term care facility soon

The Life of Robert

Born 1937 (age 87)

1950
Age 13
Lavender Scare

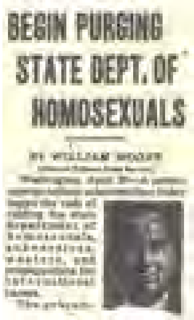
1969
Age 32
Stonewall Riots

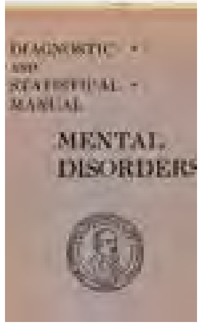
1982
Age 45
HIV/AIDS Epidemic

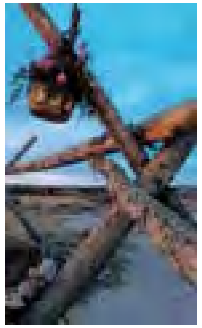
1996
Age 59
Defense of Marriage Act

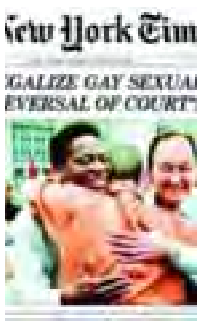
2003
Age 66
Lawrence v. Texas

2016
Age 79
Pulse Nightclub Shooting









1952
Age 15
DSM Published

1978
Age 41
Harvey Milk Murdered

1993
Age 56
"Don't Ask, Don't Tell"

1998
Age 61
Matthew Shepherd Murdered

2015
Age 78
Obergefell v. Hodges

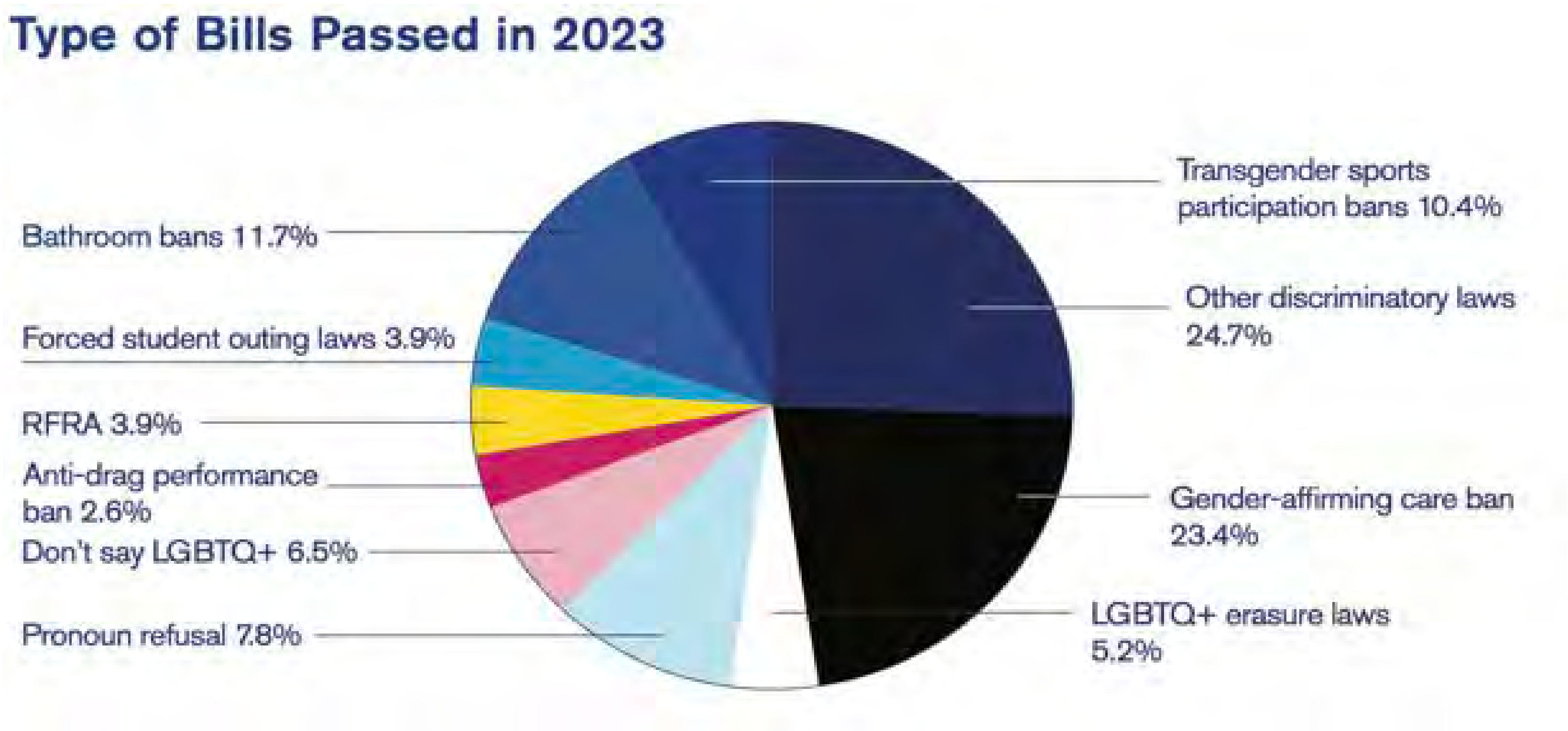
2020
Age 83
LGBTQ Workplace Rights

DSM: Diagnostic and Statistical Manual

With progress,
is it all “Just History?”

National State of Emergency for LGBTQ+ Americans

We have officially declared a state of emergency for LGBTQ+ people in the United States for the first time following an unprecedented and dangerous spike in anti-LGBTQ+ legislative assaults sweeping state houses this year.



Type of Bills Passed in 2023

SOURCE: Human Rights Campaign (2023): LGBTQ+ AMERICANS UNDER ATTACK: A REPORT AND REFLECTION ON THE 2023 STATE LEGISLATIVE SESSION

HPM Professionals Identify LGBT Discrimination

54% — **Believed** LGB Patients were more likely to experience discrimination

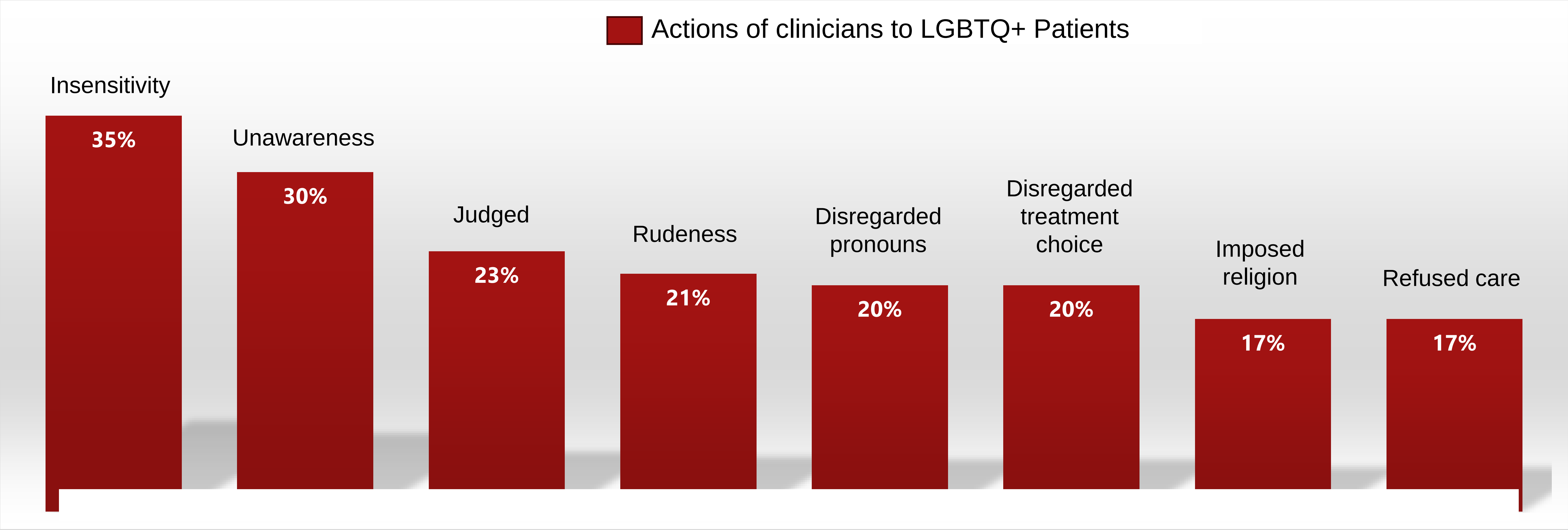
24% — **Observed** discriminatory care toward LGB patients

33% — **Observed** discrimination against LGBT patients' spouses/partners

SOURCE: Stein et al., 2020. J Palliative Medicine

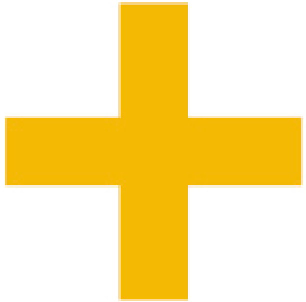
New Study Finds Seriously Ill LGBTQ+ Patients and Care Partners Experience Discrimination

- Cross-sectional, mixed methods study (n = 290)
- Differences further observed with race and geography



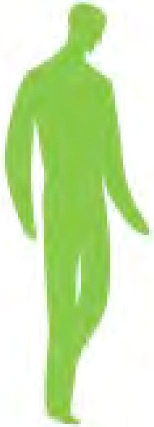
Stein et al., 2023, Health Affairs

Healthcare barriers that LGBTQIA+ patients may experience



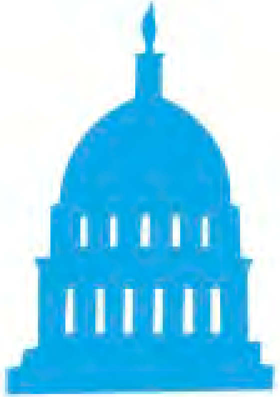
HEALTH CARE ORGANIZATIONS

- Lack of training for healthcare staff
- Lack of culturally competent caregiver support and bereavement groups
- Heterosexist assumptions of patient's sexual and gender identity



INDIVIDUAL AND SOCIETAL

- Estrangement from family of origin
- Higher rates of mistrust of
- Nondisclosure of LGBTQIA+ status
- Fear of discrimination
- Complexity with religion/spirituality
- Isolation and lack of social support

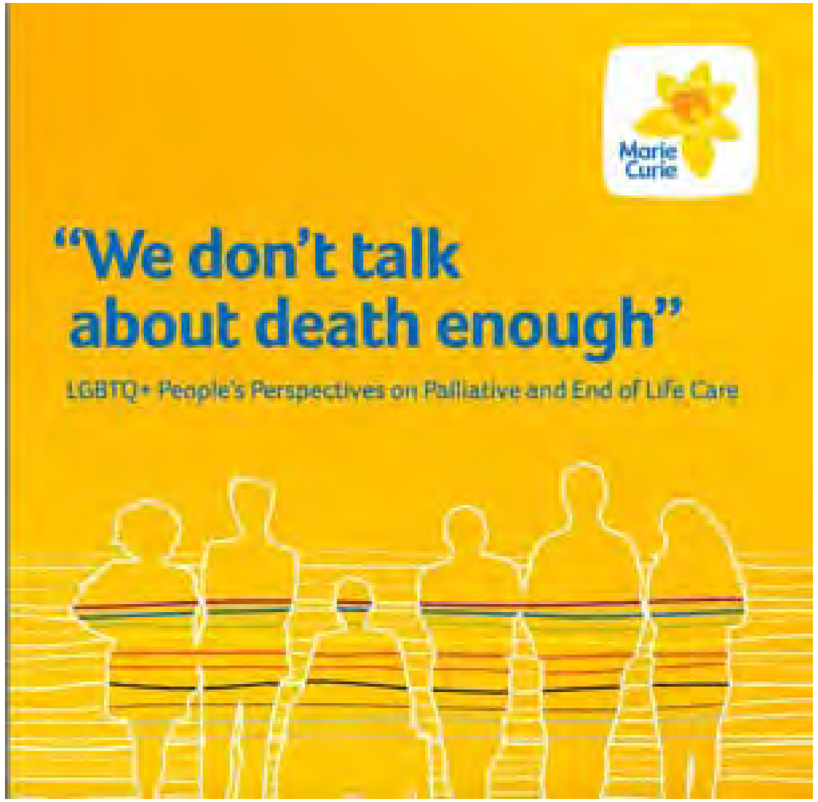


LEGAL AND SOCIAL SYSTEM

- Variability in and potential fragility of legal protections (local/state)
- Lack of comprehensive legal protections
- Absence of portability related to benefits

Maingi et al., 2018, J Pain Symp Mgmt; Rosa et al., 2023, Pall Med; Griggs et al., 2017, J Clin Onc

Key Problems at the End of Life



Marie Curie

“We don’t talk about death enough”

LGBTQ+ People’s Perspectives on Palliative and End of Life Care

- Anticipating Discrimination
- Complexities of religion
- Assumptions about identity and family structure
- Varied support networks
- Unsupported grief and bereavement
- Increased pressure on caregivers

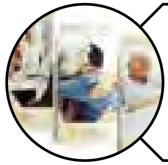
Marie Curie (2016) “Hiding who I am” - The reality of end-of-life care for LGBT people.

How can we **make palliative care more inclusive** to LGBTQIA+ patients and families?

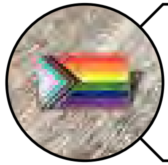
What steps has Dartmouth Health taken to be more welcoming to transgender and gender diverse patients?

