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

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Palliative Care Echo Session #1 October 1, 2024

Learning Objectives

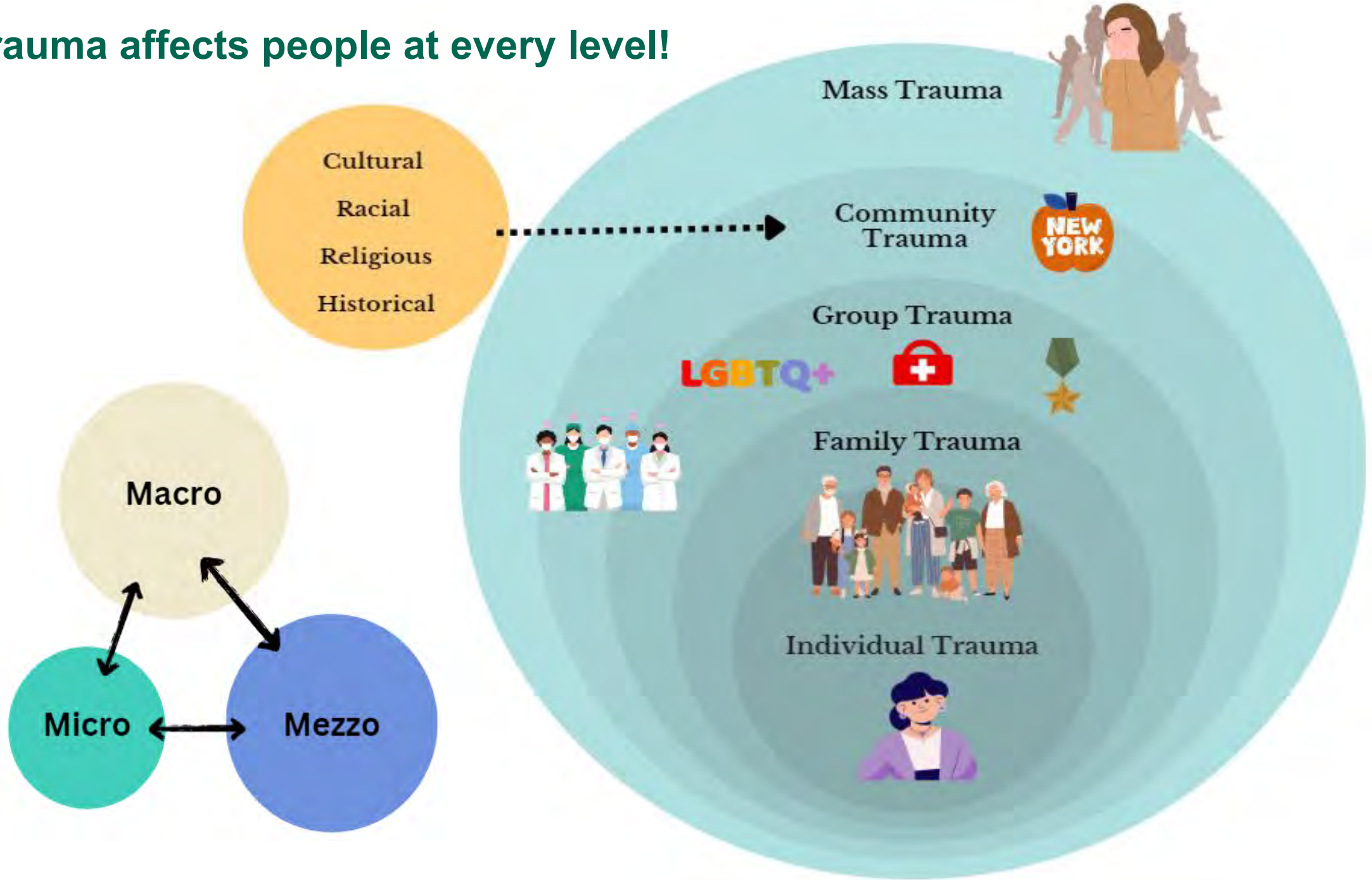
By the end of this session, ECHO participants will be able to:

- 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.

EVENTS → EXPERIENCES → EFFECTS

Trauma affects people at every level!



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

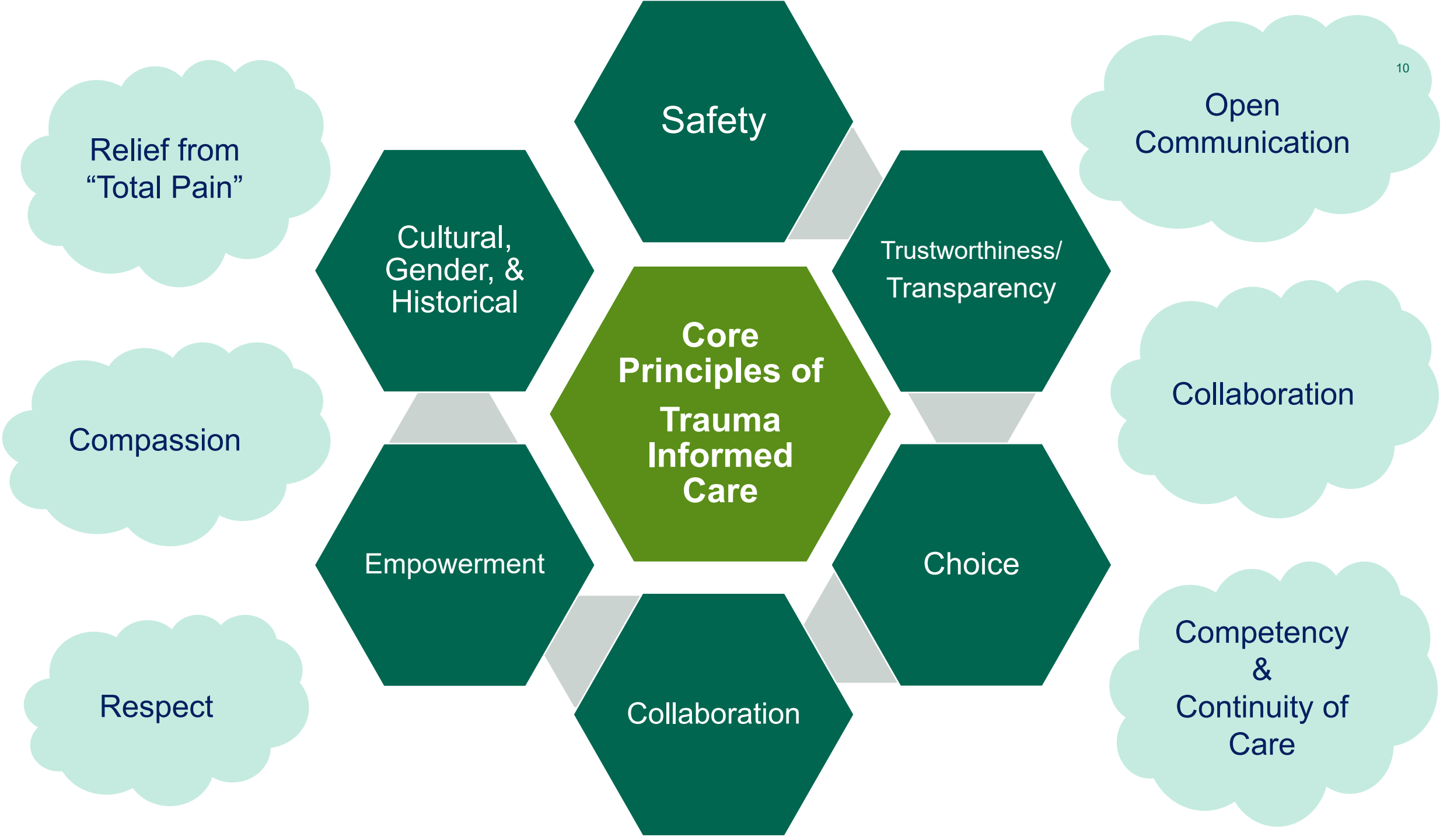
Trauma-informed approach is defined as:

"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


Relief from "Total Pain"
Compassion
Respect
Safety
Cultural, Gender, & Historical
Trustworthiness/ Transparency
Core Principles of Trauma Informed Care
Empowerment
Choice
Collaboration
Open Communication
Collaboration
Competency & Continuity of Care

Ask questions to assess an individual's trauma history.

