

### 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:

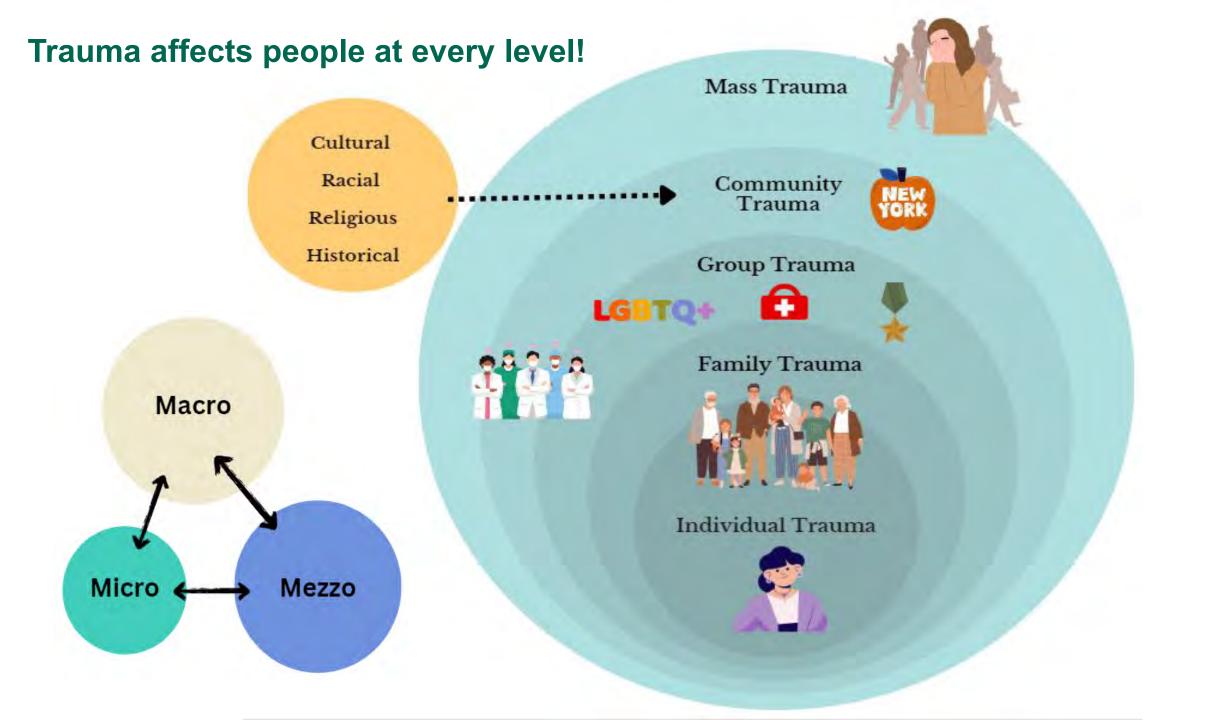
- Define trauma and identify trauma responses in our patients
- Demonstrate a trauma-informed approach to assessment, communication, and interaction with our patients
- Reflect on strategies to be a more trauma-informed provider