- We provide comprehensive provider and staff education on gender-affirming care on a regular basis.
- We continue to work with Geisel Medical School at Dartmouth to provide medical students with up-to-date education on gender-affirming care.
- Single occupancy bathrooms are available to patients and employees throughout the hospital campus.
- Our Electronic Medical Records have the ability to capture information related to Sexual Orientation and Gender Identity (SOGI). Patients are able to indicate an affirmed/chosen name that appears next to the legal name listed in the chart. Patients are also able to list their pronouns in their medical records. Patients can self-report and update this information at any time by using the myDH patient portal or by connecting with their Dartmouth Health care team. For more information on system-wide SOGI collection, please visit our We Ask Because We Care page.

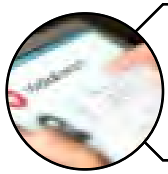
Ideas to Consider



Diversity in materials that are distributed

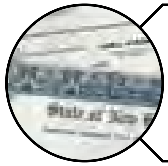


LGBTQIA+ visible signs of support

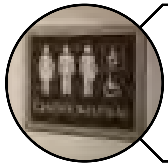


Patient forms contain inclusive, gender-neutral language that allows for self identification

Ensure that phrasing of questions we ask does not assume heterosexuality



Explore preferences specific to patients who are transgender



Gender neutral restrooms

> “It should not be the job of the patient, who is already vulnerable and afraid, to have to come out.
>
> It is the provider’s job to make it safe and welcoming and invite people to present their whole self.”

Liz Margolies, LCSW
Founder and Executive Director
National LGBT Cancer Network

National
LGBT
Cancer
Network

Support for Patients and Care Partners

Cancer Support Group

- Meet three times weekly on Zoom
- Sign up at cancer-network.org

SUPPORT GROUPS

In OUT: the National Cancer Survey, LGBTQI+-specific support groups were the top request made by LGBTQI+ cancer survivors. In response the National LGBT Cancer Network is currently running cancer peer-support groups. This is a healing space to lean on your LGBTQ+ community for support throughout your cancer journey. Join us today!

Additional Resources to Explore

aahpm

AMERICAN ACADEMY OF HOSPICE AND PALLIATIVE MEDICINE

LGBT
Special Interest Group

LGBTQ+ Resource Guide

NHPCO

National
LGBT
Cancer
Network

HPNA

Hospice & Palliative Nurses Association

Advancing Expert Care in Serious Illness

LGBTQ
Special Interest Group

NATIONAL LGBTQIA+ HEALTH EDUCATION CENTER

A PROGRAM OF THE FENWAY INSTITUTE

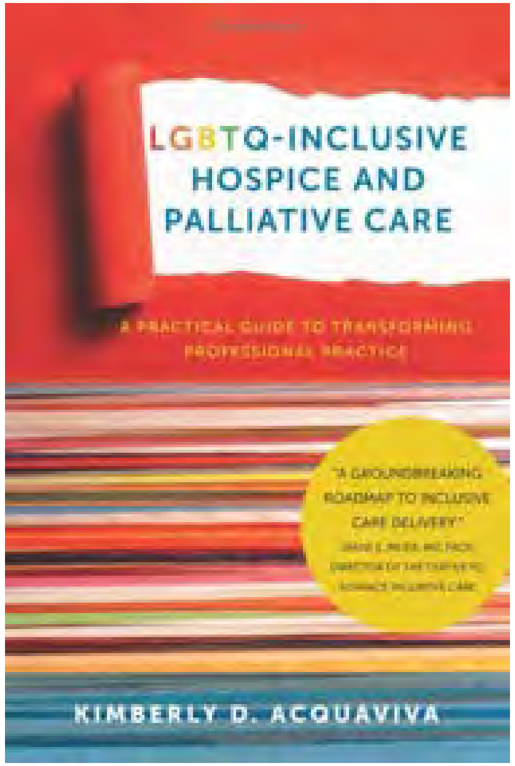
National LGBTQIA+
Health Education Center

capc

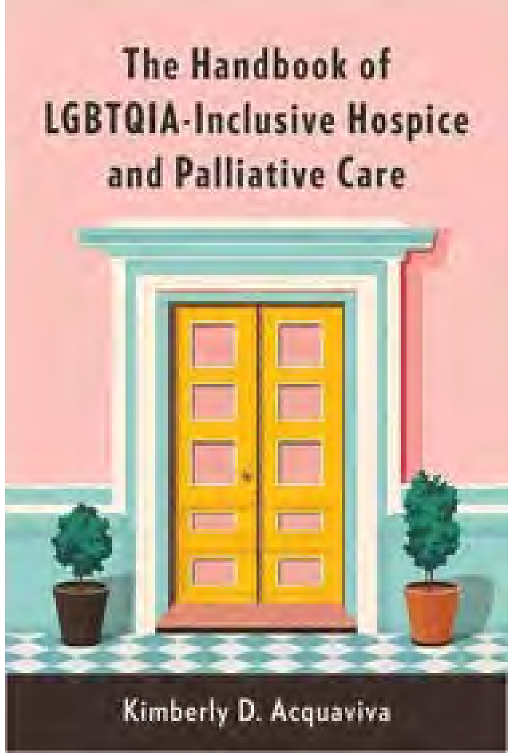
"Providing Inclusive and Affirmative Palliative Care for the LGBTQ+ Community"

Additional Resources to Explore

Two recent books have been published that take a deeper dive



Harrington Park Press
Published: May 2017



Columbia University Press
Published: October 2023

Resources

Daniel, H., Butkus, R., & Health and Public Policy Committee of American College of Physicians (2015). Lesbian, Gay, Bisexual, and Transgender Health Disparities: Executive Summary of a Policy Position Paper From the American College of Physicians. Annals of internal medicine, 163(2), 135–137.

Griggs, J., Maingi, S., Blinder, V., Denduluri, N., Khorana, A. A., Norton, L., Francisco, M., Wollins, D. S., & Rowland, J. H. (2017). American Society of Clinical Oncology Position Statement: Strategies for Reducing Cancer Health Disparities Among Sexual and Gender Minority Populations. Journal of clinical oncology : official journal of the American Society of Clinical Oncology, 35(19), 2203–2208.

Lick, D. J., Durso, L. E., & Johnson, K. L. (2013). Minority Stress and Physical Health Among Sexual Minorities. Perspectives on psychological science : a journal of the Association for Psychological Science, 8(5), 521–548.

Maingi, S., Bagabag, A. E., & O'Mahony, S. (2018). Current Best Practices for Sexual and Gender Minorities in Hospice and Palliative Care Settings. Journal of pain and symptom management, 55(5), 1420–1427.

Marie Curie (2016) “Hiding who I am” - The reality of end of life care for LGBT people. Marie Curie. https://www. mariecurie.org.uk/globalassets/media/documents/policy/ policy-publications/june-2016/reality-end of life-care- lgbt-people.pdf

Rosa, W. E., Roberts, K. E., Braybrook, D., Harding, R., Godwin, K., Mahoney, C., Mathew, S., Atkinson, T. M., Banerjee, S. C., Haviland, K., Hughes, T. L., Walters, C. B., & Parker, P. A. (2023). Palliative and end-of-life care needs, experiences, and preferences of LGBTQ+ individuals with serious illness: A systematic mixed-methods review. Palliative medicine, 37(4), 460–474.

Stein, G. L., Beckerman, N. L., & Sherman, P. A. (2010). Lesbian and gay elders and long-term care: identifying the unique psychosocial perspectives and challenges. Journal of gerontological social work, 53(5), 421–435.

Stein, G. L., Berkman, C., O'Mahony, S., Godfrey, D., Javier, N. M., & Maingi, S. (2020). Experiences of Lesbian, Gay, Bisexual, and Transgender Patients and Families in Hospice and Palliative Care: Perspectives of the Palliative Care Team. Journal of palliative medicine, 23(6), 817–824.

THANK YOU

Medical Aid in Dying (MAID)
Overview
DHMC-Palliative Care ECHO

Diana Barnard, MD
Associate Professor of Family Medicine
Division of Palliative Medicine
UVM Health Network-Porter Medical Center
Dbarnard@portermedical.org