“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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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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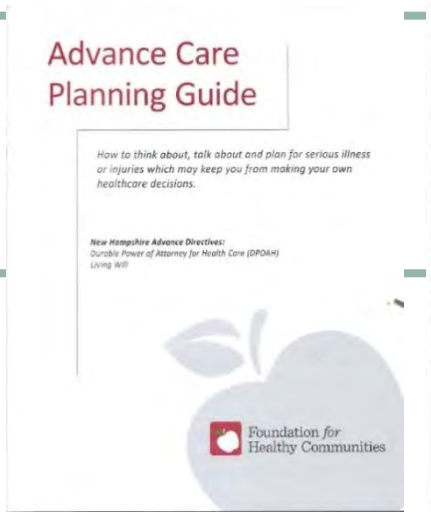
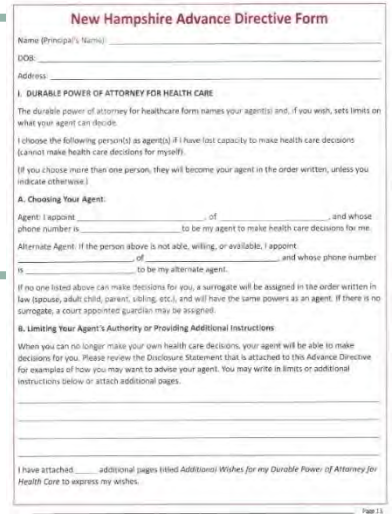
Recent Research



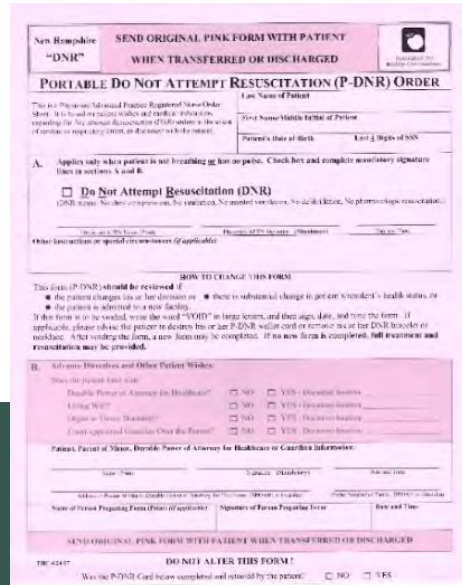


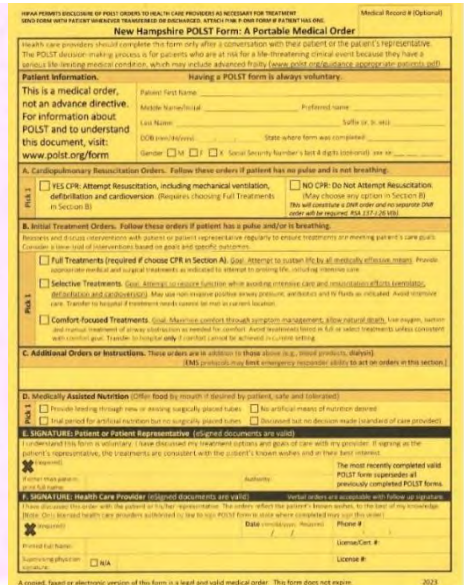
Advance Directives (AD's) are not available

- 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

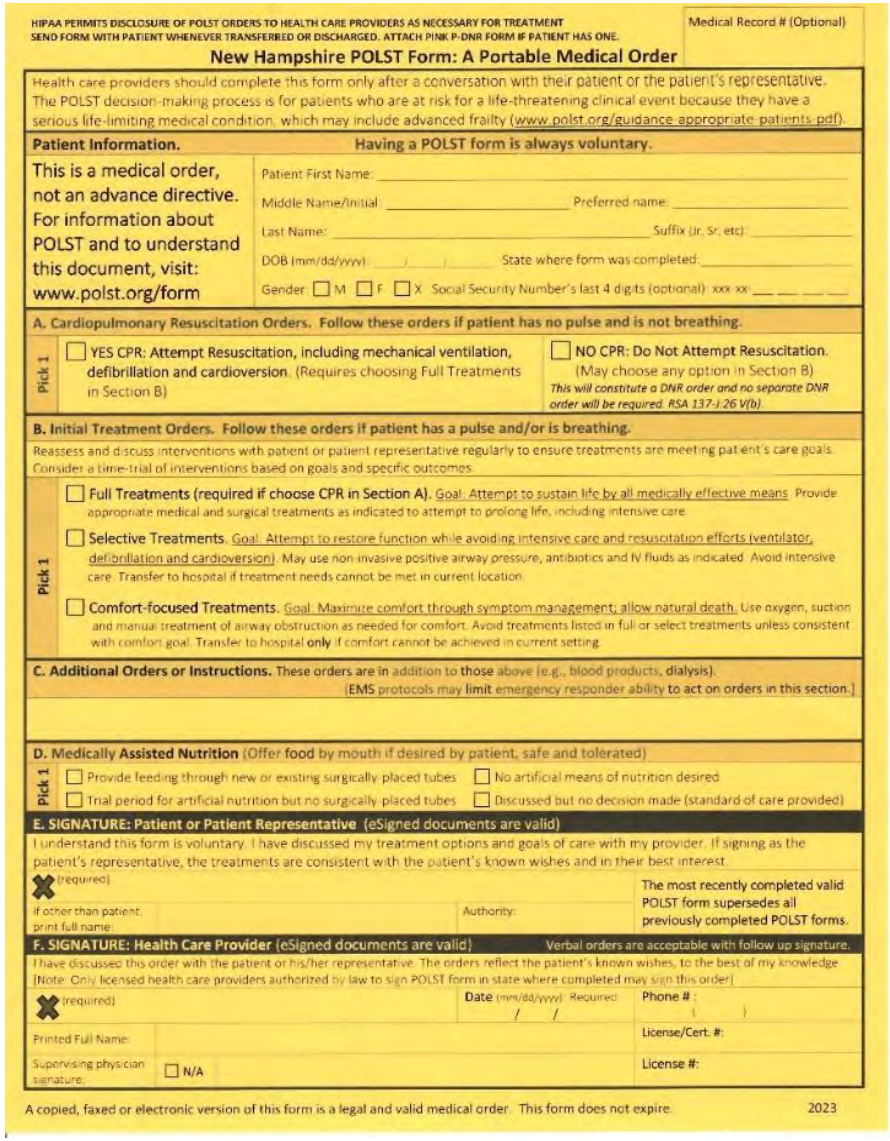
- @10% of elderly ill patients in ED are asked about AD's
- @80% thought ED providers should be aware
- <40% expressed desire to discuss goals of care





*References in chat

What PC Providers can offer the ED



HIPAA PERMITS DISCLOSURE OF POLST ORDERS TO HEALTH CARE PROVIDERS AS NECESSARY FOR TREATMENT
SEND FORM WITH PATIENT WHENEVER TRANSFERRED OR DISCHARGED. ATTACH PINK P-DNR FORM IF PATIENT HAS ONE.

Medical Record # (Optional)

New Hampshire POLST Form: A Portable Medical Order

Health care providers should complete this form only after a conversation with their patient or the patient's representative. The POLST decision-making process is for patients who are at risk for a life-threatening clinical event because they have a serious life-limiting medical condition, which may include advanced frailty (www.polst.org/guidance-appropriate-patients.pdf).

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

Patient First Name:
Middle Name/Initial: Preferred name:
Last Name: Suffix (Jr, Sr, etc):
DOB (mm/dd/yyyy): / / State where form was completed:
Gender ☐ M ☐ F ☐ X Social Security Number's last 4 digits (optional): xxx xx ___ ___ ___ ___

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)
This will constitute a DNR order and no separate DNR order will be required. RSA 137-J:26 V(b)

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

Reassess and discuss interventions with patient or patient representative regularly to ensure treatments are meeting patient's care goals. Consider a time-trial of interventions based on goals and specific outcomes.

Pick 1

☐ **Full Treatments (required if choose CPR in Section A).** Goal: Attempt to sustain life by all medically effective means. Provide appropriate medical and surgical treatments as indicated to attempt to prolong life, including intensive care.

☐ **Selective Treatments.** Goal: Attempt to restore function while avoiding intensive care and resuscitation efforts (ventilator, defibrillation and cardioversion). May use non-invasive positive airway pressure, antibiotics and IV fluids as indicated. Avoid intensive care. Transfer to hospital if treatment needs cannot be met in current location.

☐ **Comfort-focused Treatments.** Goal: Maximize comfort through symptom management; allow natural death. Use oxygen, suction and manual treatment of airway obstruction as needed for comfort. Avoid treatments listed in full or select treatments unless consistent with comfort goal. Transfer to hospital **only** if comfort cannot be achieved in current setting.

C. Additional Orders or Instructions. These orders are in addition to those above (e.g., blood products, dialysis).
[EMS protocols may limit emergency responder ability to act on orders in this section.]

D. Medically Assisted Nutrition (Offer food by mouth if desired by patient, safe and tolerated)

Pick 1

☐ Provide feeding through new or existing surgically placed tubes ☐ No artificial means of nutrition desired
☐ Trial period for artificial nutrition but no surgically placed tubes ☐ Discussed but no decision made (standard of care provided)

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

I understand this form is voluntary. I have discussed my treatment options and goals of care with my provider. If signing as the patient's representative, the treatments are consistent with the patient's known wishes and in their best interest.

✖ (required)

If other than patient, print full name: Authority:

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

F. SIGNATURE: Health Care Provider (eSigned documents are valid) Verbal orders are acceptable with follow up signature.

I have discussed this order with the patient or his/her representative. The orders reflect the patient's known wishes, to the best of my knowledge. (Note: Only licensed health care providers authorized by law to sign POLST form in state where completed may sign this order.)

✖ (required) Date (mm/dd/yyyy): Required / / Phone # : ( )

Printed Full Name: License/Cert. #:

Supervising physician signature: ☐ N/A License #:

A copied, faxed or electronic version of this form is a legal and valid medical order. This form does not expire. 2023

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

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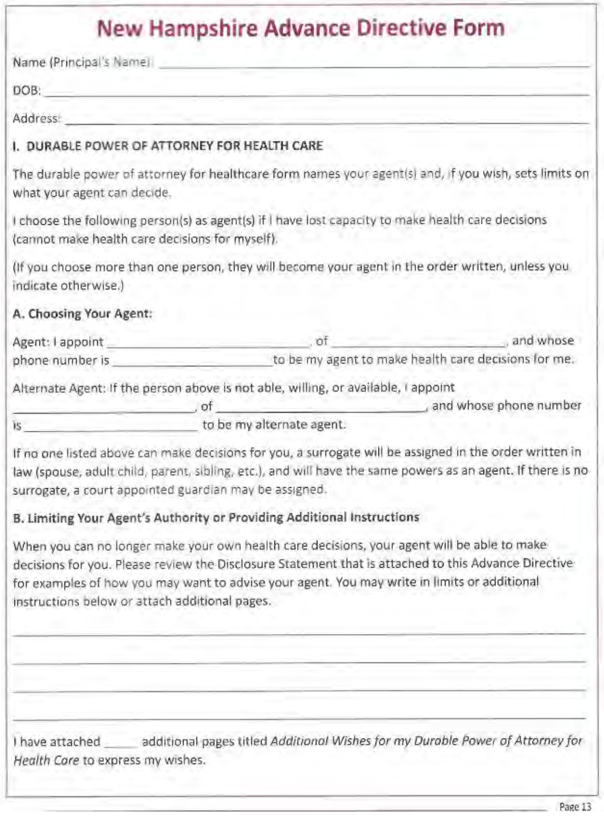
What PC Providers can offer the ED

New Hampshire Forms



New Hampshire Advance Directive Form

Name (Principal's Name): ______

DOB: ______

Address: ______

I. DURABLE POWER OF ATTORNEY FOR HEALTH CARE

The durable power of attorney for healthcare form names your agent(s) and, if you wish, sets limits on what your agent can decide.