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

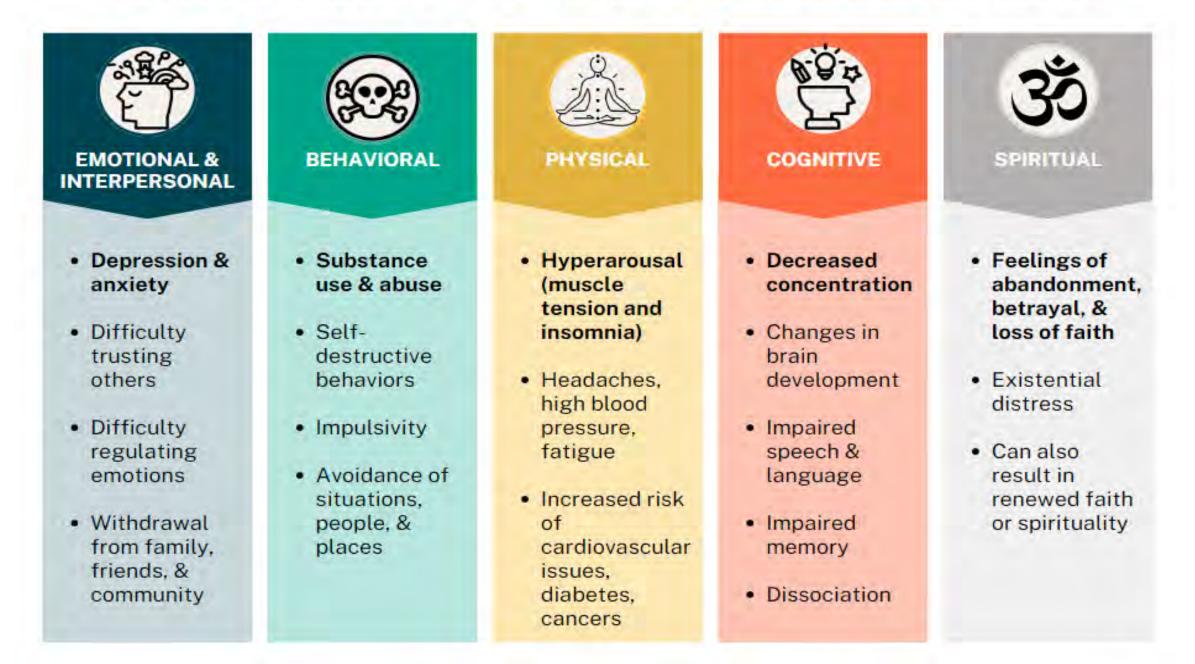


### $EVENTS \rightarrow EXPERIENCES \rightarrow EFFECTS$



#### TRAUMA CAUSES PHYSICAL AND MENTAL ILLNESS.

7



# 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."







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





#### 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 **traumainformed approach** while caring for people living with serious illness?

Please type your answers in the chat!



### Thank you!





#### References

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### Palliative Medicine in the Emergency Department

### Phil Lawson MD November, 2024





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





- 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..."





### **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; <u>https://doi.org/10.3390/cancers16162835</u>



### **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

| -   | New Hampshire Advance Directive Form   |  |  |
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| Auvalle Cale  | Address  |  |  |
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| Planning Guide  | The durable power of attorney for healthcare form names your agentist and, if you wosh, sets limits o<br>what your agent can decide.   |  |  |
| How to think about, talk about and plan for serious illness   | Licknose the following person(s) as agent(s) if i have fost capacity to make health care decisions<br>(cannot make health care decisions for myself).  |  |  |
| or injuries which may keep you from making your own<br>healthcare decisions.                          | (If you choose more then one person, they will become your agent in the order written, unless you indicate otherwise.)   |  |  |
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|   | Agent: Lappoint, of, and whose phone number is to be my agent to make health care decisions for me.  |  |  |
| New Hampshire Advance Directives:<br>Durable Power of Attorney for Health Care (DPDAH)<br>Living With | Alternate Agent: If the person above is not able, willing, or available, I appoint<br>   |  |  |
|   | b Use in the one based above can make becisions for you, a surrogate will be assigned in the order written in<br>law (popular, adult child, pawr. sibling, etc.), and will have the same powers as an agent. If there is n<br>surrogate, a court appointer guardian may be assigned.   |  |  |
|   | 8. 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<br>decisions for you. Teast evolve the Boucours Susament that is attached to the Advance Directive<br>for examples thore you may ware to advance your agent. You may write in limits or additional<br>instructions below or attach additional pages. |  |  |
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|---|---|---|--|---|--|--|
| The POLST decision-mak  | king proces   | lete this form only after a convers<br>s is for patients who are at risk for<br>on, which may include advanced f  | a life-threatening clinica   |   |  |  |
| Patient Information.  | tient Information. Having a POLST form is always voluntary.   |   |  |   |  |  |
| This is a medical or  | rder,   | Patient First Name:   |  |   |  |  |
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| A. Cardiopulmonary Re   | suscitation   | Orders. Follow these orders if p  | atient has no pulse and  | l is not breathing.   |  |  |
|   |   | tation, including mechanical venti<br>rsion. (Requires choosing Full Trea   | atments (May ch<br>This will constit   | Do Not Attempt Resuscitation.<br>oose any option in Section B)<br>utte a DNR order and no separate DNR<br>quired. RSA 137-J-26 V(b).  |  |  |
| B. Initial Treatment Or   | ders. Follo   | w these orders if patient has a pu  | lise and/or is breathing   | y   |  |  |
|   |   | h patient or patient representative re<br>ased on goals and specific outcomes   |  | its are meeting patient's care goals.   |  |  |
| Selective Treat   | ical and surgit   | al treatments as indicated to attempt i<br>Attempt to restore function while a  | voiding intensive care and   | resuscitation efforts (ventilator,  |  |  |
| Selective Treat<br>Care Transfer to I<br>Comfort-focuse<br>and manual treat<br>with comfort goal  | ical and surgio<br>ments. <u>Goa</u><br>d cardioversi<br>hospital if tre<br>ed Treatme<br>tment of airw<br>al. Transfer to  | Attempt to restore function while a<br>on). May use non-invasive positive airw<br>atment needs cannot be met in current<br>nts. Goal. Maximuse comfort through<br>ay obstruction as needed for comfort.<br>hospital only if comfort cannot be ach<br>us. These orders are in addition to th   | voiding intensive care and<br>vay pressure, antibiotics and<br>clocation<br>symptom management, a<br>Avoid treatments listed in fu-<br>eved in current setting<br>ose above (e.g., blood pro-  | resuscitation efforts (ventilator,<br>IV fluids as indicated. Avoid intensive<br><u>Ilow natural death.</u> Use oxygen, suction<br>il or select treatments unless consistent  |  |  |
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#### Out of hospital arrest