Disclosures

Will discuss off label use of FDA approved medications

I provide expert legislative testimony for access to MAID

I am occasionally reimbursed for testifying time
By Compassion and Choices

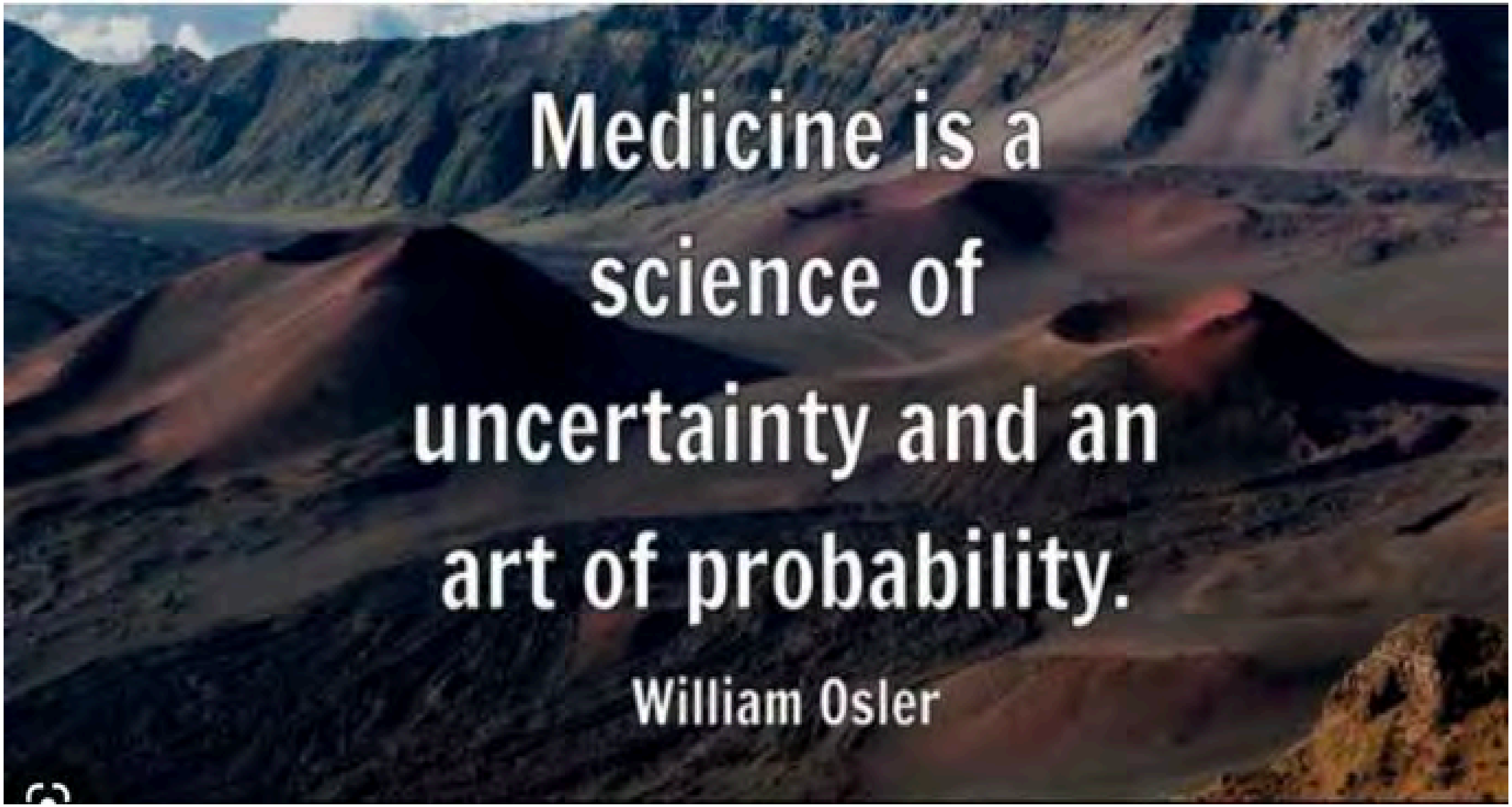
Objectives

Describe Medical Aid in Dying (MAID) and eligibility criteria

Explore motivation behind requests for MAID

Deepen awareness of multidimensional suffering

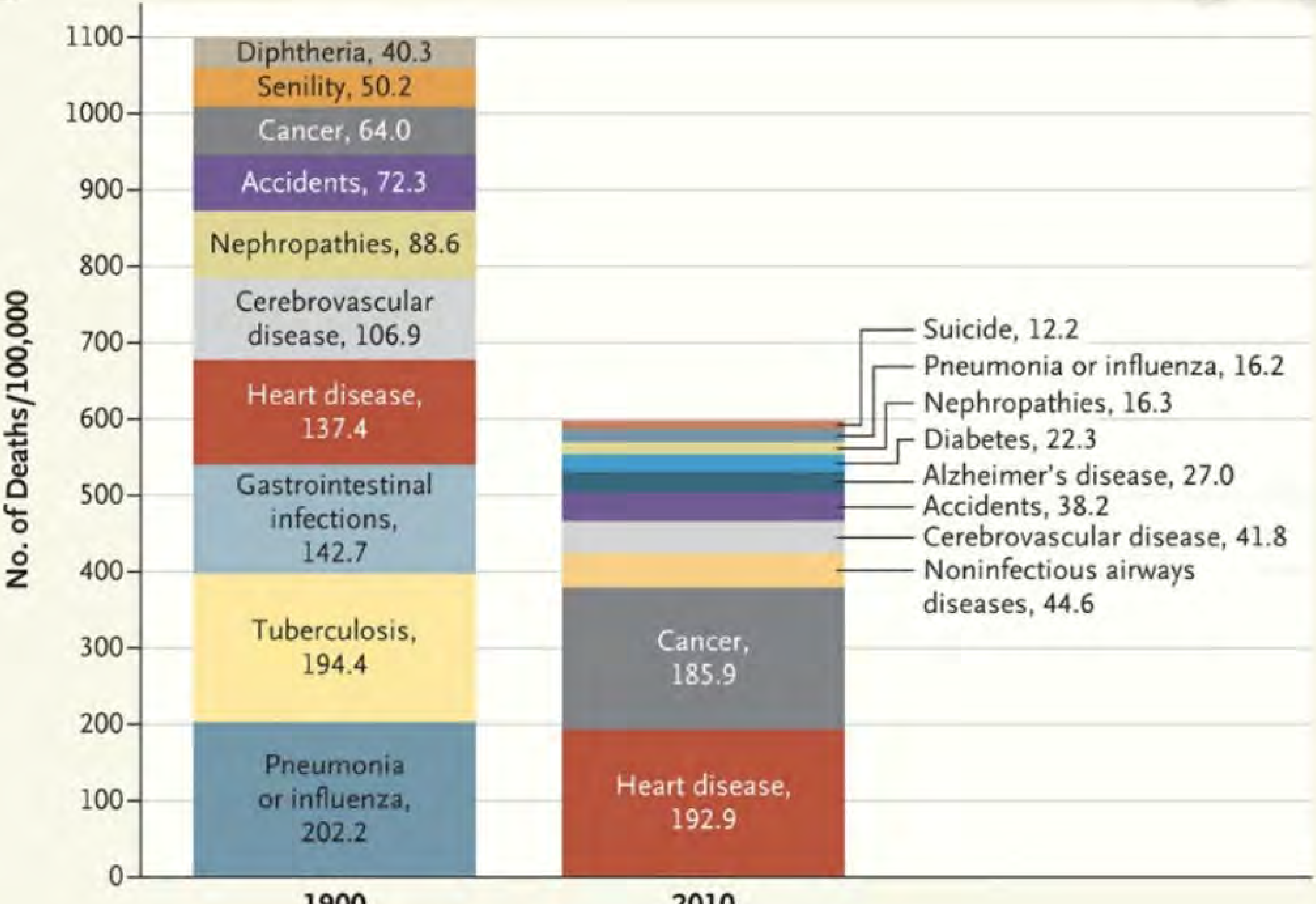
William Osler, 1800s



Medicine is a science of uncertainty and an art of probability.

William Osler

Cause of Death 1900 vs. 2010



What IS Medical Aid in Dying

A practice that legally allows a physician

to prescribe a lethal dose of medication

for a *capable*
terminally ill adult
With a *<6 month* prognosis
to *voluntarily self-administer*

for the purpose of *hastening death*

End of Life

Unique

Individual

Deeply Personal

Enduring Impact

Patient Preferences for end of life care

At home

Family/loved ones present

Comfortable

We all Die

- I WANT A SECOND OPINION

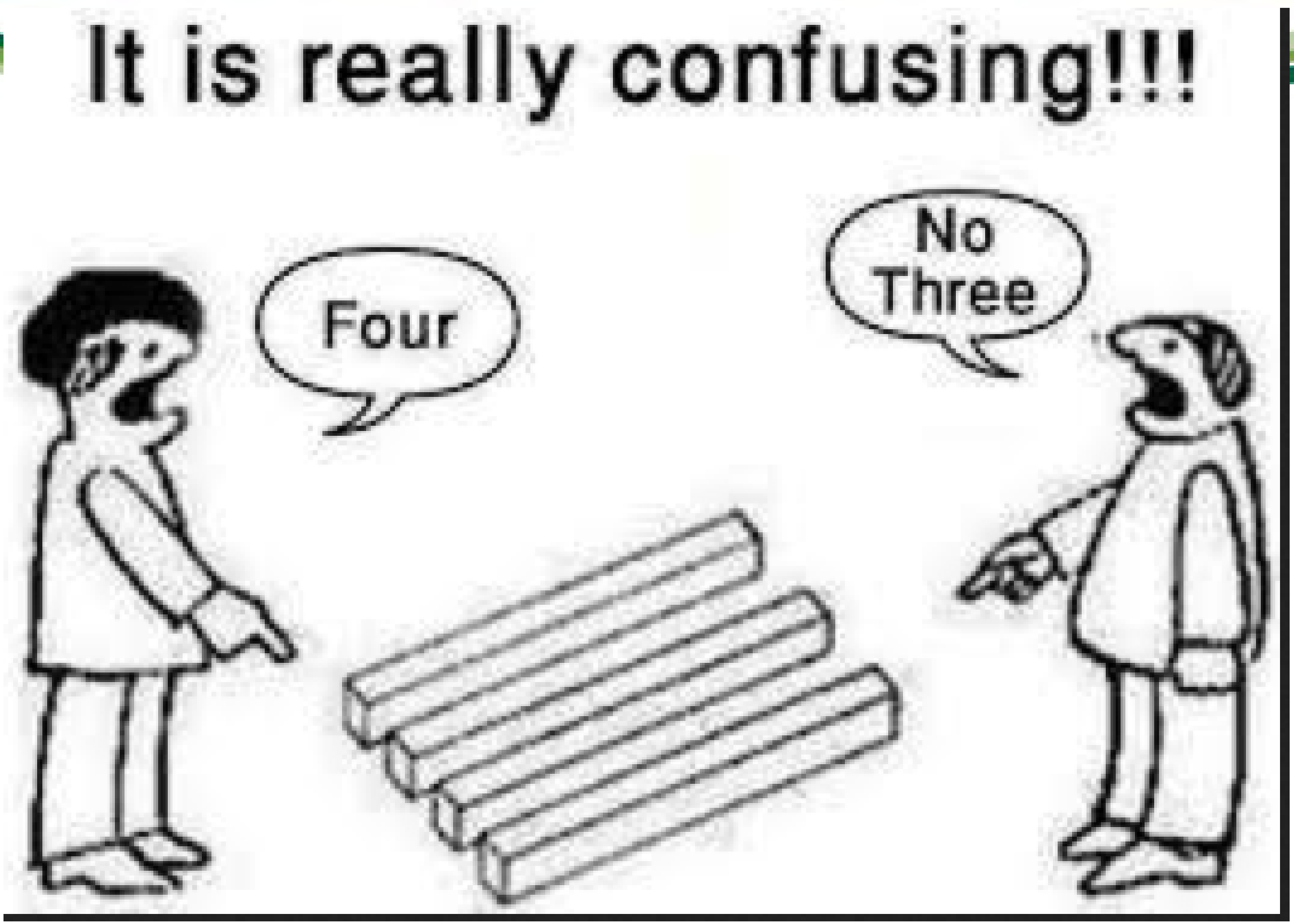
JOB 2007

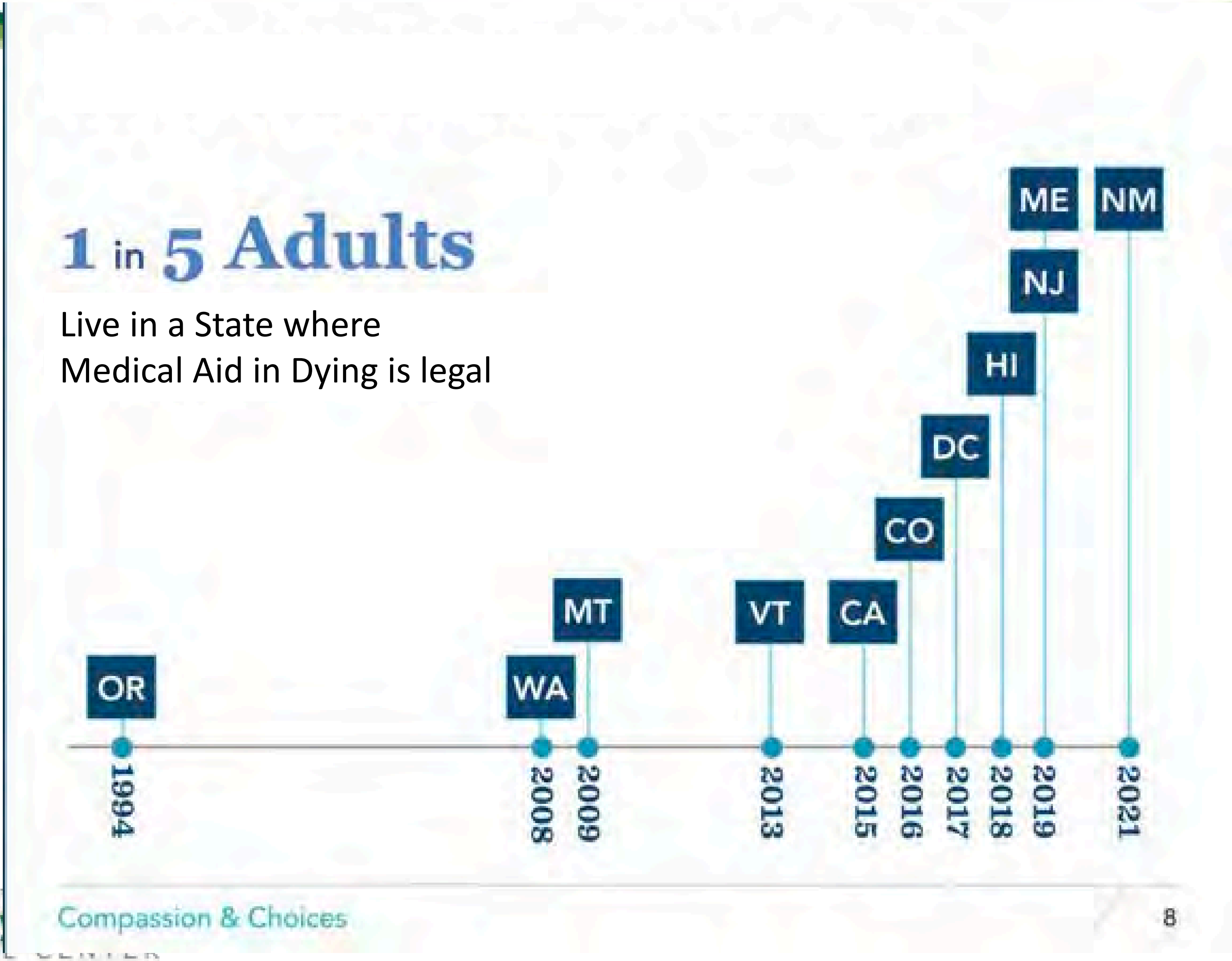
Experience in Oregon (27 years)

- Most common reasons for using MAID
  - Loss of autonomy
  - Loss of ability to engage in meaningful activities
  - Loss of bodily functions
  - Burden on family, friends, caregivers

  - less common…. Uncontrolled pain or fear or it, financial concerns

https://www.oregon.gov/oha/ph/providerpartnerresources/evaluationresearch/deathwithdignityact/pages/ar-index.aspx