I choose the following person(s) as agent(s) if I have lost capacity to make health care decisions (cannot make health care decisions for myself).

(If you choose more than one person, they will become your agent in the order written, unless you indicate otherwise.)

A. Choosing Your Agent:

Agent: I appoint ______, of ______, and whose phone number is ______ to be my agent to make health care decisions for me.

Alternate Agent: If the person above is not able, willing, or available, I appoint ______, of ______, and whose phone number is ______ to be my alternate agent.

If no one listed above can make decisions for you, a surrogate will be assigned in the order written in law (spouse, adult child, parent, sibling, etc.), and will have the same powers as an agent. If there is no surrogate, a court appointed guardian may be assigned.

B. Limiting Your Agent's Authority or Providing Additional Instructions

When you can no longer make your own health care decisions, your agent will be able to make decisions for you. Please review the Disclosure Statement that is attached to this Advance Directive for examples of how you may want to advise your agent. You may write in limits or additional instructions below or attach additional pages.

I have attached ____ additional pages titled *Additional Wishes for my Durable Power of Attorney for Health Care* to express my wishes.

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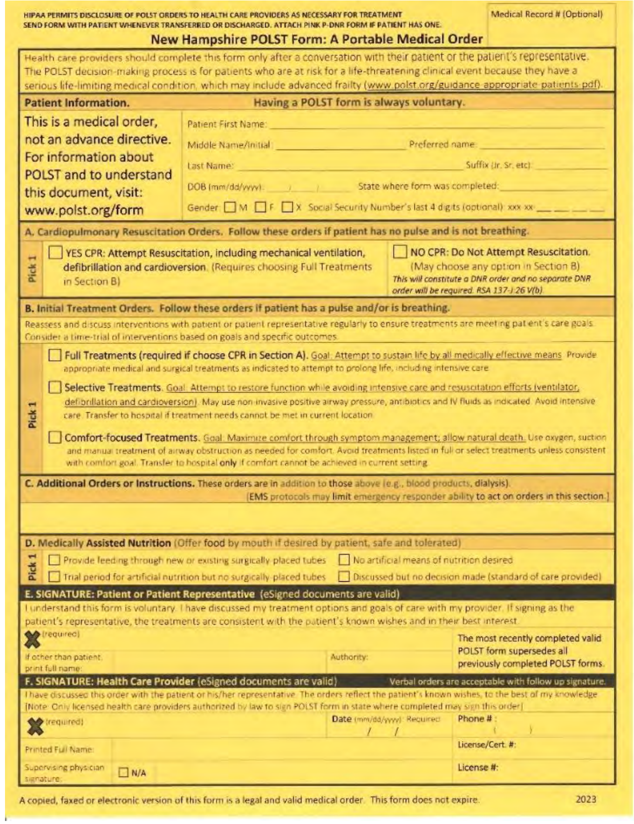

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Patient First Name: / Middle Name/Initial: / Preferred name: / Last Name: / Suffix (Jr, Sr, etc): / DOB (mm/dd/yyyy): / State where form was completed: / Gender ☐ M ☐ F ☐ X Social Security Number's last 4 digits (optional): xxx-xx-____

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

☐ 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) *This will constitute a DNR order and no separate DNR order will be required. RSA 137-J:26 V(b)*

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.

D. Medically Assisted Nutrition

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

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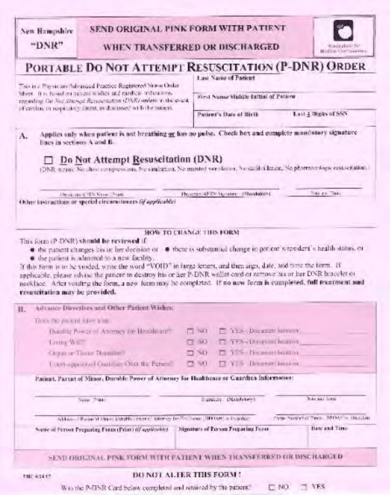

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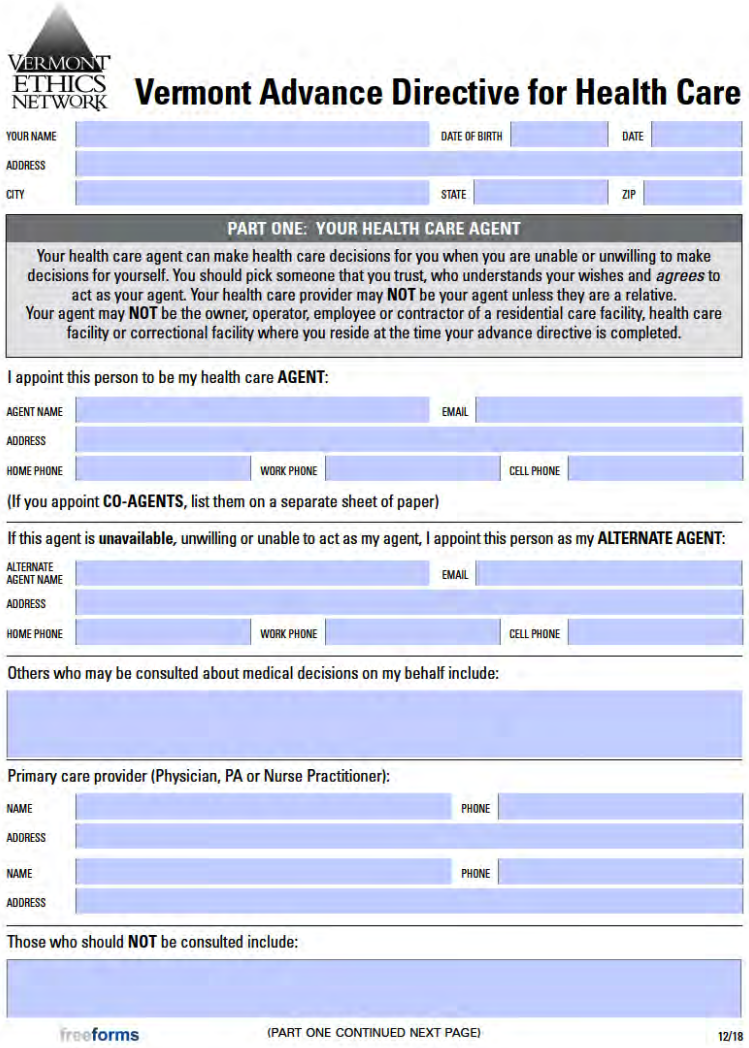
What PC Providers can offer the ED

Vermont Forms

- Short Form
- Long Form
- Registry
- COLST



VERMONT ETHICS NETWORK

Vermont Advance Directive for Health Care

YOUR NAME | DATE OF BIRTH | DATE

ADDRESS

CITY | STATE | ZIP

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**:

AGENT NAME | EMAIL

ADDRESS

HOME PHONE | WORK PHONE | CELL PHONE

(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**:

ALTERNATE AGENT NAME | EMAIL

ADDRESS

HOME PHONE | WORK PHONE | CELL PHONE

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

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

NAME | PHONE

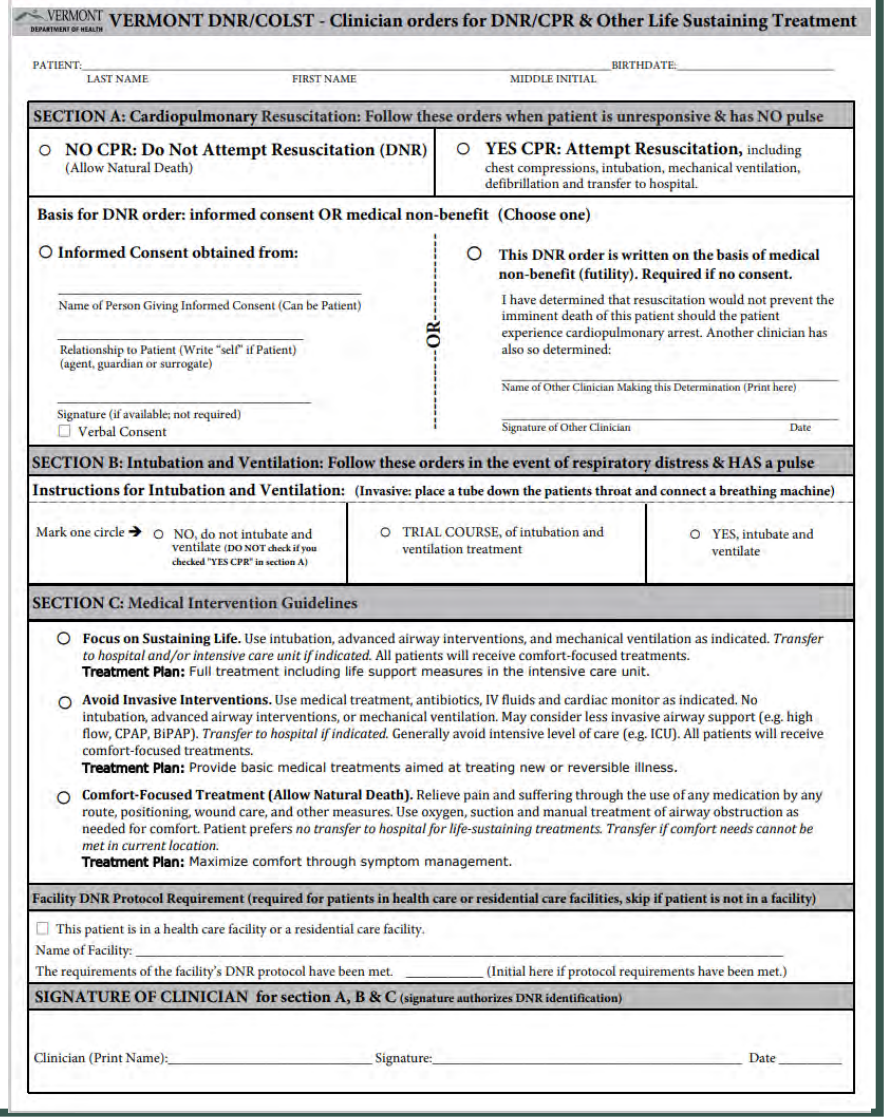
ADDRESS

NAME | PHONE

ADDRESS

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

freeforms (PART ONE CONTINUED NEXT PAGE) 12/18



VERMONT DEPARTMENT OF HEALTH **VERMONT DNR/COLST - Clinician orders for DNR/CPR & Other Life Sustaining Treatment**

PATIENT: _____ BIRTHDATE: _____
LAST NAME FIRST NAME MIDDLE INITIAL

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,** including chest compressions, intubation, mechanical ventilation, defibrillation and transfer to hospital.

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

○ **Informed Consent obtained from:**

Name of Person Giving Informed Consent (Can be Patient)

Relationship to Patient (Write "self" if Patient) (agent, guardian or surrogate)

Signature (if available; not required)

☐ Verbal Consent

OR

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

I have determined that resuscitation would not prevent the imminent death of this patient should the patient experience cardiopulmonary arrest. Another clinician has also so determined:

Name of Other Clinician Making this Determination (Print here)

Signature of Other Clinician Date

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

Instructions for Intubation and Ventilation: (Invasive: place a tube down the patients throat and connect a breathing machine)

Mark one circle ➔ ○ NO, do not intubate and ventilate (DO NOT check if you checked "YES CPR" in section A) | ○ TRIAL COURSE, of intubation and ventilation treatment | ○ YES, intubate and ventilate

SECTION C: Medical Intervention Guidelines

○ **Focus on Sustaining Life.** Use intubation, advanced airway interventions, and mechanical ventilation as indicated. *Transfer to hospital and/or intensive care unit if indicated.* All patients will receive comfort-focused treatments.
Treatment Plan: Full treatment including life support measures in the intensive care unit.

○ **Avoid Invasive Interventions.** Use medical treatment, antibiotics, IV fluids and cardiac monitor as indicated. No intubation, advanced airway interventions, or mechanical ventilation. May consider less invasive airway support (e.g. high flow, CPAP, BiPAP). *Transfer to hospital if indicated.* Generally avoid intensive level of care (e.g. ICU). All patients will receive comfort-focused treatments.
Treatment Plan: Provide basic medical treatments aimed at treating new or reversible illness.

○ **Comfort-Focused Treatment (Allow Natural Death).** Relieve pain and suffering through the use of any medication by any route, positioning, wound care, and other measures. Use oxygen, suction and manual treatment of airway obstruction as needed for comfort. Patient prefers *no transfer to hospital for life-sustaining treatments. Transfer if comfort needs cannot be met in current location.*
Treatment Plan: Maximize comfort through symptom management.

Facility DNR Protocol Requirement (required for patients in health care or residential care facilities, skip if patient is not in a facility)

☐ This patient is in a health care facility or a residential care facility.

Name of Facility: _____

The requirements of the facility's DNR protocol have been met. _____ (Initial here if protocol requirements have been met.)

SIGNATURE OF CLINICIAN for section A, B & C (signature authorizes DNR identification)

Clinician (Print Name): _____ Signature: _____ Date _____

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?”*

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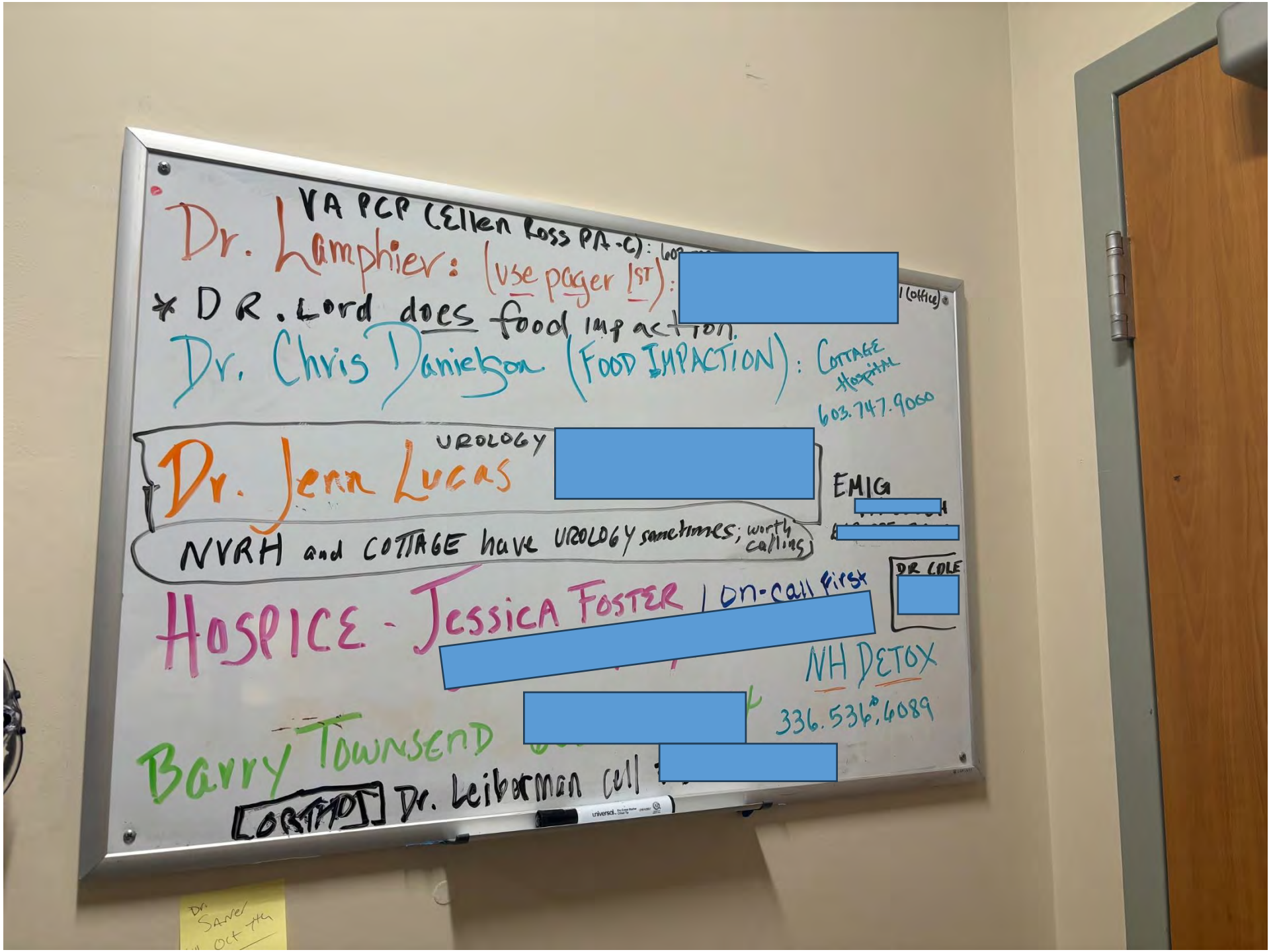
VA PCP (Ellen Ross PA-C):
Dr. Lamphier: (use pager 1ST):
* DR. Lord does food impaction.
Dr. Chris Danielson (FOOD IMPACTION): COTTAGE Hospital
603.747.9000
UROLOGY
Dr. Jenn Lucas
EMIG
NVRH and COTTAGE have UROLOGY sometimes; worth calling
DR COLE
HOSPICE - Jessica Foster | on-call first
NH DETOX
336.536.4089
Barry Townsend
[ORTHO] Dr. Leiberman cell
Dr Sarver

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

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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. Make Directives/ Orders available to ED staff (POLST, P-DNR, AD…)
   - Train ED staff to see them and use them
   - “Fix” the Electronic Medical Record barrier!
2. Build, Model and Distribute Tools for ED staff to assist in:
   - 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. Set Quality Improvement goals for ED Palliative presence
   - Start with active patients

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End of talk

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EMS

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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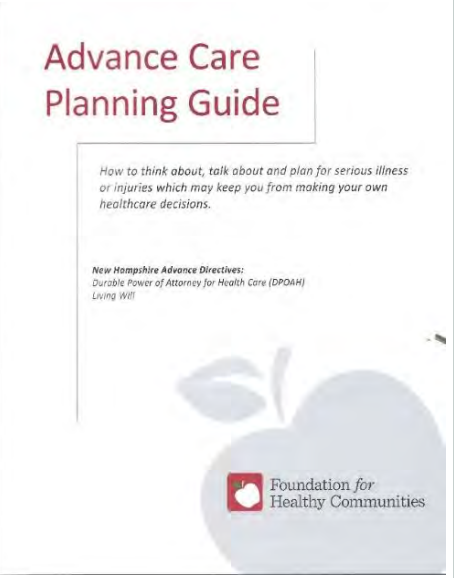
Conclusions from research