- Goal concordant vs goal discordant care
- POLST as a starting place in the ED



HIPAA PERMITS DISCLOSURE OF POLST ORDERS TO HEALTH CARE PROVIDERS AS NECESSARY FOR TREATMEN

SEND FORM WITH PATIENT WHENEVER TRANSFERRED OR DISCHARGED, ATTACH PINK P-DNR FORM IF PATIENT HAS ONI

#### **New Hampshire Forms**

Page 13

#### Advance Care **Planning Guide**

How to think about, talk about and plan for serious illness or injuries which may keep you from making your own healthcare decisions.

Foundation for

New Hompshire Advance Directives Durable Power of Attorney for Health Care (DPOAH) Living Will

#### 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: , of and whose Agent: Lappoint 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 \_\_\_\_ 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 Healthy Communities 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.

Name (Principal's Name)

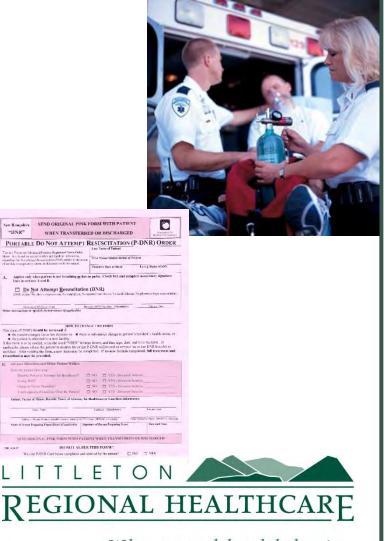
New Hampshire Advance Directive Form

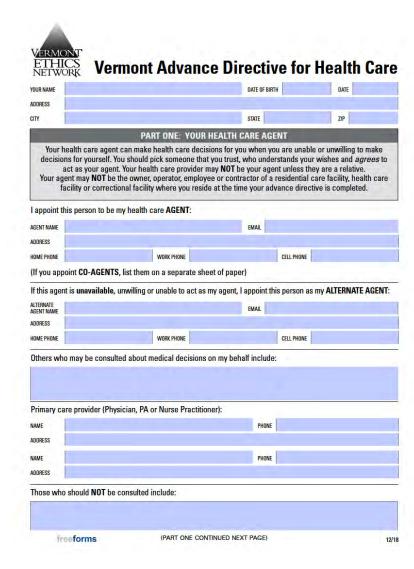
I have attached \_\_\_\_\_\_ additional pages titled Additional Wishes for my Durable Power of Attorney for Health Care to express my wishes.