It is really confusing!!!
Four
No Three

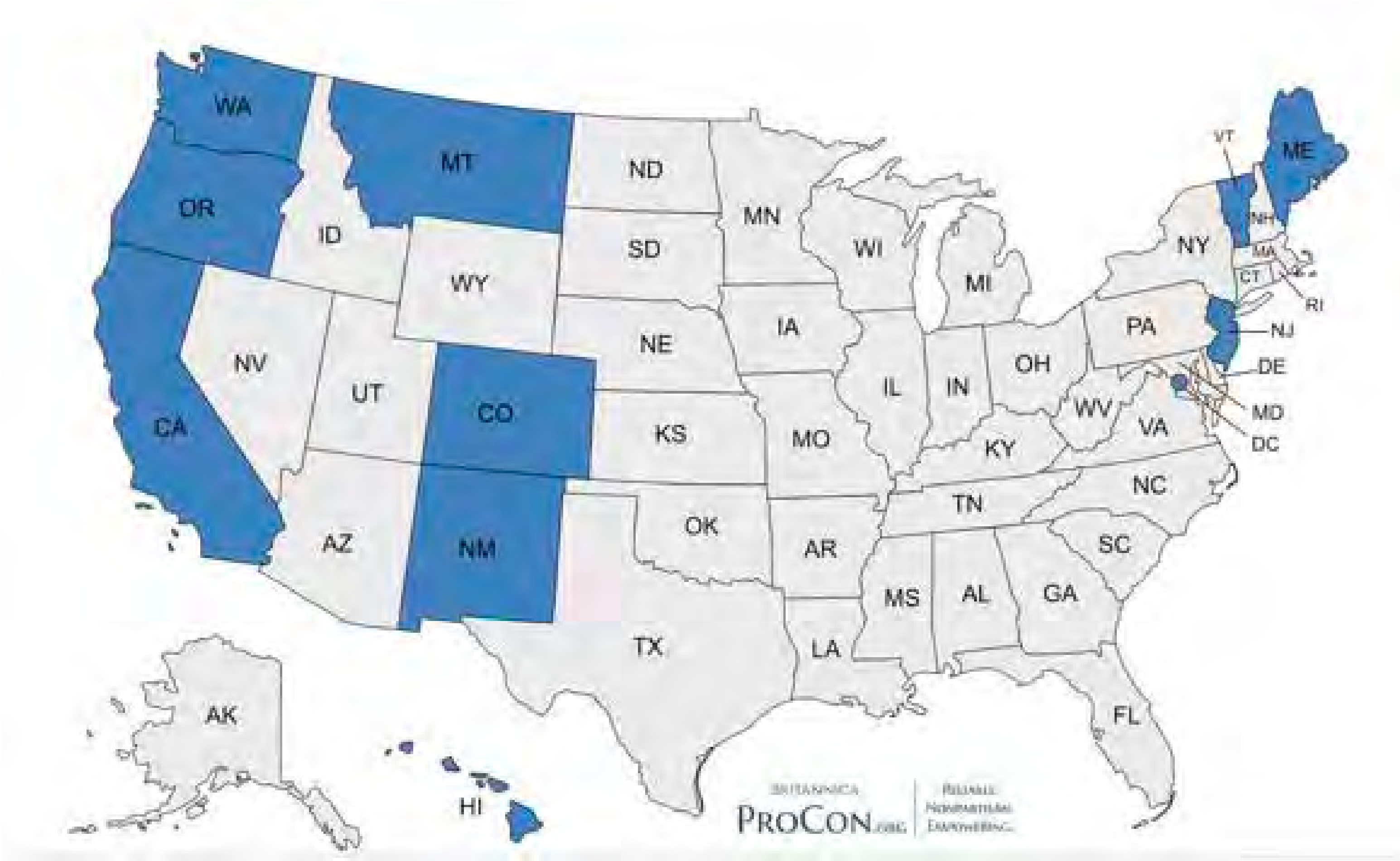


1 in 5 Adults

Live in a State where
Medical Aid in Dying is legal

Compassion & Choices

https://www.britannica.com/procon



Suffering- Dr. Eric Cassell, NEJM, 1982

Dr. Eric Cassell- N Engl J Med. 1982; 306:639–45

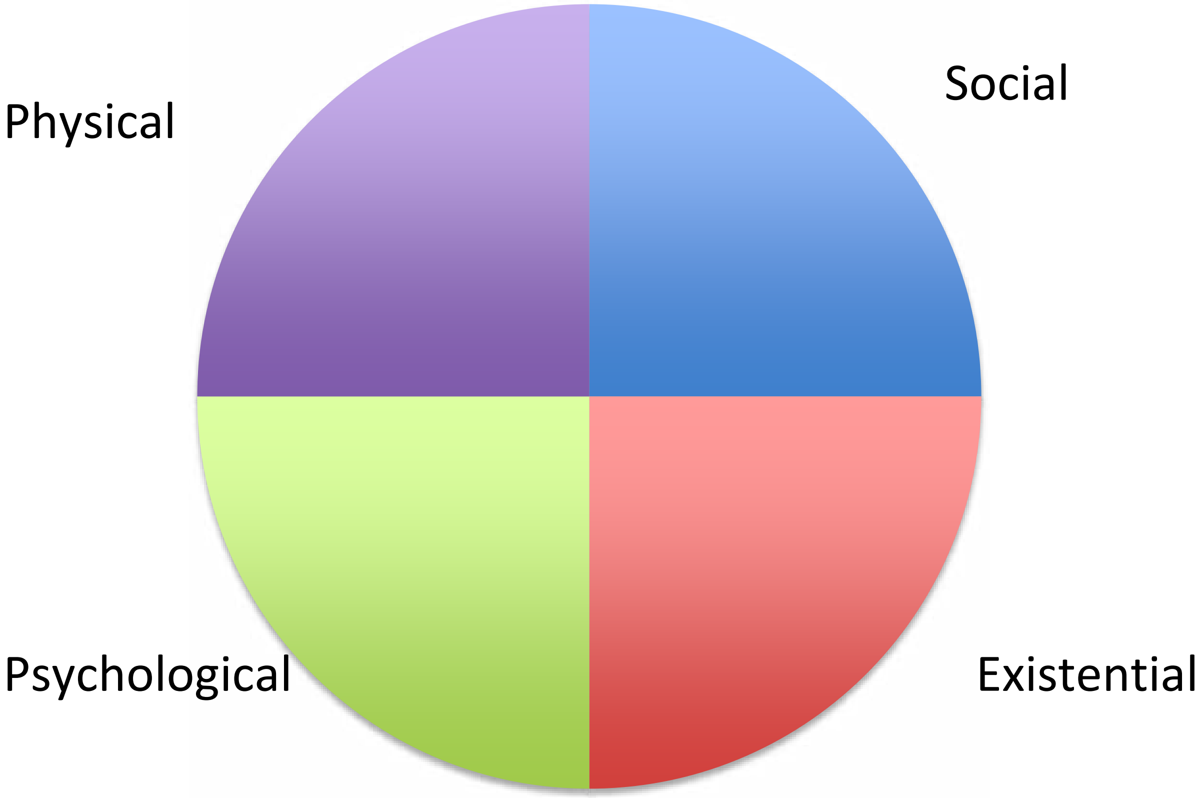
Suffering is experienced by persons, not merely by bodies, and has its source in challenges that threaten the intactness of the person as a complex social and psychological entity.

Suffering can include physical pain but is by no means limited to it. The relief of suffering and the cure of disease must be seen as twin obligations of a medical profession that is truly dedicated to the care of the sick.

Physicians' failure to understand the nature of suffering can result in medical intervention that (though technically adequate) not only fails to relieve suffering but becomes a source of suffering itself.

Total Suffering (adapted)

Dame Cicely Saunders



http://www.csi.kcl.ac.uk/keypub.html

Prognostication

- More than Dying
  - Functional decline
  - Need for assistance

- Dynamic
  - NOT a proclamation
  - Best case/Worst case scenarios
  - Uncertainty; Ranges

Responding to MAID requests (and/or any EOL suffering)

- “Tell Me More…..”
- Humble Curiosity
- Explore fears/concerns
- Validate
- Understand previous experience
- Identify supports and strengths

Responding to requests for MAID

- Emphasize voluntary nature, ability to pause/stop
- Discuss other options to maintain control and to minimize suffering
- Early and Honest discussion of Hospice

- *Normalize* option to decline or to stop burdensome treatments which may prolong suffering near end of life

- Consider alternatives to MAID
    - Palliative Sedation
    - Voluntarily Stopping Eating and Drinking (VSED)

- Explore family/loved one concerns
- Parallel planning

MAID Process in VT

Prescribing Physician First Verbal Request

- Assess Eligibility
- Provide Patient Information

Prescribing Physician Second Request

- at least 15 days later

Consulting Physician Request

Patient Written Request

Contact Pharmacy with Prescription

File Vermont Department of Health Paperwork

For those considering MAID

Regular assessment:

- Hospice
- Suffering
- Prognosis
- RED FLAGS
  - Cognition
  - Frailty
  - Swallowing, Cachexia
  - Nausea, vomiting, bowel functioning
  - Intervene if needed (paracentesis, enemas, steroids)
- Parallel Planning

MAID Pharmacology (www.acamaid.org)

- Premedicate
  - Ondansetron 8 mg
  - Metoclopramide 20 mg
  - Wait 30 minutes
- MAID mixture in 2 ounces Apple Juice
  - Digoxin 100mg
  - Diazepam 1,000mg
  - Morphine 15,000mg
  - Amitriptyline 8,000mg
  - Phenobarbital 5,000mg
- Procedure
  - Sometimes burning and bitterness, 1 tsp. sorbet can ameliorate
  - Average time to death 1.1 hour
  - 85% < 2 hours or less
  - Occasional (1/100) prolonged dying
  - Non oral administration also highly effective (rectal, feeding tubes)

Data collection

- Each state collects slightly different data
- Vermont Dept of Health (VDH) issues biennial reports
- https://www.healthvermont.gov/systems/end-life-decisions/patient-choice-and-control-end-life

Unofficial (publicly disclosed) Vermont data

-Numbers of prescribers and those accessing law are increasing
-7/1/23-6/30/24 period
-96 people qualified; 24 Vermonters, 72 non-residents

Running total May,2013-June,2024 (11 years)
-184 Individuals have qualified for MAID by VDH criteria
    -Majority (75%) Cancer
    -ALS, other neurodegenerative disease

Challenges for Out of State Patients

- Understanding of law
- Willing prescriber
- Prognostication
- Communication
- Difficulty in timing/scheduling of travel and ingestion

Opportunities with more access

- We are still learning

- Growing Wayfinder program

- Increased public discussion, interest, demand for better
  - Options at the end of life
  - The best (patient centered) end of life care possible

Patient Choices Vermont

Clinician’s Guide to Medical Aid in Dying:
https://www.patientchoices.org/clinicians-guide.html

Non-Resident Checklist:

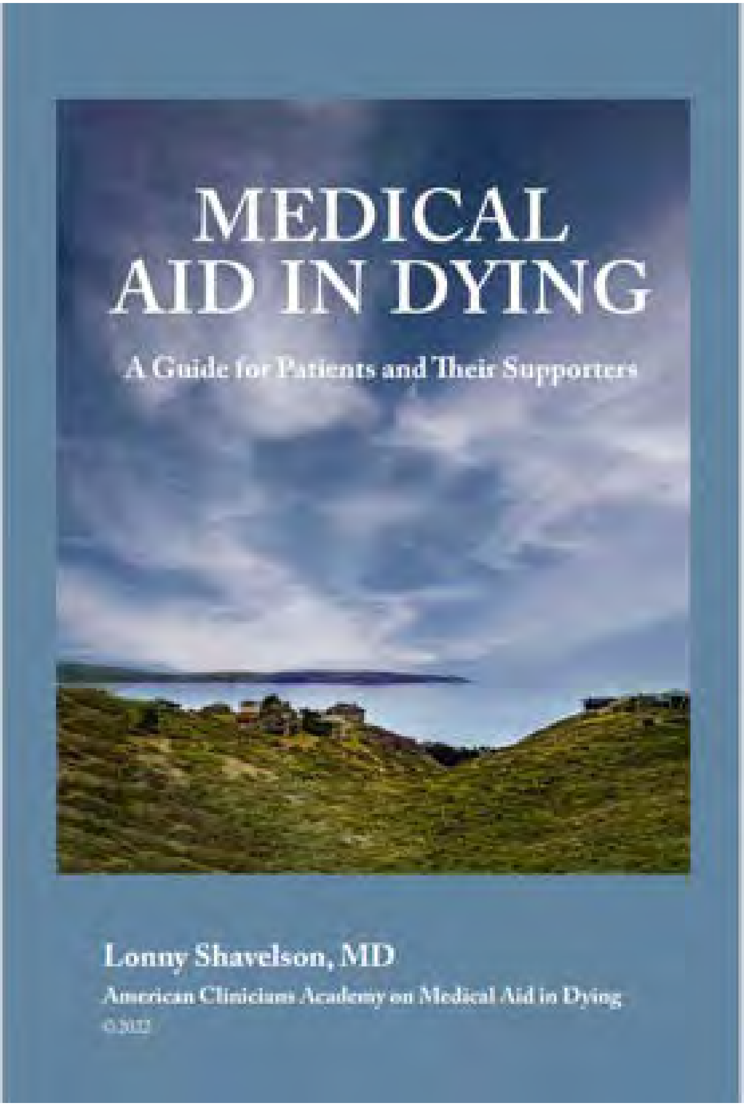
https://www.patientchoices.org/non-residents.html

PCV Helpline:

- Assistance for clinicians, patient, families
- 802-448-0542

The University of Vermont
MEDICAL CENTER

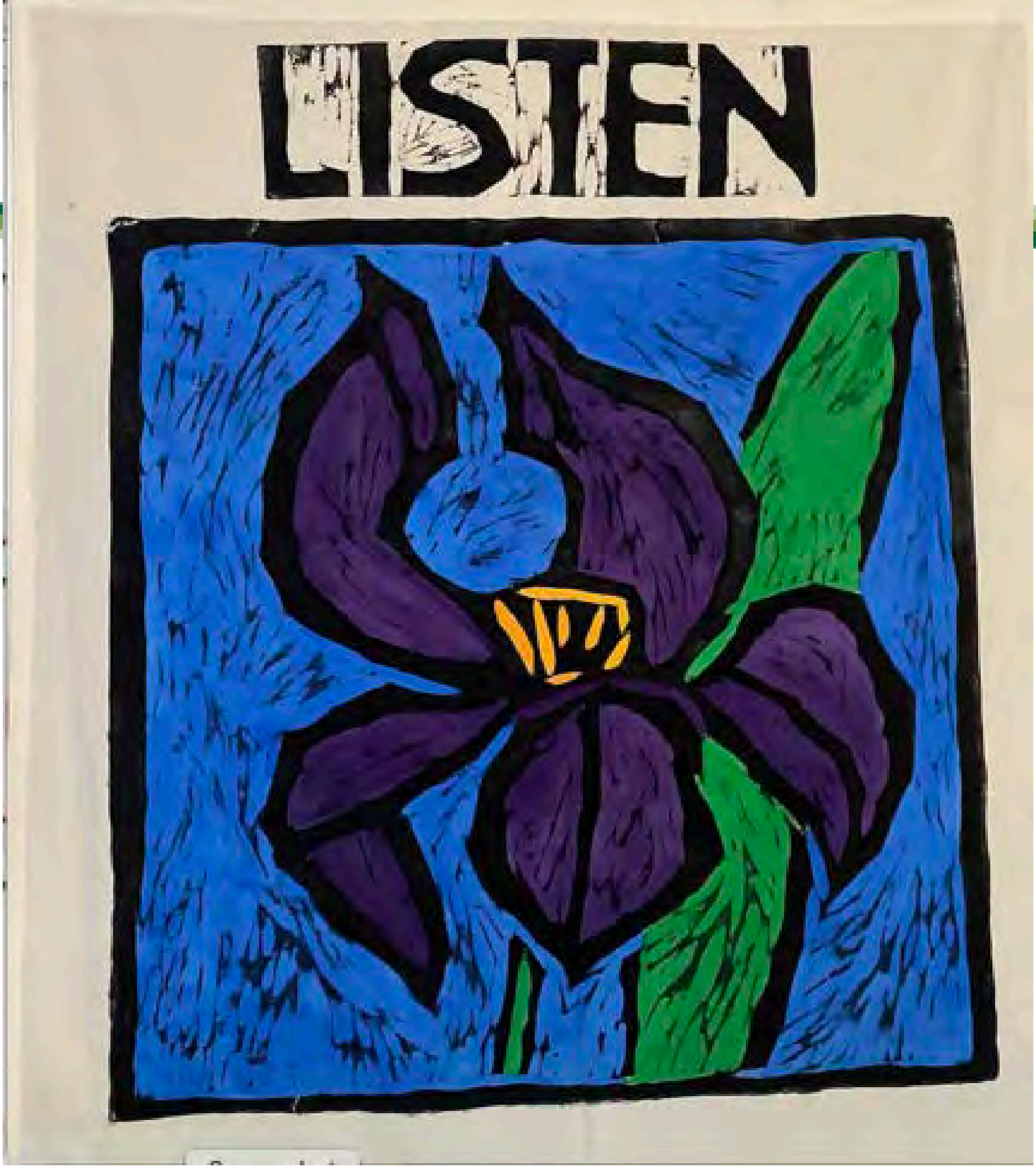
Aid-in-Dying-Patient-Guide.pdf (acamaid.org)