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

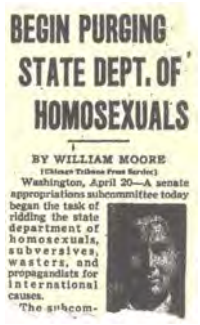
- **87-year-old male** with **metastatic prostate cancer** to the **lungs and bone**
- He is s/p radiation and chemotherapy
- Symptoms: Fatigue, anorexia, back/shoulder pain, shortness of breath, constipation
- Social: He lives in VT with his partner Scott (35 years) & cat Oliver
- He has had two recent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

The Life of Robert

Born 1937 (age 87)

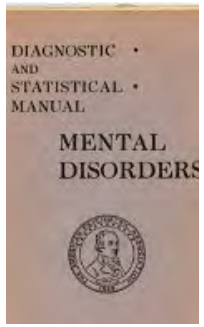
1950
Age 13

Lavender Scare



1952
Age 15

DSM Published



1969
Age 32

Stonewall Riots

1978
Age 41

Harvey Milk Murdered

1982
Age 45

HIV/AIDS Epidemic

1993
Age 56

"Don't Ask, Don't Tell"

1996
Age 59

Defense of Marriage Act

1998
Age 61

Matthew Shepherd Murdered

2003
Age 66

Lawrence v. Texas

2015
Age 78

Obergefell v. Hodges

2016
Age 79

Pulse Nightclub Shooting

2020
Age 83

LGBTQ Workplace Rights

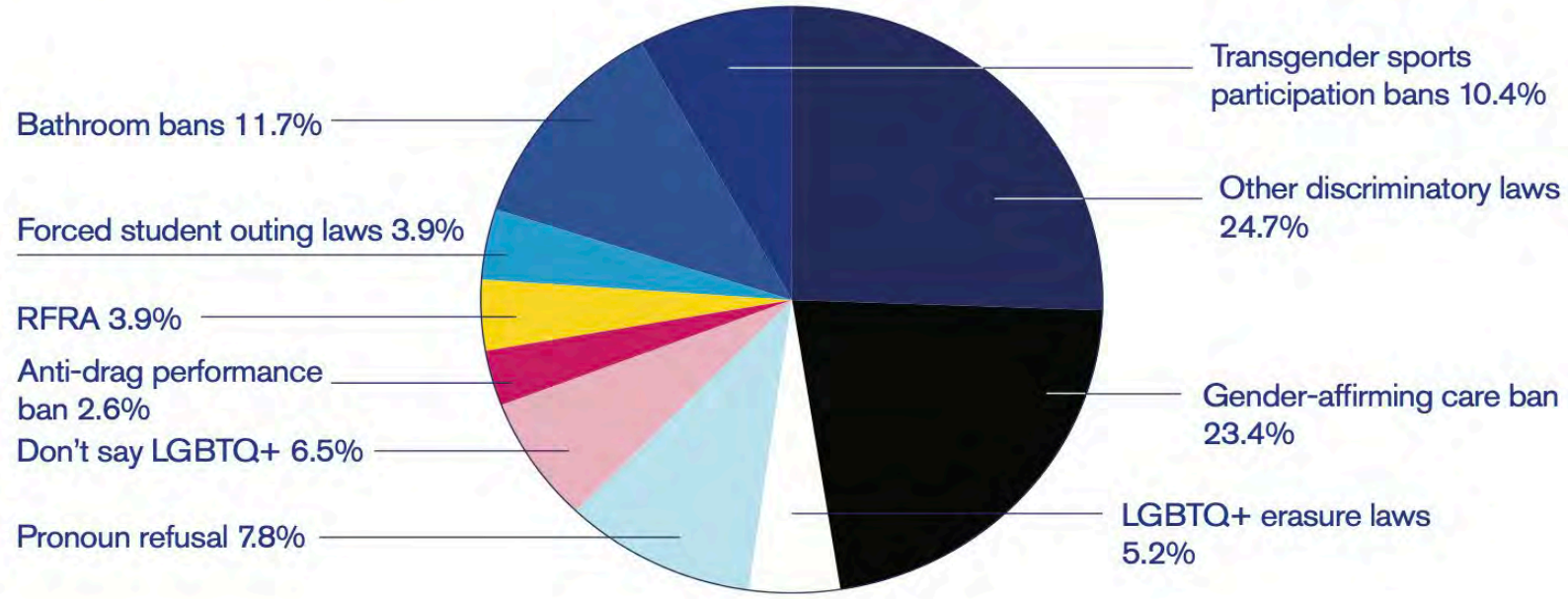
DSM: Diagnostic and Statistical Manual

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

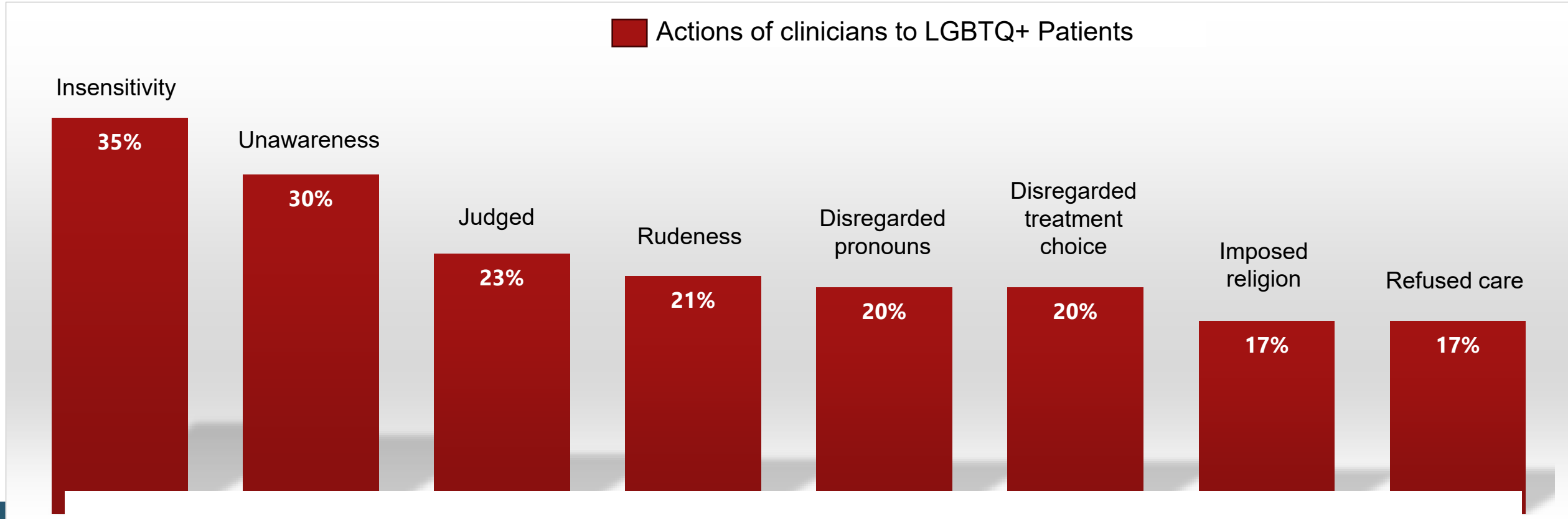
24% — **Observed** discriminatory care toward LGB patients

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

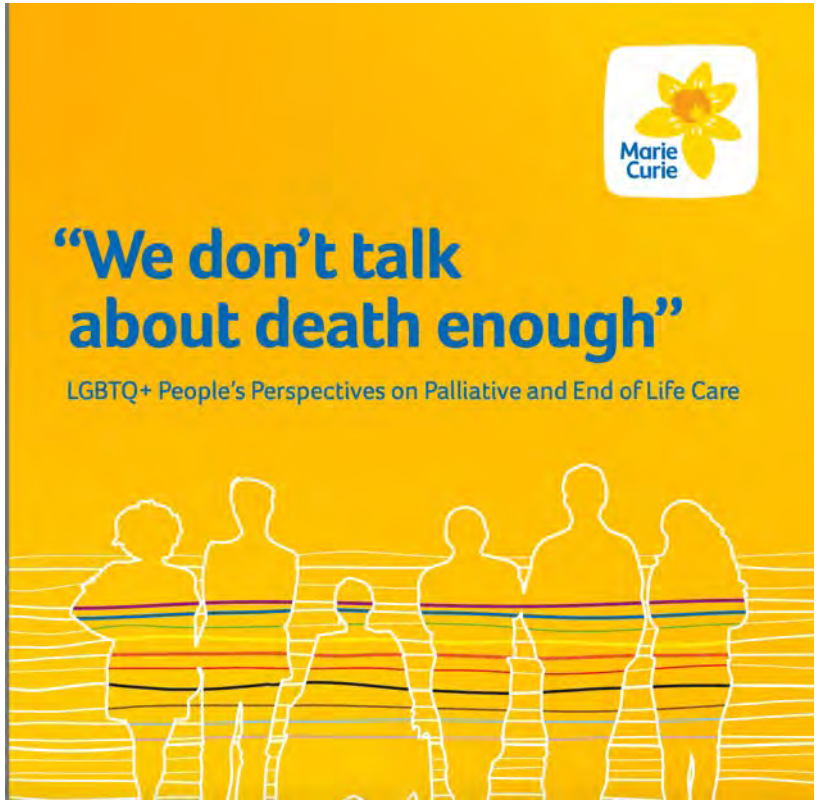
- Estrangement from family of origin
- Higher rates of mistrust of
- Nondisclosure of LGBTQIA+ status
- Fear of discrimination
- Complexity with religion/spirituality
- Isolation and lack of social support

LEGAL AND SOCIAL SYSTEM

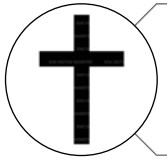
- Variability in and potential fragility of legal protections (local/state)
- Lack of comprehensive legal protections
- Absence of portability related to benefits

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



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

OUT
THE NATIONAL CANCER SURVEY

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!