|   | ition, which may include advanced frailty (www  |  |
|---|---|--|
| Patient Information.  | Having a POLST form is a  | lways voluntary.   |
| This is a medical order,  | Patient First Name:   |  |
| not an advance directive.   | Middle Name/Initial   | Preferred name   |
| For information about   | Last Name:  | Suffix (Ir. Sr. etc)   |
| POLST and to understand   | DOB (mm/dd/ww). / State   |  |
| this document, visit:   |   |  |
| www.polst.org/form  | Gender M F X Social Security Nu   | mber's last 4 digits (optional) xxx xx   |
| A. Cardiopulmonary Resuscitation  | on Orders. Follow these orders if patient ha  | s no pulse and is not breathing.   |
|   | citation, including mechanical ventilation,   | NO CPR: Do Not Attempt Resuscita   |
| defibrillation and cardiov<br>in Section B)   | version. (Requires choosing Full Treatments   | (May choose any option in Section<br>This will constitute a DNR order and no separati<br>order will be required. RSA 137-J.26 V(b).  |
| B. Initial Treatment Orders Foll  | low these orders if patient has a pulse and/o   |  |
|   | with patient or patient representative regularly to   |  |
|   | s based on goals and specific outcomes.   |  |
| defibrillation and cardiover<br>care. Transfer to hospital if t<br>Comfort-focused Treatm<br>and manual treatment of a  | (sion). May use non-invasive positive airway pressure<br>reatment needs cannot be met in current location<br>nents. Goal. Maximute comfort through symptom<br>way obstruction as needed for comfort. Avoid treation.  | management; allow natural death. Use oxyge<br>ments listed in full or select treatments unless o   |
| defibrillation and cardiover<br>care. Transfer to hospital if t<br>Comfort-focused Treatm<br>and manual treatment of a<br>with comfort goal. Transfer   | sign) May use non-invasive positive airway pressure<br>reatment needs cannot be met in current location<br>neurophysical. Maximume comfort through symptom<br>reary obstruction as needed for comfort. Avoid treat<br>to bespital only if comfort cannot be achieved in cur-<br>ons. These orders are in addition to those above.   | e, antibiotics and IV fluids as indicated. Avoid int<br>management; allow natural death. Use oxyge<br>ments listed in full or select treatments unless o<br>rent setting.  |
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Medical Record # (Optional

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





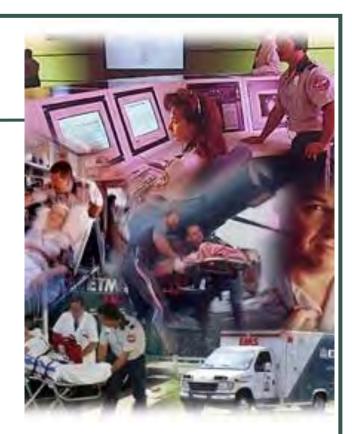
### **Vermont Forms**

- Short Form
- Long Form
  - Registry
    - COLST

| ATIENT:   |  | BIRTH  | IDATE:  |  |
|---|--|--|---|--|
| LAST NAME   | FIRST NAME   | MIDDLE INITIAL   |   |  |
| SECTION A: Cardiopulmonary Re   | suscitation: Follow the  | se orders when patient is unr  | esponsive & has NO pulse  |  |
| <ul> <li>NO CPR: Do Not Attempt F<br/>(Allow Natural Death)</li> </ul>  | Resuscitation (DNR)  | <ul> <li>YES CPR: Attempt I<br/>chest compressions, intubal<br/>defibrillation and transfer to</li> </ul>  | tion, mechanical ventilation,   |  |
| Basis for DNR order: informed co  | nsent OR medical non-  | benefit (Choose one)   |   |  |
| O Informed Consent obtained fro   | d Consent obtained from:   |  | O This DNR order is written on the basis of medical non-benefit (futility). Required if no consent.   |  |
| Name of Person Giving Informed Consent  | (Can be Patient)   | I have determined that resuscitation would not prevent the<br>imminent death of this patient should the patient<br>experience cardiopulmonary arrest. Another clinician has  |   |  |
| Relationship to Patient (Write "self" if Patie<br>(agent, guardian or surrogate)  | ent)   | also so determined:  | ng this Determination (Print here)  |  |
| Signature (if available; not required)  |  | Signature of Other Clinician   | Date  |  |
| Verbal Consent  |  | orginatine of orace cannear  | 1740C   |  |
| ventilate (D) NO, do not intuba<br>ventilate (D) NOT du<br>checked "YES CPR" in sec   | sck if you ventil:   | . COURSE, of intubation and<br>tion treatment  | <ul> <li>YES, intubate and ventilate</li> </ul>   |  |
| ventilate (po Nor du<br>checked "YES CPR" in sec  | sckifyou ventile<br>tion A)<br>Guidelines  | tion treatment   | ventilate   |  |
| ventilate (no Nor da<br>decked YIS CPR' in sec<br>SECTION C: Medical Intervention<br>O Focus on Sustaining Life. Use in<br>to hospital and/or intensive care  | ck if you ventile<br>tion A)<br>Guidelines<br>tubation, advanced airway<br>unit if indicated. All patient  | tion treatment   | ventilate<br>ntilation as indicated. Transfer<br>atments.   |  |
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### 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





### **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



### 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<br>me to put a tube down to help you breath?" | "We are considering putting you on a breathing<br>machine, but I am worried about what might<br>happen to you if we do; and we have options to help<br>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<br>to be treated if your condition gets worse. CPR is an<br>option that has risks for you"                          |
|   | LITTLETON  |

**REGIONAL HEALTHCARE** 

### **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"

Where good health begins.