MEDICAL
AID IN DYING

A Guide for Patients and Their Supporters

Lonny Shavelson, MD
American Clinicians Academy on Medical Aid in Dying
©2022


LISTEN

References/Information

- Patient Choices Vermont

  https://www.patientchoices.org
- American Academy of Medical Aid in Dying

  https://www.acamaid.org/
- Vermont Department of Health

  https://healthvermont.gov/systems/end-life-decisions/patient-choice-and-control-end-life

Vermont Ethics Network

https://vtethicsnetwork.org/palliative-and-end-of-life-care/medical-aid-in-dying-act-39

- Oregon Health Authority

  Oregon Health Authority : Oregon's Death with Dignity Act : Death with Dignity Act : State of Oregon
- Compassion and Choices

  https://www.compassionandchoices.org/research/doc2doc-program/

THE University of Vermont MEDICAL CENTER

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https://www.liebertpub.com/doi/pdf/10.1089/jpm.2015.0092

The Nature of Suffering and the Goals of Medicine; N Engl J Med 1982; 306:639-645; DOI: 10.1056/NEJM198203183061104

Being Mortal:Medicine and What Matters in the End; Atul Gawande, ISBN-13: 9780805095159; Holt Henry & Company, Inc, 2014

Palliative ECHO: Severe Mental Illness and Palliative Care

H. Samuel Landsman, M.D.

Dartmouth-Health, Department of Psychiatry

Disclosures

- I have no financial or other conflicts to disclose with respect to this presentation

Objectives

- Define severe persistent mental illness (SPMI)
- Describe the morbidity and mortality related to those with SPMI
- Describe health care inequities that may be experienced by those with SPMI
- Outline challenges with decision making for those with SPMI
- Provide ideas for care of those with SPMI

Definitions

- Palliative Care
- Psychiatry
- Severe and Persistent Mental Illness (SPMI)
- Decision making capacity
    - Informed consent

Palliative Care and Psychiatry

- Similarities/Overlap
- Differences
- Palliative Psychiatry?

Severe Persistent Mental Illness (SPMI)

- SPMI: a mental illness that is chronic or recurrent, requires ongoing intensive psychiatric treatment, and significantly impairs functioning
- ~ 6% of the population
- Associated with premature mortality across all age groups

Morbidity and Mortality for People with SPMI

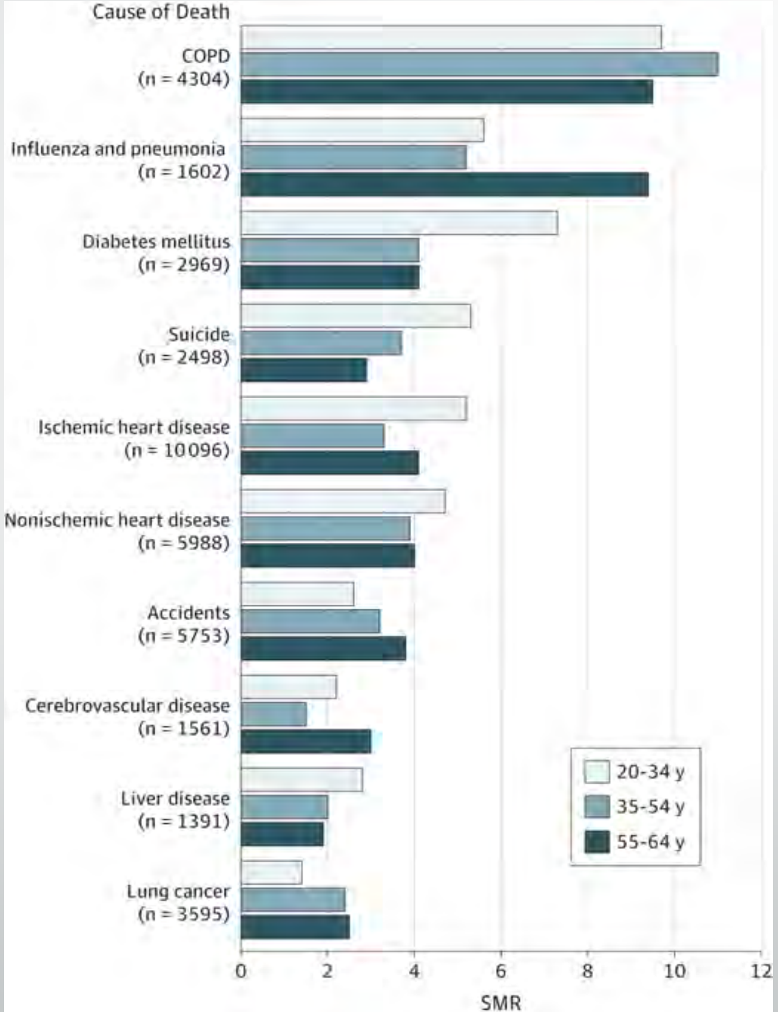

Figure. Standardized Mortality Ratios of Adult Medicaid Beneficiaries Diagnosed as Having Schizophrenia for 10 Common Causes of Death by Age Group (January 1, 2001, to December 31, 2007)

Decision Making Capacity

- **Decision-making capacity is a clinical determination that refers to whether a patient has the mental capability to:**
    - Understand relevant information,
    - Appreciate the medical situation they are in and its possible consequences,
    - Reason through risks, benefits and alternatives of treatment options, and
    - Communicate a choice freely and voluntarily based on their own values.

https://vtethicsnetwork.org/

Decision Making Capacity – "Sliding Scale"

Levelsof Capacity

The ability to…

…reach a reasonable decision (reasonable person standard)

…give risk/benefit-related reason

…give a rational reason

…give a reason

…understand relevant information

…understand one's situation and its consequences

…express or communicate a preference or choice

https://vtethicsnetwork.org/

Decision Making Capacity – Continued

- Presume Capacity
- Provide Informed Consent
  - (*may need repetition, multiple modalities)
- IF deemed incapacitated, ALL efforts to restore capacity
- Delay if possible
- Engage alternate decision maker if necessary

https://vtethicsnetwork.org/

Advanced Care Planning

- Who makes decisions?

Health Care Equity/Access to Care

- Compared to the general population, people with SPMI may:

  - Avoid or delay engaging in medical treatment
  - Have difficulty communicating symptoms
  - Experience symptoms differently
  - Have increased SES barriers to care
  - Have increased medical comorbidities

Health Care Equity/Access to Care

- Compared to the general population, people with SPMI may:
  - Experience stigma from providers when attempting to access care
    - Provider/Societal Stigma
      - Blame person for health issue
      - Assume LACK of capacity, adherence
      - (False) concern for violence
    - Self Stigma
  - Subsequently seek less care, receive poorer care

Challenges for patients and providers

- Challenges building therapeutic relationships
  - Mistrust: “Symptom-related” or “Reality-Based?”
- “Difficult Historians”
- “Limited” understanding of medical information
- “Nonadherence” or “imperfect adherence”

Challenges for patients and providers

- Limited Comfort or Expertise
  - Of non-psychiatric physicians working with people with SPMI
  - Of mental health providers working with people with life-limiting medical illness
- Provider disagreement about treatment priorities and goals of care

Specific Mental Health Issues

- Psychosis
- PTSD and other Trauma Related Issues
- Personality Disorders
- Severe Depression and Suicide
- Depression and Anxiety
    - Treatment path dependent on prognosis
- *Anorexia Nervosa

Tips

- Assume palliative needs are similar between SPMI and non-SPMI
    - Until proven otherwise
- Individualize the approach
    - Focus on therapeutic relationship, hope, dignity, respect and **non-abandonment**
- Low threshold to Consult Psychiatry
    - Especially for patients with Bipolar Disorder, Schizophrenia, and PTSD
- Assess for Suicide
    - Assessing risk of suicide does not increase the risk of suicide, but medical illness DOES
- Use Psychostimulants (for Depression) and Benzodiazepines (for Anxiety)
    - At end of life, when **time** matters
- Trauma-Informed Care

Riordan et al. J Pall Med. 2018.

Trauma-Informed Care

Trauma-Informed Care (TIC)

It isn't about what's wrong with a person. it's about what happened to a person.

TIC is a strengths-based framework which recognises the complex nature and effects of trauma and promotes resilience and healing.

5 KEY PRINCIPALS:

Safety
Creating areas that are calm & comfortable

Trust
Providing clear and consistent information

Choice
Providing an individual options in their treatment

Collaboration
Maximising collaboration among health care staff, patients and their families in organisations & treatment planning

Empowerment
Noticing capabilities in an individual

UNIVERSAL SCREENING

Prevents misdiagnosis and inappropriate treatment planning

THE FOUR R'S OF TIC

REALISE
All people at all levels have a basic realisation about trauma, and how it can affect i ndivudaks, families, and communitiies

RESIST RE-TRAUMATISATION
Organisational practices may compound trauma unintentionally, trauma informed organisations avoid this.

RECOGNISE
People within organisations are able to recognise the signs and symptoms of trauma

RESPOND
Programmes, organisations and communities respond by practicing a trauma-informed approach

> *"Trying to implement trauma-specific clinical practices without first implementing trauma-informed organisational culture change is like throwing seeds on dry land."*

Sandra Bloom, Creator of the Sancturay Model

Final Thoughts and Tips/Recommendations

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Advance Care Planning for Patients with Dementia: The Serious Illness Conversation-D

Amelia Cullinan, MD

March 4, 2025

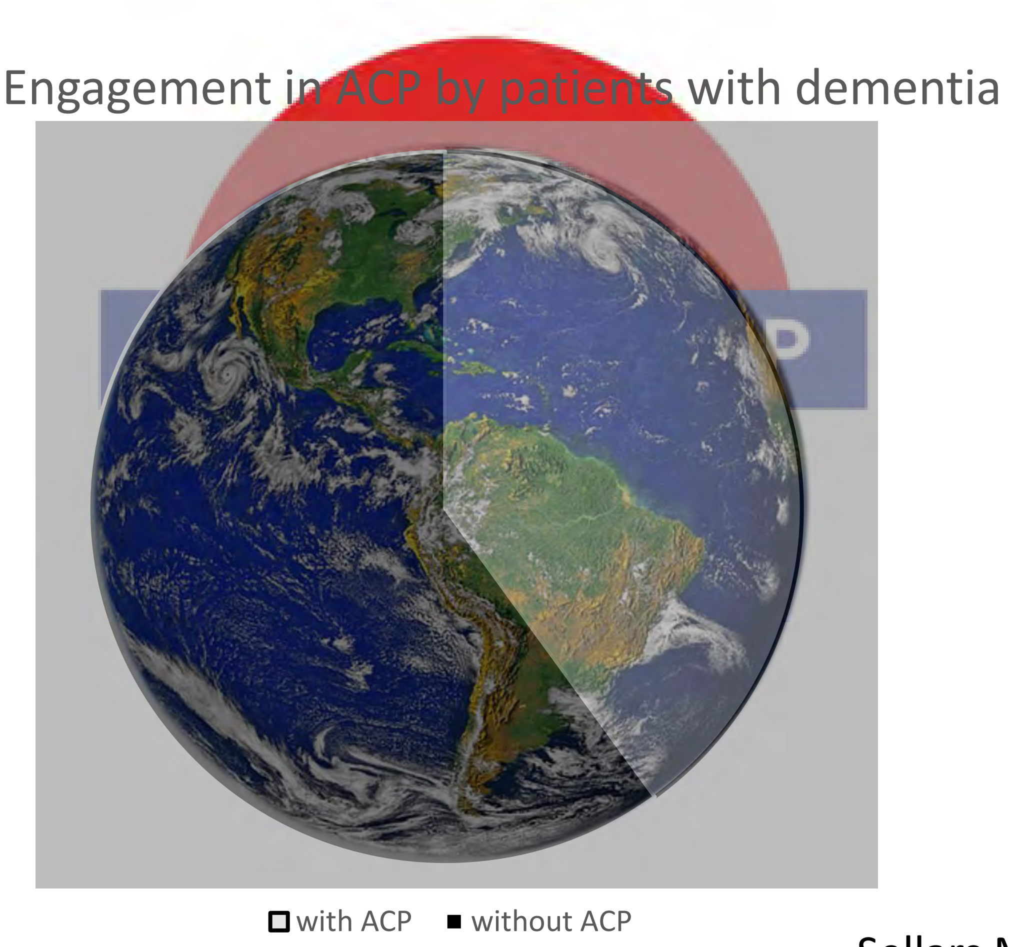
I have no disclosures!