LEARN MORE

Additional Resources to Explore

aahpm
AMERICAN ACADEMY OF HOSPICE AND PALLIATIVE MEDICINE

LGBT
Special Interest Group

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

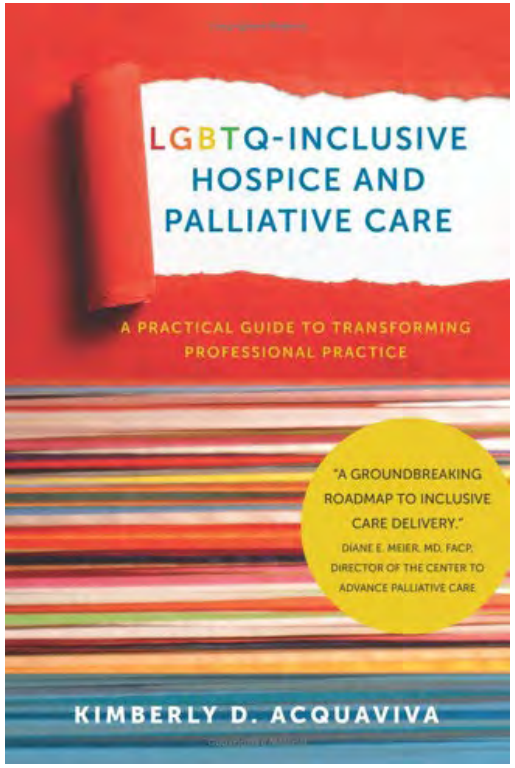
National LGBTQIA+
Health Education Center

capc

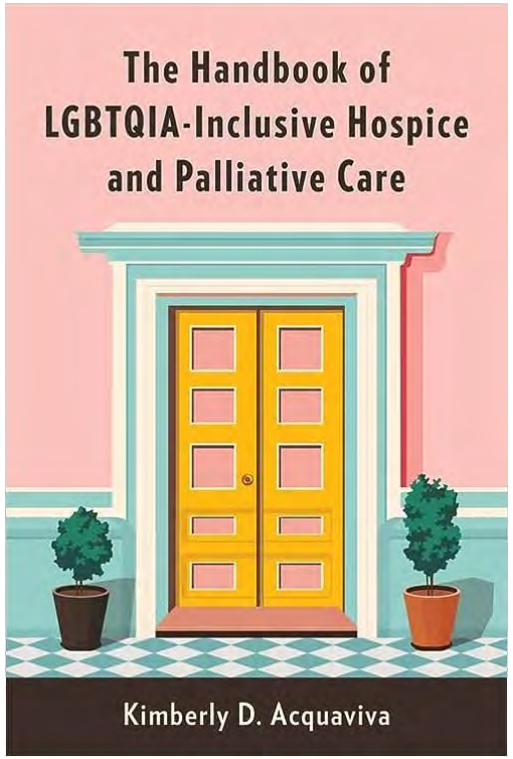
"Providing Inclusive and Affirmative Palliative Care for the LGBTQ+ Community"

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

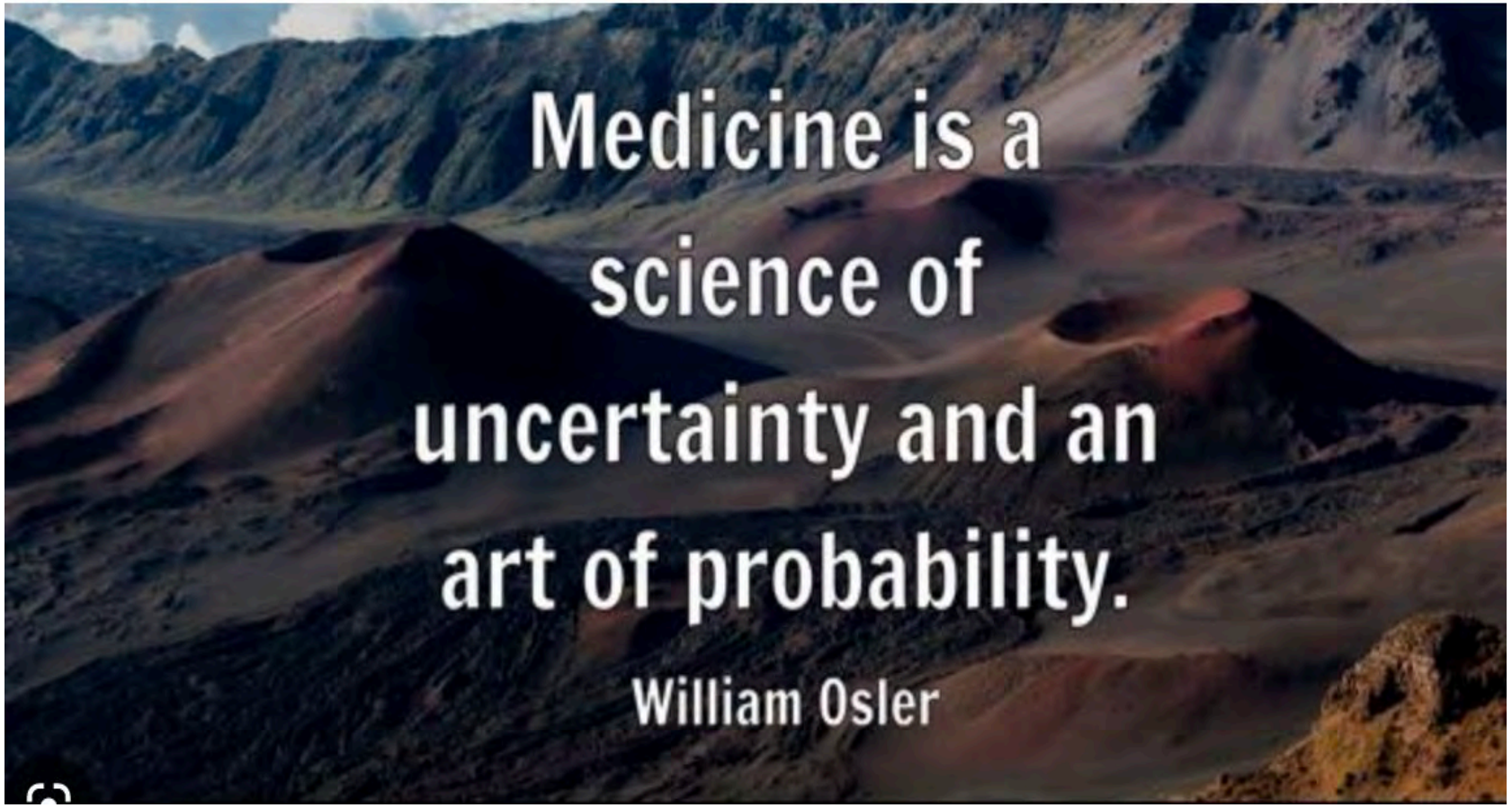
Objectives

Describe Medical Aid in Dying (MAID) and eligibility criteria

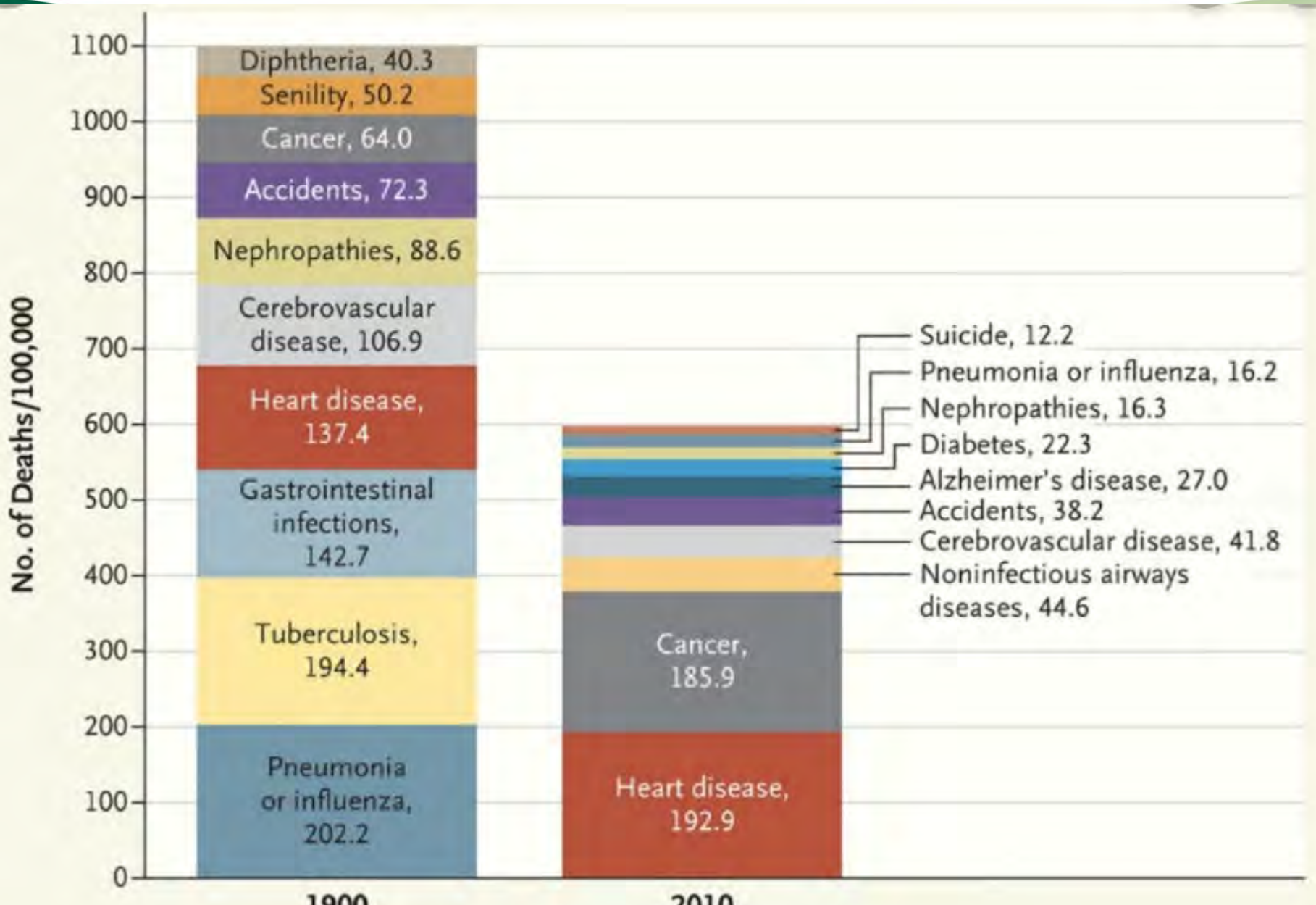
Explore motivation behind requests for MAID