REGIONAL HEALTHCAR

#### 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?



### **Reasonable CPR outcome data**

| Location and Original setting/function     | Survival to Discharge<br>from Hospital | Survival with 'good'<br>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)                     |



# 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?"



Dr. Lord does food impaction Dr. Chvis Janiebon (FOOD IMPACTION) I (office) Corratie Hospital 603.747.9000 UROLOGY EMIG NVRH and COTTRGE have UROLDGY sametimes; with callings the HOSPICE - Jessica Foster 100-call first DR LOLE NH DETOX Evry Townsend LORAMON Dr. Leiberman (el] 2 336.536,4089

# 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

# 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. <u>Volume 39, Issue 1</u>; <u>https://doi.org/10.1177/08258597221149402</u> 2024



# 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.





# **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



# 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. <u>Set Quality Improvement goals for ED Palliative presence</u>
  - Start with active patients





# End of talk





# 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





# **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



Where good health begins.

Advance Care

**Planning Guide** 

healthcare decisions

New Hampshire Advance Directives: Durable Power of Attorney for Health Care (DPDA

How to think about, talk about and plan for serious illness or injuries which may keep you from making your own



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**

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



## **Disclosures**

None

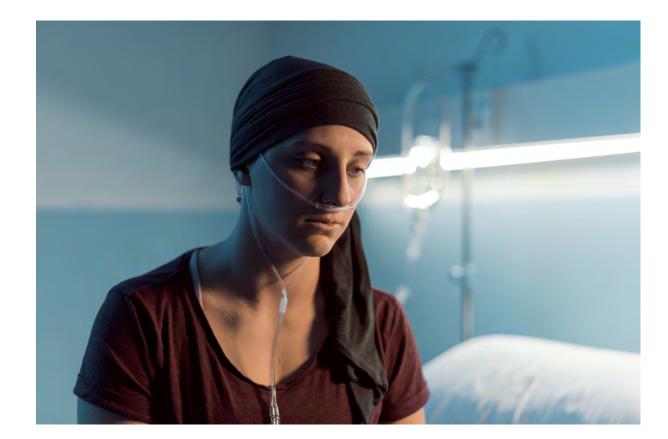


# How do we define LGBTQIA+

| 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)