Learning Objectives

By the end of this session, learners will be able to…

1. Describe at least 2 barriers to Advance Care Planning (ACP) for patients with dementia.
2. List at least 2 benefits of ACP for patients with dementia and their care partners.
3. Recall 3 key recommendations for ACP conversations with patients with dementia and their care partners
4. Compare and contrast the original Serious Illness Conversation Guide with the SIC-Dementia Guide

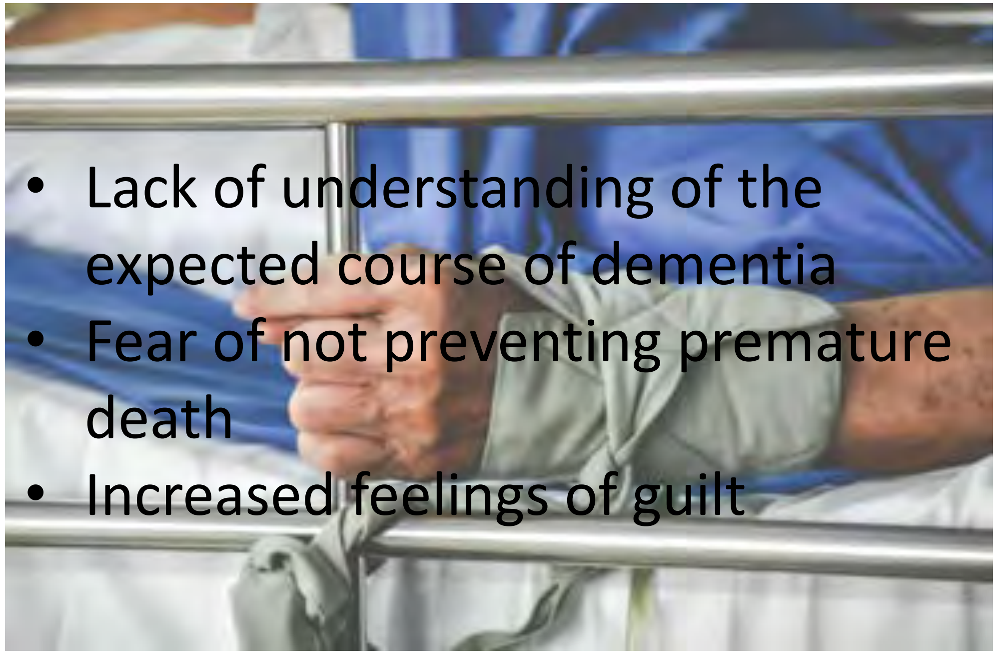
Let’s talk about the gap:
dementia is prevalent and not enough patients have engaged in advance care planning (ACP)



47 million
worldwide,
and rising

Sellars M Palliative Medicine 2019, Vol 33(3) 274-290..

This gap in ACP puts patients with dementia and their care partners at risk of suffering and strain



- Lack of understanding of the expected course of dementia
- Fear of not preventing premature death
- Increased feelings of guilt

Sellars M Palliative Medicine 2019, Vol 33(3) 274-290.
Dixon J Journal of Pain and Symptom Management 2018, Vol 55 (1) 132-150.

Why do so few patients with dementia engage in ACP?

Patient and care partner (CP) barriers to ACP

Care Partners (CP)

- Fear of having too much control
- Fear of upsetting the patient
- Too soon
- Not knowing which person's wishes to honor – the patient before or with dementia?

William Utermohlen

Sellars M Palliative Medicine 2019, Vol 33(3) 274-290.
Dixon J Journal of Pain and Symptom Management 2018, Vol 55 (1) 132-150.
Mezey MD Clinics in Geriatric Medicine 2000 Vol 16(2)

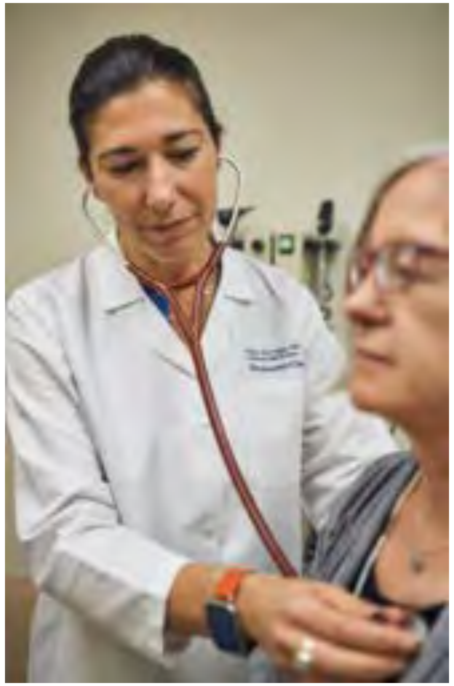
Healthcare professionals’ barriers to ACP

Too early:

- Don’t want to upset the patient or CP
- Want to wait until things reach a “terminal” stage

Too late:

- Concern that patients lack capacity to discuss it



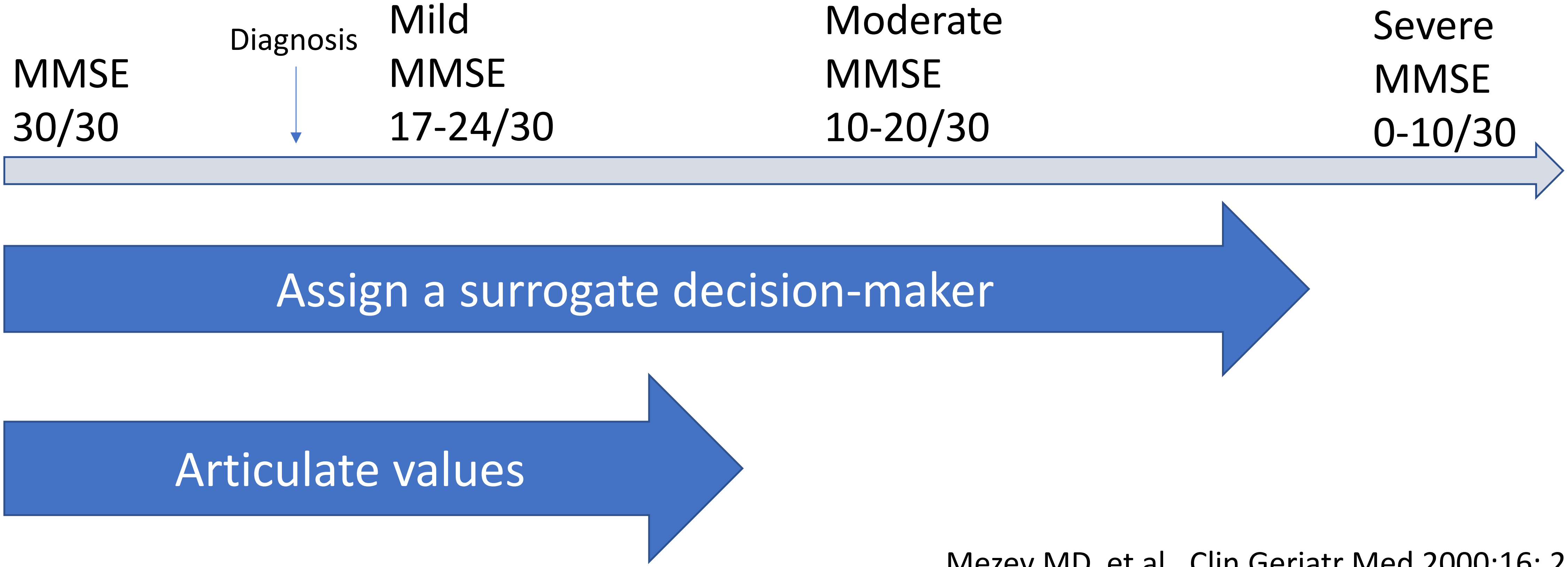
Lack of time for conversations

Fear

- of failure – letting the patient & CP down, not having things to help
- lack of confidence

Dixon J Journal of Pain and Symptom Management 2018, Vol 55 (1) 132-150.
Mezey MD Clinics in Geriatric Medicine 2000 Vol 16(2)
Brannan S J Med Ethics. 2016 Jun;42(6):409-10.

Patients with dementia will lose capacity eventually, but they can take an active role in ACP for a considerable portion of their illness



Mezey MD, et al. Clin Geriatr Med 2000;16: 255-268.
Pennington C Age and Ageing 2018; 47:778-784

ACP benefits both patients with dementia and their CPs

Patients with dementia

↑
- Death in preferred place
- Coping

↓
- Depression
- Decisional conflict
- Hospital admissions
- # of inpatient days
- PEG tubes
- Death in hospital
- ICU use in severe dementia

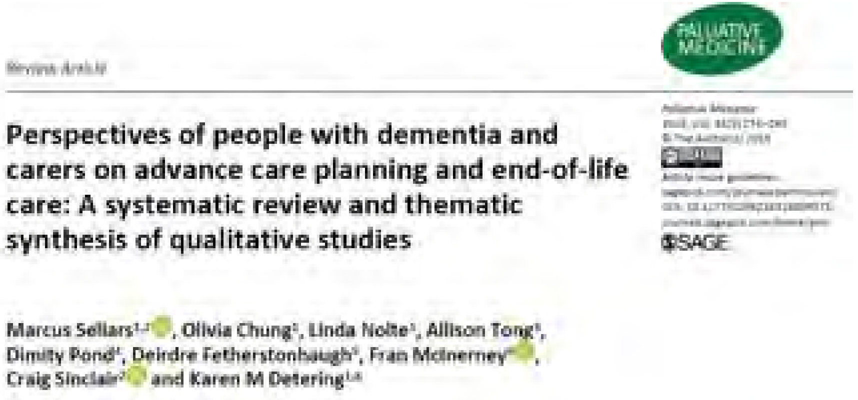
Care Partners

↑
- Satisfaction with pt care at EOL
- Satisfaction with conversations
- Quality of life

↓
- Feeling of responsibility for death
- Depression
- Anxiety

Sellars M Palliative Medicine 2019, Vol 33(3) 274-290.
Dixon J Journal of Pain and Symptom Management 2018, Vol 55 (1) 132-150

Filling the Gap: What do CPs want from healthcare clinicians?


Review Article

Perspectives of people with dementia and carers on advance care planning and end-of-life care: A systematic review and thematic synthesis of qualitative studies

Marcus Sellars, Olivia Chung, Linda Nolte, Allison Tong, Dimity Pond, Deirdre Fetherstonhaugh, Fran McInerney, Craig Sinclair and Karen M Detering

Education about what to expect

Iterative conversations

Recommendations from clinicians they trust

Best practices for ACP for patients with dementia

“Yo
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ly

- **First conversation**
  - Soon after diagnosis
  - Assign health care agent
  - Elicit values and goals
- **Revisit**
  - Changes in health status
  - After hospitalizations
  - Changes in place of residence
  - Changes in financial situation

Start early, revisit often

Listen for cues

Mezey MD, et al. Clin Geriatr Med 2000;16: 255-268
Pennington C Age and Ageing 2018; 47:778-784
Piers R BMC Palliative Care 2018 17:88

Best practices for ACP for patients with dementia

Patient Clinician Care Pa

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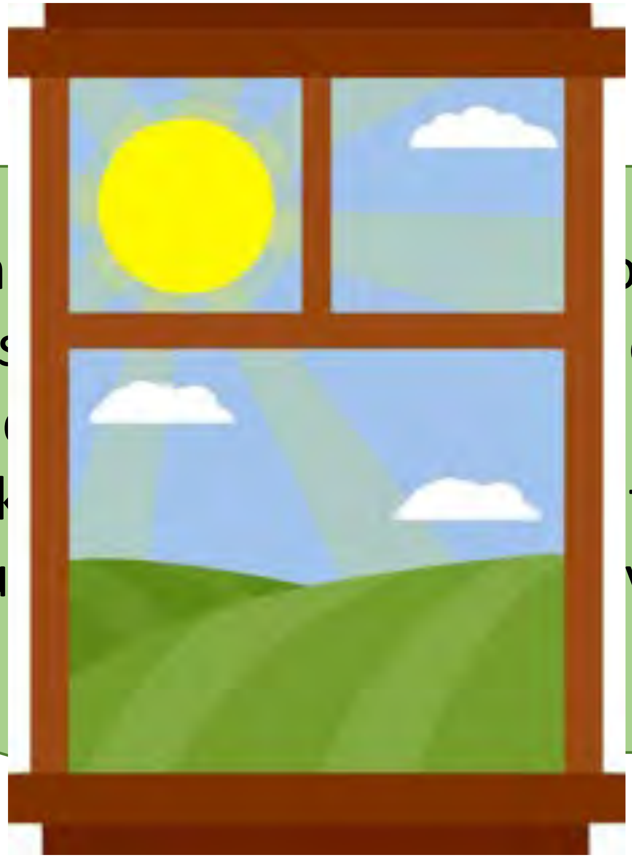