Deepen awareness of multidimensional suffering

William Osler, 1800s



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

THE University of Vermont MEDICAL CENTER

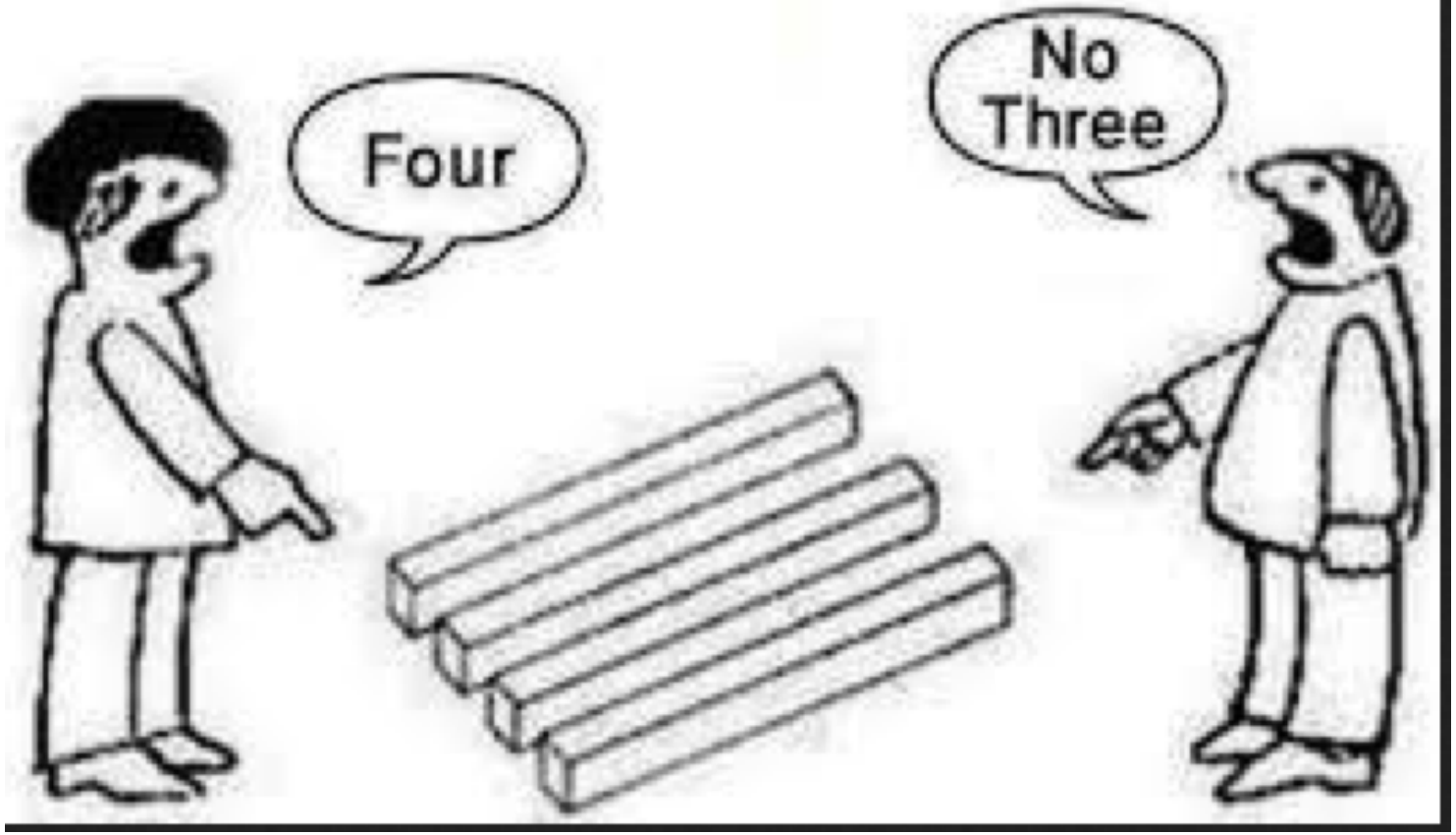
Experience in Oregon (27 years)

- 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

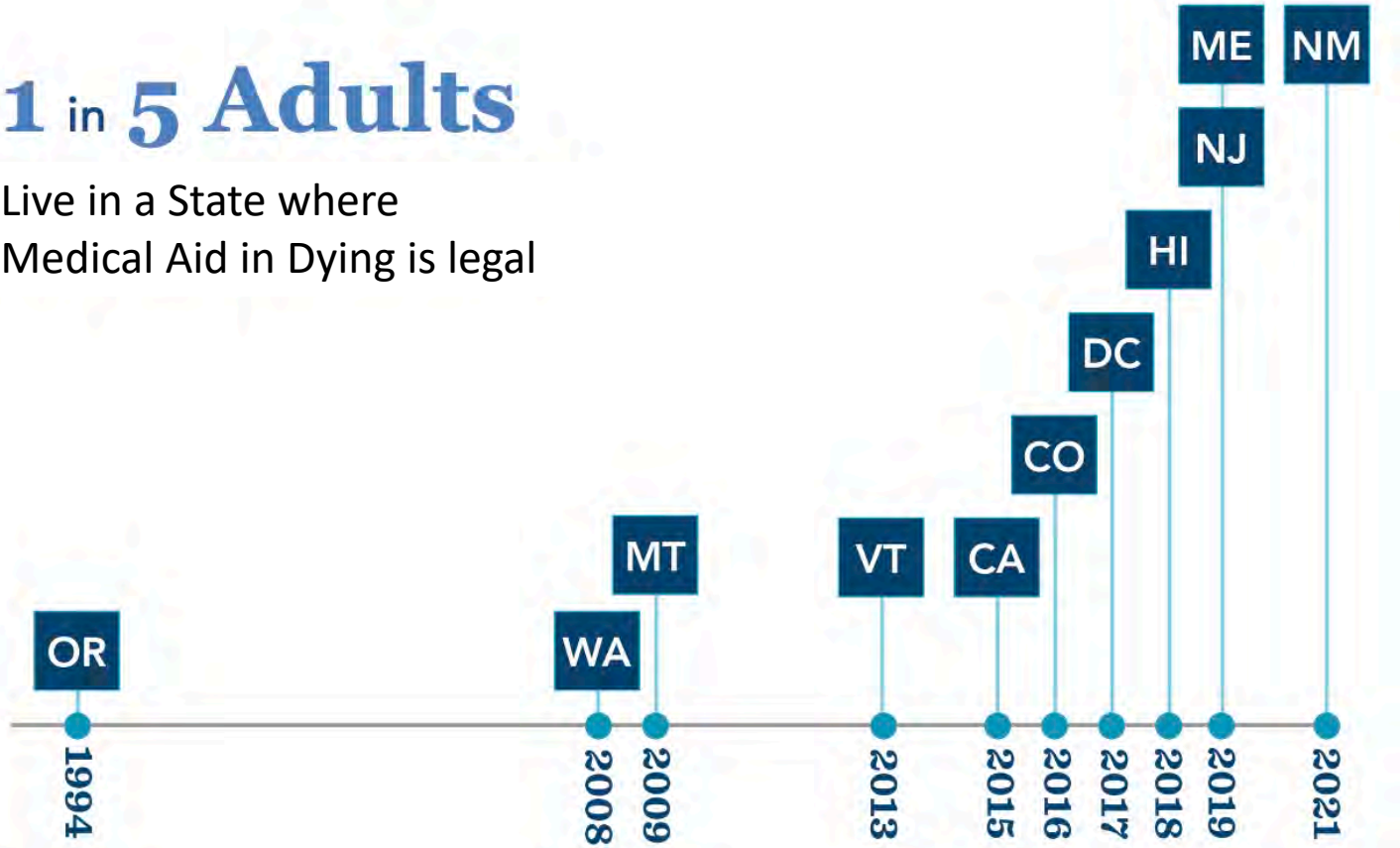
https://www.oregon.gov/oha/ph/providerpartnerresources/evaluationresearch/deathwithdignityact/pages/ar-index.aspx

It is really confusing!!!