Optimize conditions

Assume capacity and empower HCP

Start early, revisit often

Listen for cues

Mezey MD, et al. Clin Geriatr Med 2000;16: 255-268
Pennington C Age and Ageing 2018; 47:778-784
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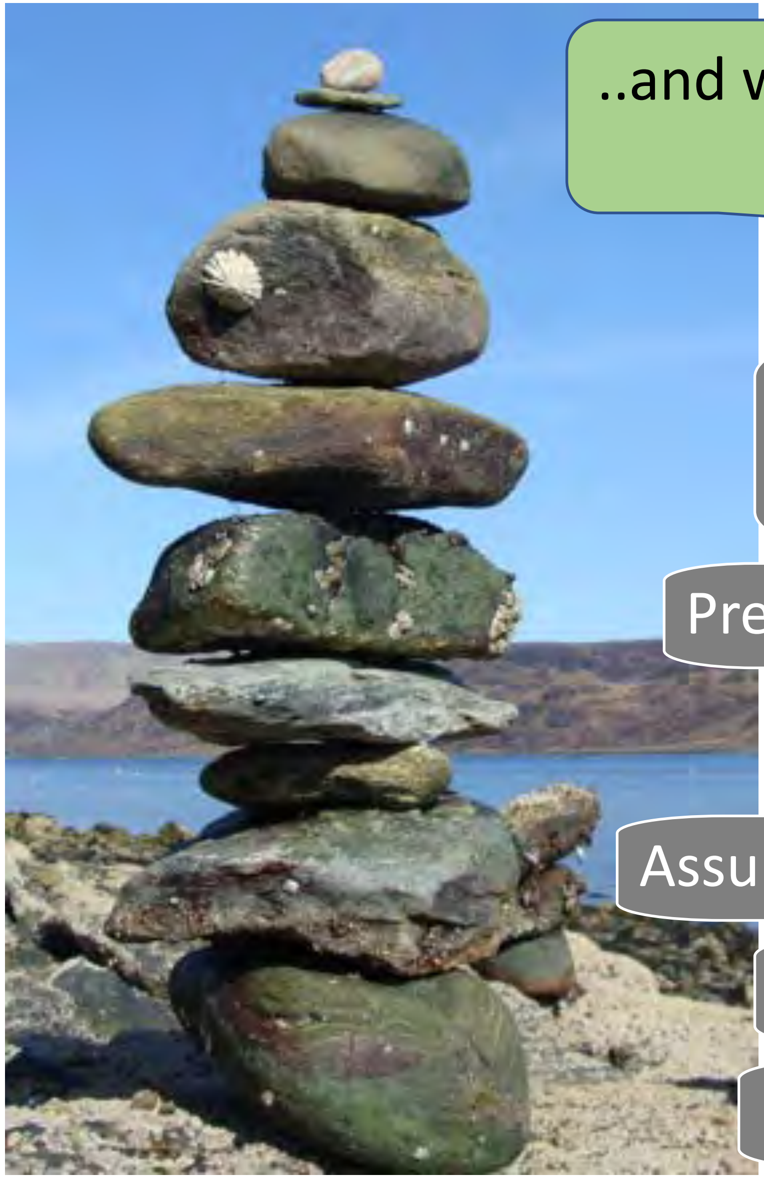
Best practices for ACP for patients with dementia



..and why does that feel right for you?”

“When you’re at the end of your life, where do you want to be cared for, at home or in a hospital?

“when you’re dying, will you want lots of treatments to try and get you more time, or would you like us to keep you comfortable and let nature take its course?”

- Elicit values and goals; make recommendations
- Prepare CP for the road ahead
- Optimize conditions
- Assume capacity and empower HCP
- Start early, revisit often
- Listen for cues

Mezey MD, et al. Clin Geriatr Med 2000;16: 255-268
Pennington C Age and Ageing 2018; 47:778-784
Piers R BMC Palliative Care 2018 17:88

Best practices for ACP for patients with dementia

Document

Expect emotion

Elicit values and goals; make recommendations

Prepare CP for the road ahead

Optimize conditions

Assume capacity and empower HCP

Start early, revisit often

Listen for cues

Mezey MD, et al. Clin Geriatr Med 2000;16: 255-268
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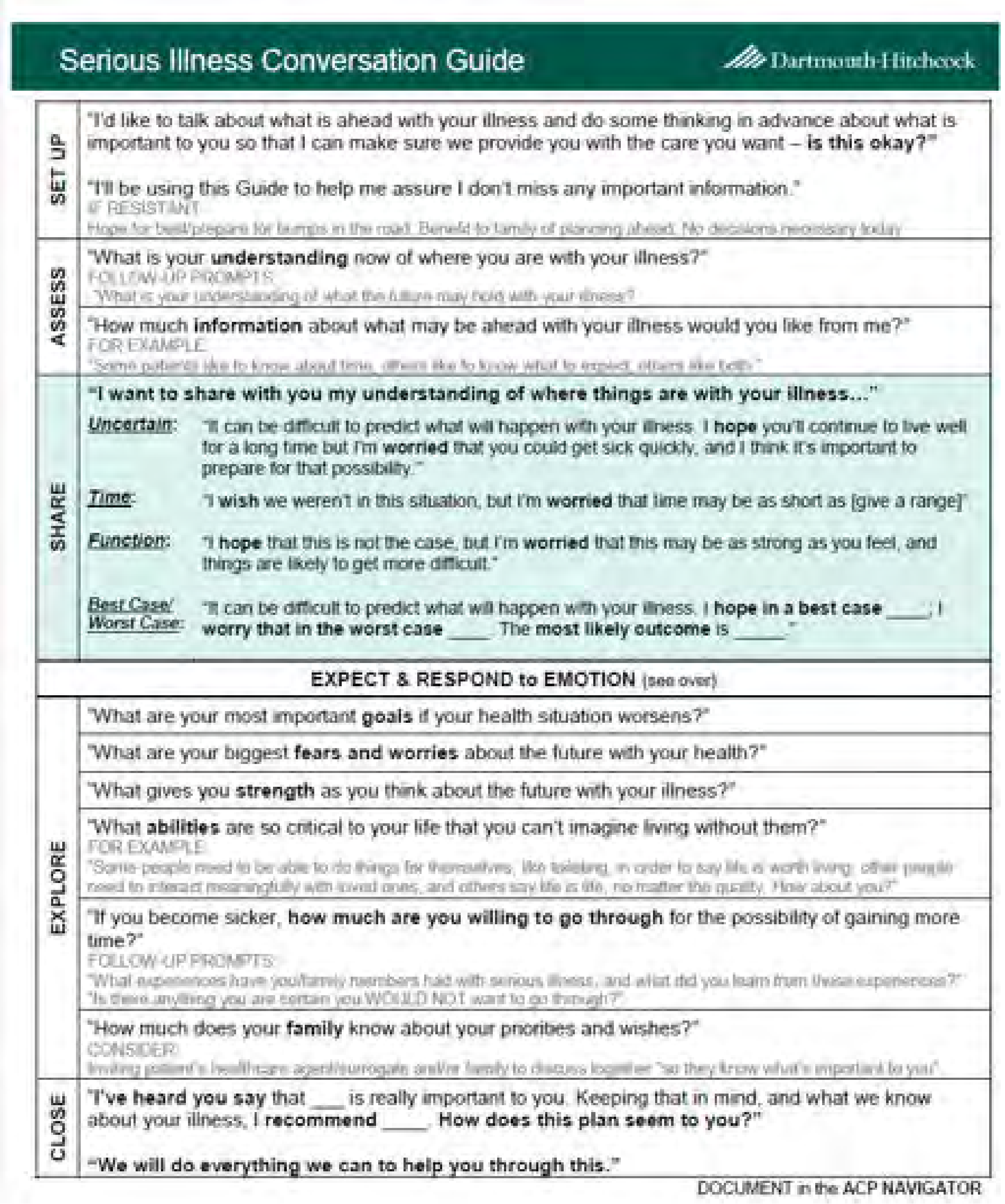
Piers R BMC Palliative Care 2018 17:88

The Serious Illness Conversation

an evidence-based, clinician-facing tool to facilitate discussion of values and goals for future care



Serious Illness Conversation Guide

Dartmouth-Hitchcock

SET UP	"I'd like to talk about what is ahead with your illness and do some thinking in advance about what is important to you so that I can make sure we provide you with the care you want – **is this okay?**" "I'll be using this Guide to help me assure I don't miss any important information." IF RESISTANT: Hope for best/prepare for bumps in the road. Benefit to family of planning ahead. No decisions necessary today
ASSESS	"What is your **understanding** now of where you are with your illness?" FOLLOW-UP PROMPTS: "What is your understanding of what the future may hold with your illness?"
	"How much **information** about what may be ahead with your illness would you like from me?" FOR EXAMPLE: "Some patients like to know about time, others like to know what to expect, others like both."
SHARE	**"I want to share with you my understanding of where things are with your illness..."** ***Uncertain***: "It can be difficult to predict what will happen with your illness. I **hope** you'll continue to live well for a long time but I'm **worried** that you could get sick quickly, and I think it's important to prepare for that possibility." ***Time***: "I **wish** we weren't in this situation, but I'm **worried** that time may be as short as [give a range]" ***Function***: "I **hope** that this is not the case, but I'm **worried** that this may be as strong as you feel, and things are likely to get more difficult." ***Best Case/ Worst Case***: "It can be difficult to predict what will happen with your illness. I **hope in a best case** ____; I **worry that in the worst case** ____. The **most likely outcome** is ____."
	EXPECT & RESPOND to EMOTION (see over)
EXPLORE	"What are your most important **goals** if your health situation worsens?"
	"What are your biggest **fears and worries** about the future with your health?"
	"What gives you **strength** as you think about the future with your illness?"
	"What **abilities** are so critical to your life that you can't imagine living without them?" FOR EXAMPLE: "Some people need to be able to do things for themselves, like toileting, in order to say life is worth living; other people need to interact meaningfully with loved ones, and others say life is life, no matter the quality. How about you?"
	"If you become sicker, **how much are you willing to go through** for the possibility of gaining more time?" FOLLOW-UP PROMPTS: "What experiences have you/family members had with serious illness, and what did you learn from these experiences?" "Is there anything you are certain you WOULD NOT want to go through?"
	"How much does your **family** know about your priorities and wishes?" CONSIDER: Inviting patient's healthcare agent/surrogate and/or family to discuss together "so they know what's important to you"
CLOSE	"I**'ve heard you say** that ___ is really important to you. Keeping that in mind, and what we know about your illness, I **recommend** ____. **How does this plan seem to you?**" **"We will do everything we can to help you through this."**

DOCUMENT in the ACP NAVIGATOR

Adapting the Serious Illness Conversation Guide for Dementia Care

American Journal of Hospice
& Palliative Medicine®
2024, Vol. 41(8) 942–951

DOI: 10.1177/10499091231200214
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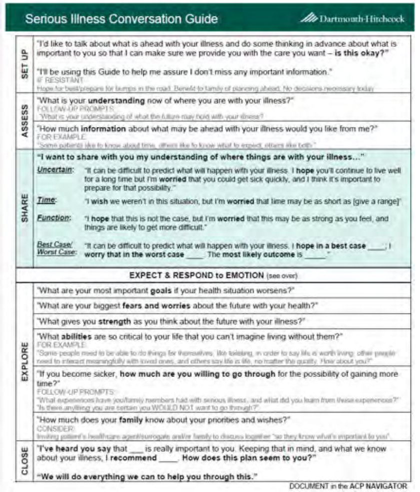
Charlotte E. Berry, BA[1]
Robert Santulli, MD[1], ar



Serious Illness Conversation Guide

SET UP	"I'd like to talk about what is ahead with your illness and do some thinking in advance about what is important to you so that I can make sure we provide you with the care you want – **is this okay?"** "I'll be using this Guide to help me assure I don't miss any important information." IF RESISTANT: Hope for best/prepare for bumps in the road. Benefit to family of planning ahead. No decisions necessary today
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SHARE	**"I want to share with you my understanding of where things are with your illness…"**
	Uncertain: "It can be difficult to predict what will happen with your illness. I **hope** you'll continue to live well for a long time but I'm **worried** that you could get sick quickly, and I think it's important to prepare for that possibility."
	Time: "I **wish** we weren't in this situation, but I'm **worried** that time may be as short as [give a range]"
	Function: "I **hope** that this is not the case, but I'm **worried** that this may be as strong as you feel, and things are likely to get more difficult."
	Best Case/ Worst Case: "It can be difficult to predict what will happen with your illness. I **hope in a best case** ____; I **worry that in the worst case** ____. The **most likely outcome** is ____."
EXPECT & RESPOND to EMOTION (see over)	
EXPLORE	"What are your most important **goals** if your health situation worsens?"
	"What are your biggest **fears and worries** about the future with your health?"
	"What gives you **strength** as you think about the future with your illness?"
	"What **abilities** are so critical to your life that you can't imagine living without them?" FOR EXAMPLE: "Some people need to be able to do things for themselves, like toileting, in order to say life is worth living; other people need to interact meaningfully with loved ones, and others say life is life, no matter the quality. How about you?"
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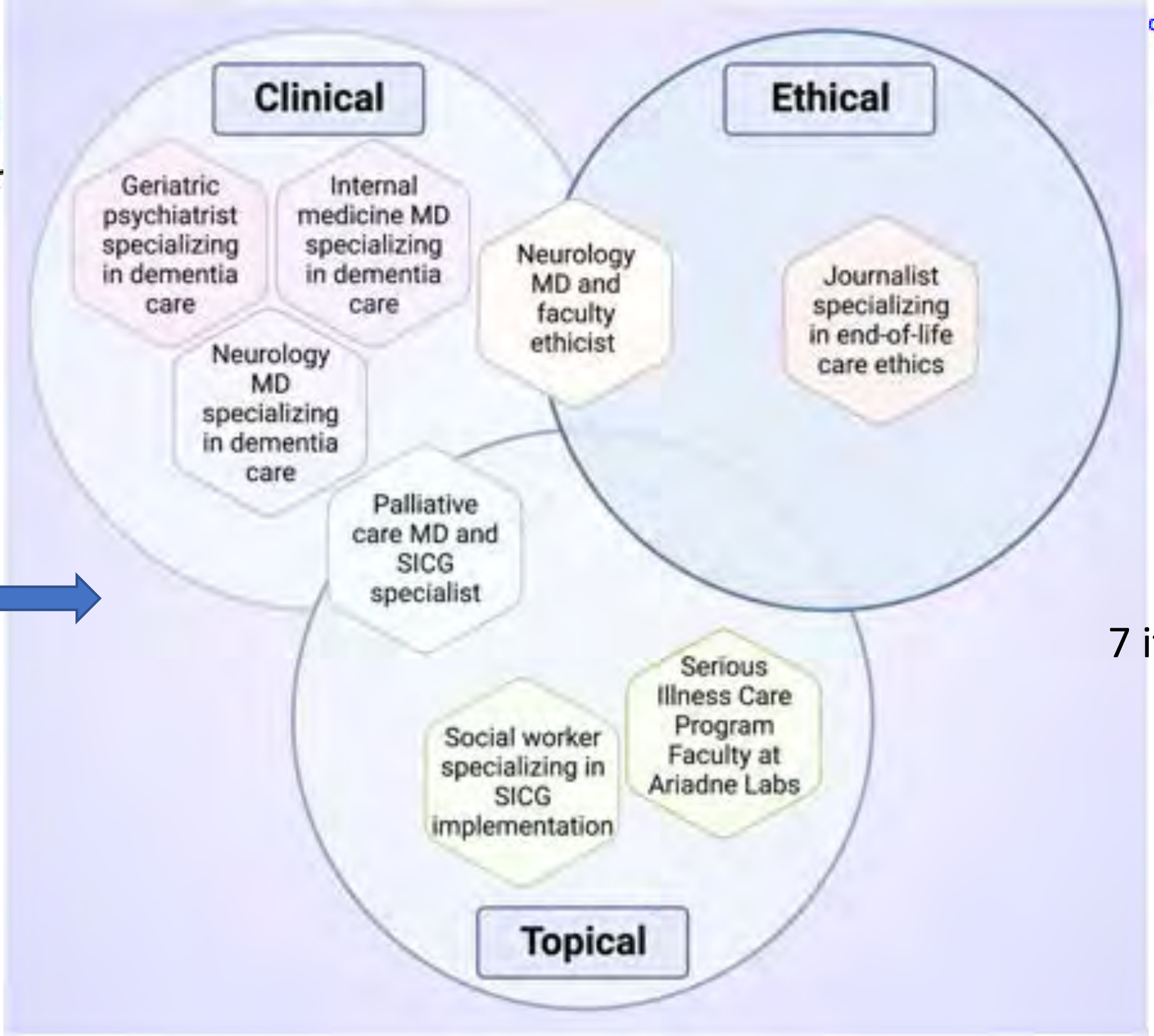
CLOSE	**"I've heard you say** that ___ is really important to you. Keeping that in mind, and what we know about your illness, I **recommend** ____. **How does this plan seem to you?"** **"We will do everything we can to help you through this."**

DOCUMENT in the ACP NAVIGATOR

SIC - Original



Clinical

Geriatric psychiatrist specializing in dementia care

Internal medicine MD specializing in dementia care

Neurology MD specializing in dementia care

Neurology MD and faculty ethicist

Ethical

Journalist specializing in end-of-life care ethics

Palliative care MD and SICG specialist

Social worker specializing in SICG implementation

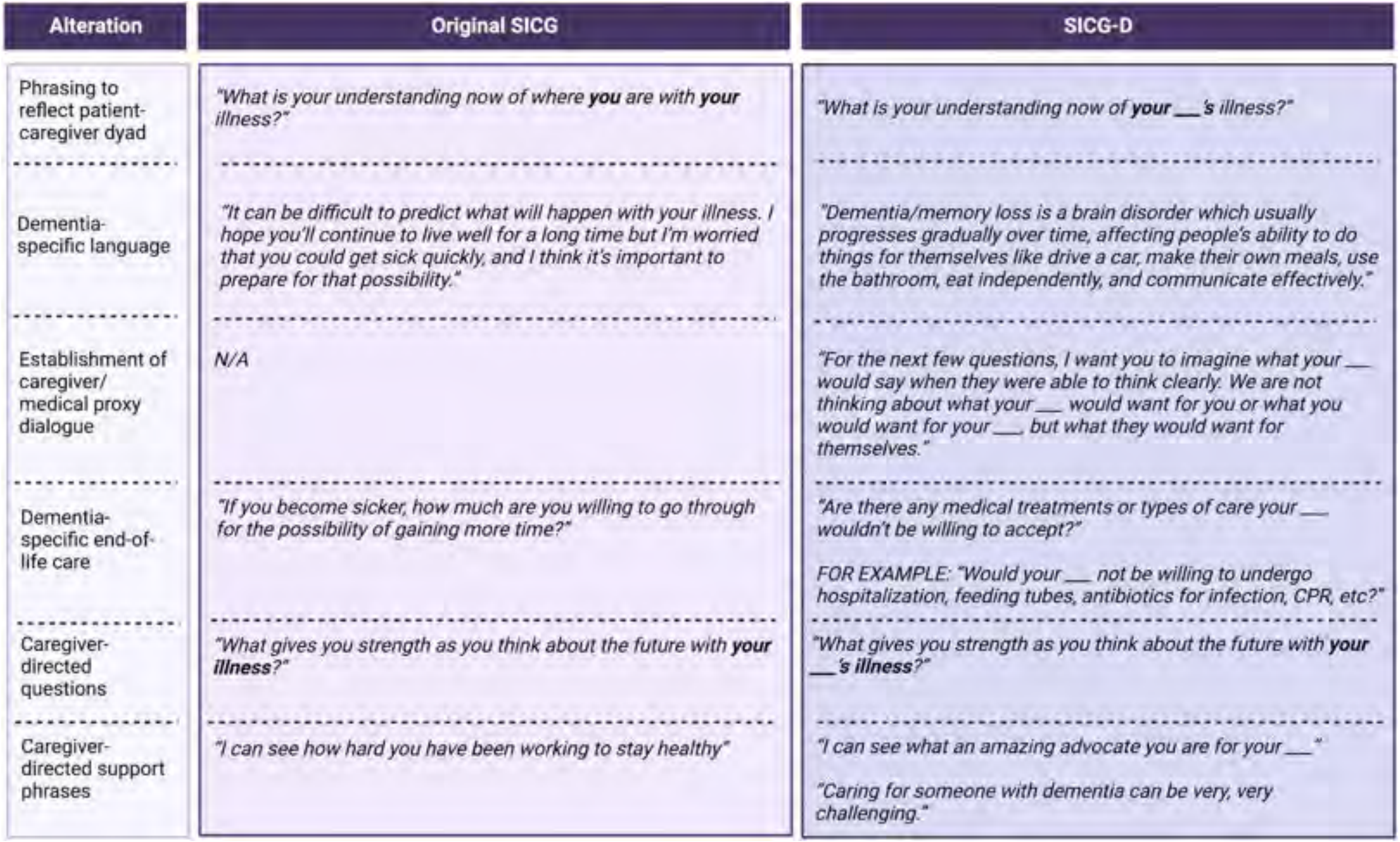
Serious Illness Care Program Faculty at Ariadne Labs

Topical

7 iterations

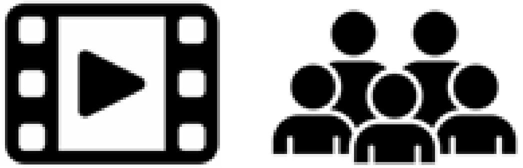
Serious Illness Conversation Guide

SIC-Dementia



Alteration	Original SICG	SICG-D
Phrasing to reflect patient-caregiver dyad	*"What is your understanding now of where **you** are with **your** illness?"*	*"What is your understanding now of **your ___'s** illness?"*
Dementia-specific language	*"It can be difficult to predict what will happen with your illness. I hope you'll continue to live well for a long time but I'm worried that you could get sick quickly, and I think it's important to prepare for that possibility."*	*"Dementia/memory loss is a brain disorder which usually progresses gradually over time, affecting people's ability to do things for themselves like drive a car, make their own meals, use the bathroom, eat independently, and communicate effectively."*
Establishment of caregiver/ medical proxy dialogue	*N/A*	*"For the next few questions, I want you to imagine what your ___ would say when they were able to think clearly. We are not thinking about what your ___ would want for you or what you would want for your ___, but what they would want for themselves."*
Dementia-specific end-of-life care	*"If you become sicker, how much are you willing to go through for the possibility of gaining more time?"*	*"Are there any medical treatments or types of care your ___ wouldn't be willing to accept?"* *FOR EXAMPLE: "Would your ___ not be willing to undergo hospitalization, feeding tubes, antibiotics for infection, CPR, etc?"*
Caregiver-directed questions	*"What gives you strength as you think about the future with **your illness**?"*	*"What gives you strength as you think about the future with **your ___'s illness**?"*
Caregiver-directed support phrases	*"I can see how hard you have been working to stay healthy"*	*"I can see what an amazing advocate you are for your ___"* *"Caring for someone with dementia can be very, very challenging."*


Serious Illness Conversation Guide

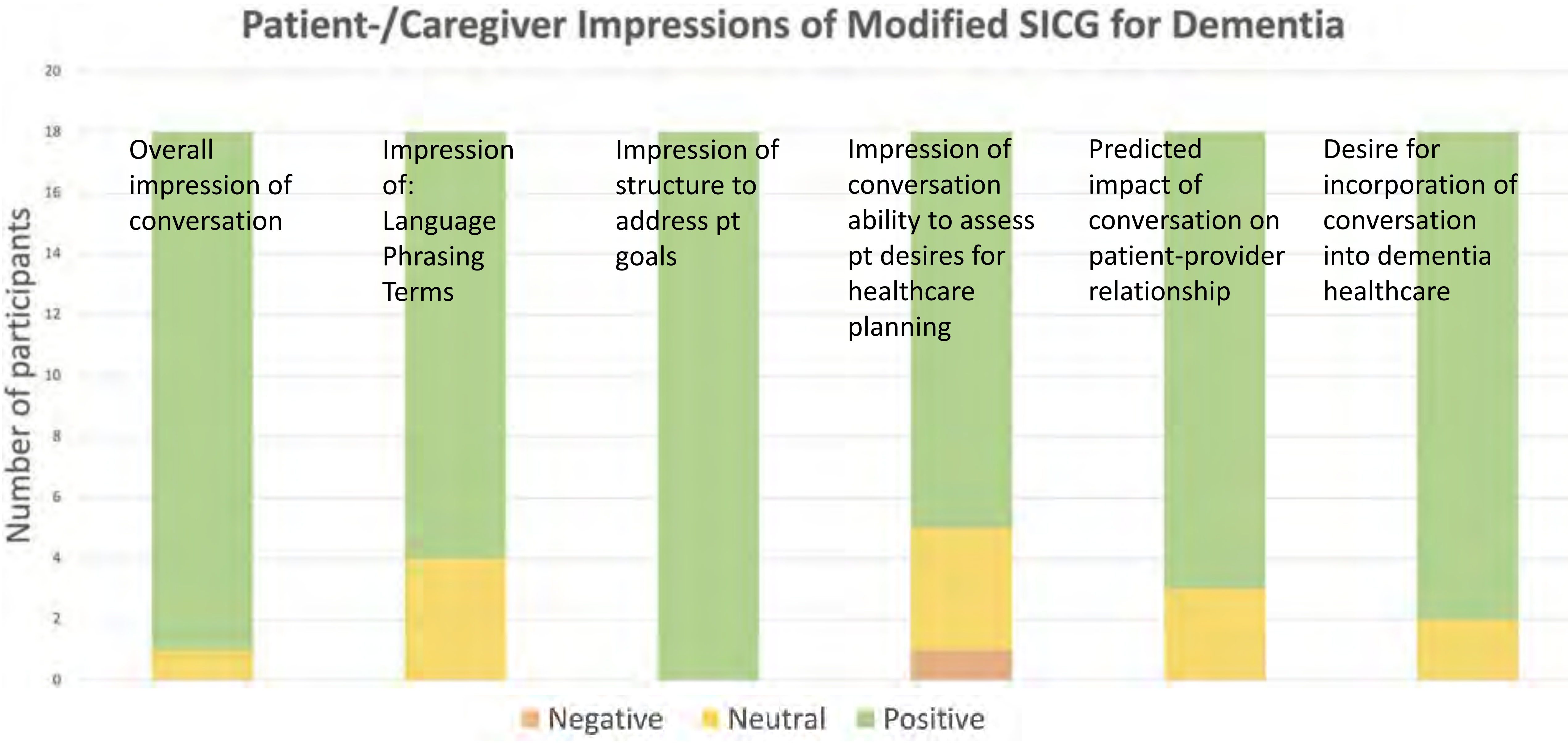

14 people with dementia
18 care partners

Thematic analysis

Anonymous quantitative survey

- Thematic analysis (n=32, 12 patient + CP, 2 pt alone, 6 CP alone)
- Appreciation of open-ended prompts
  - “It seemed more like a conversation than most appointments I have had. A lot of back and forth and open-ended questions, which I liked.”
- Value of ACP conversations
  - “These are the conversations my wife and I should have been having when she was diagnosed, but nobody initiated them with us.”
- Appreciation of inclusion of CP
  - “Things have gotten really tough in the past two years, I wish the doctors realized how tough it is for me, too.”
- Appreciation of framing for CP when acting as a surrogate
  - “I liked the line about how it’s not necessarily about what you would want for yourself. I will think about that at the next appointment we have, I think.”

Berry CE et al. Am J Hosp Pall Med 2024: 41(8) 942-951



Overall impression of conversation

Impression of: Language Phrasing Terms

Impression of structure to address pt goals

Impression of conversation ability to assess pt desires for healthcare planning

Predicted impact of conversation on patient-provider relationship

Desire for incorporation of conversation into dementia healthcare

Berry CE et al. Am J Hosp Pall Med 2024: 41(8) 942-951

Closing Pearls

- ACP in patients with dementia is feasible and impactful
- Use structured tools to assess capacity AND incorporate health care agents/surrogates in conversations
- Use structured tools for conversations about goals and values
- Talk honestly and practically about what to expect
- Empower and tend to the emotional experience of care partners
- Revisit conversations over time