1 in 5 Adults

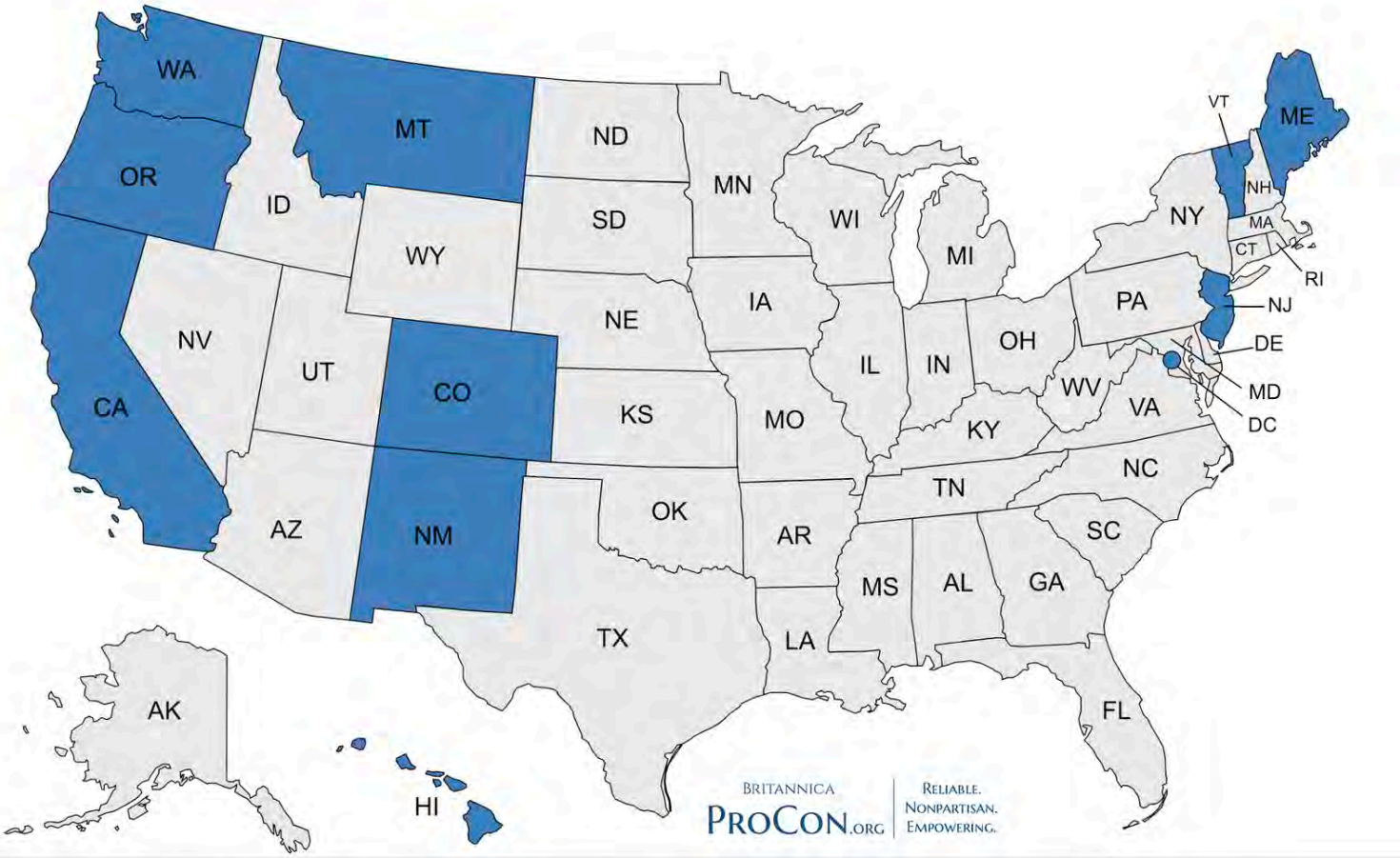
Live in a State where
Medical Aid in Dying is legal



Compassion & Choices

8

https://www.britannica.com/procon



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Suffering- Dr. Eric Cassell, NEJM, 1982

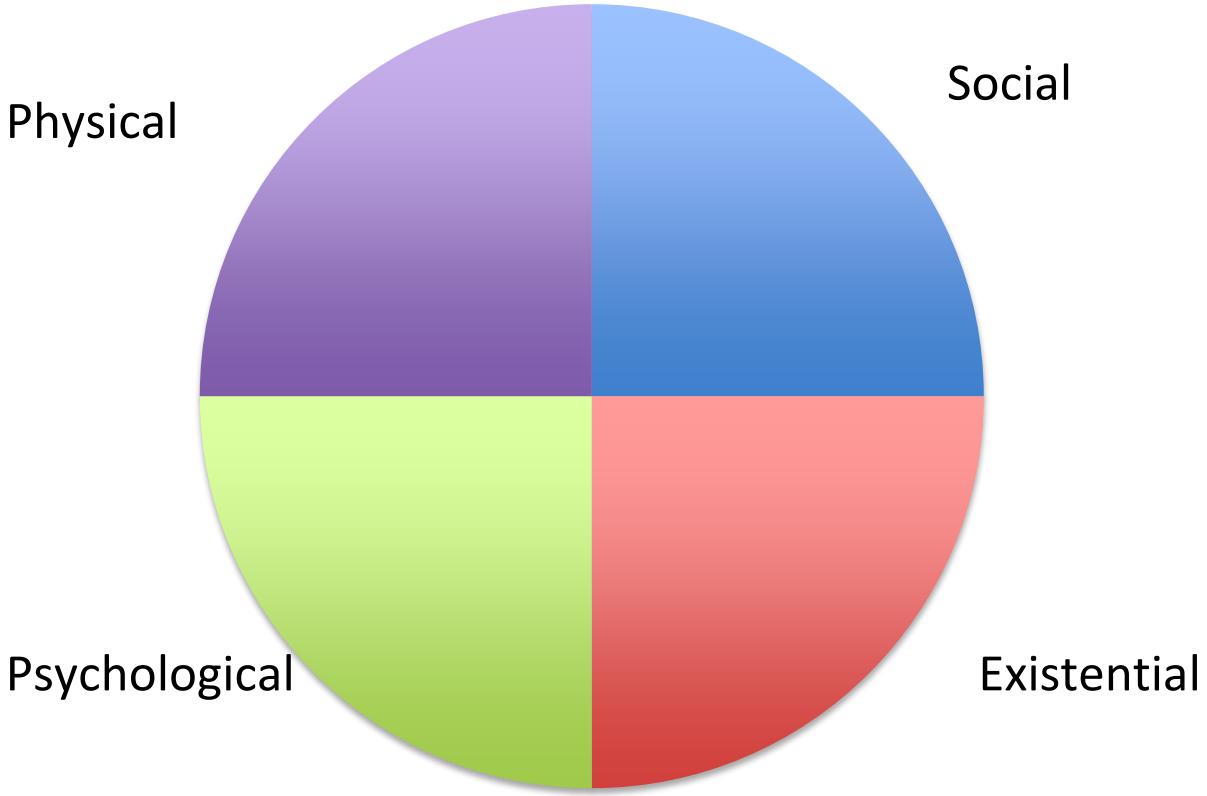
Dr. Eric Cassell- N Engl J Med. 1982; 306:639–45

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



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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

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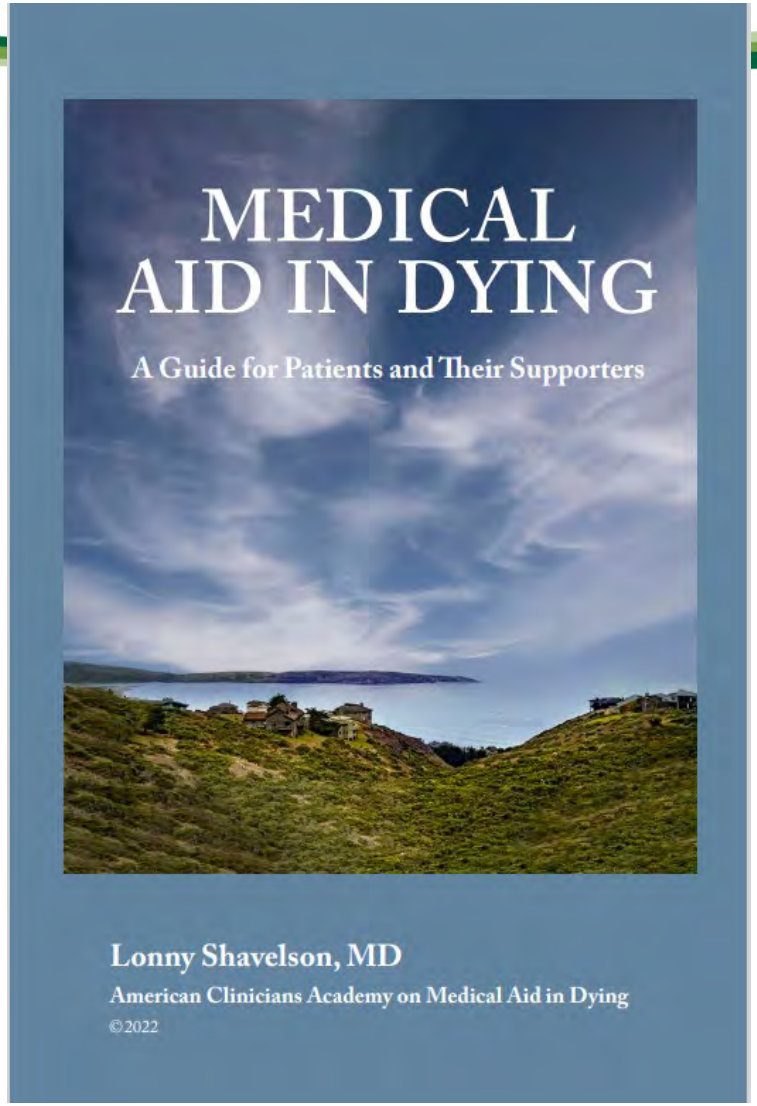
Aid-in-Dying-Patient-Guide.pdf (acamaid.org)



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LISTEN

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- Compassion and Choices
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