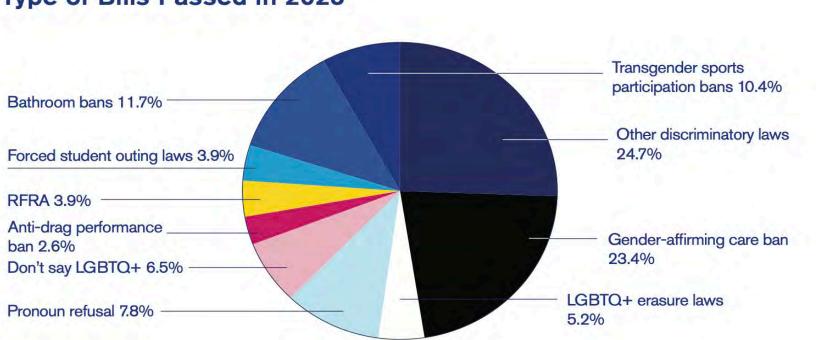


DSM: Diagnostic and Statistical Manual

# 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.



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

#### Type of Bills Passed in 2023

# HPM Professionals Identify LGBT Discrimination

**<u>Believed</u>** LGB Patients were more likely to experience discrimination

Observed discriminatory care toward LGB patients

33%

**54%** 

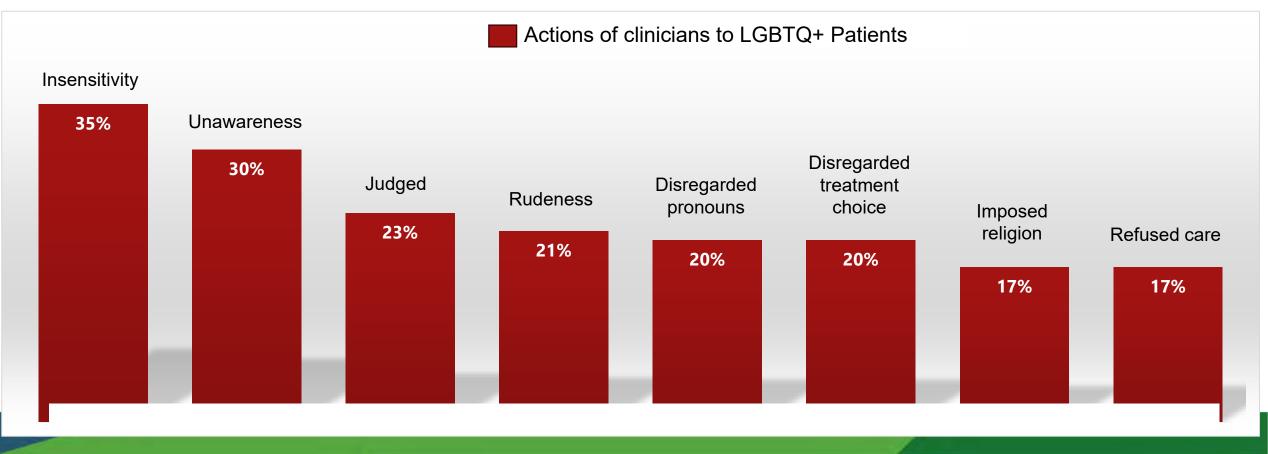
24%

**Observed** discrimination against LGBT patients' spouses/partners

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

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

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



#### 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

"We don't talk

about death enough"

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

Marie Curie



#### 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 <u>myDH</u> patient portal or by connecting with their Dartmouth Health care team. For more information on system-wide SOGI collection, please visit our <u>We Ask</u> <u>Because We Care</u> 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 <u>cancer-network.org</u>



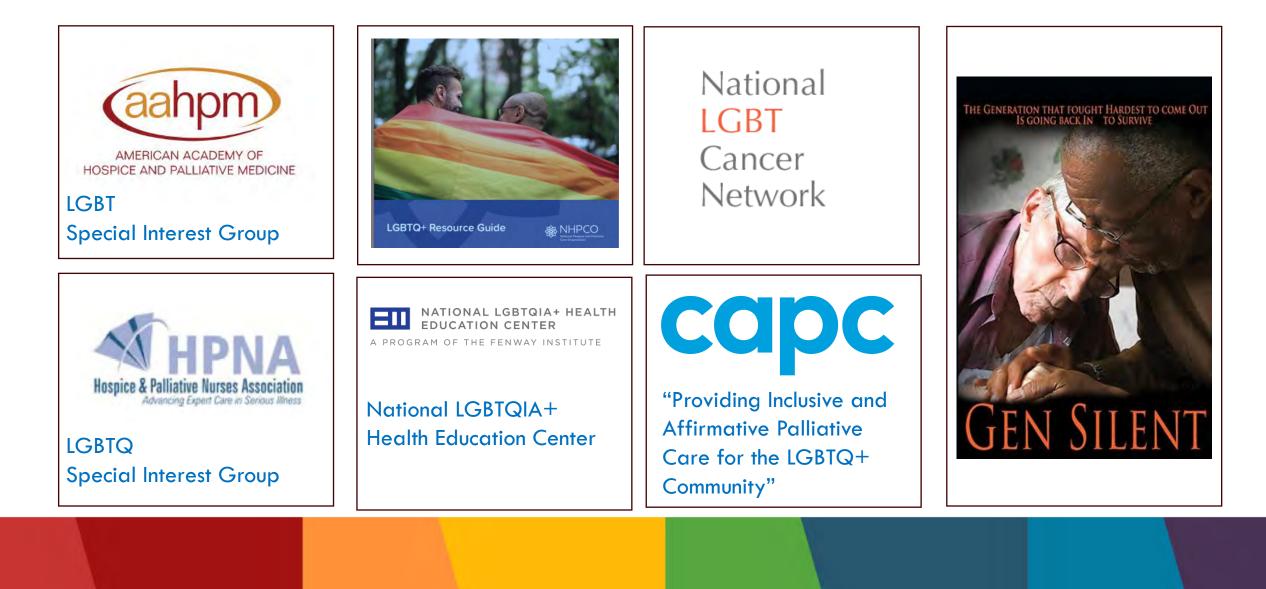
#### SUPPORT GROUPS

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 peersupport groups. This is a healing space to lean on your LGBTQ+ community for support throughout your cancer journey. Join us today!

LEARN MORE

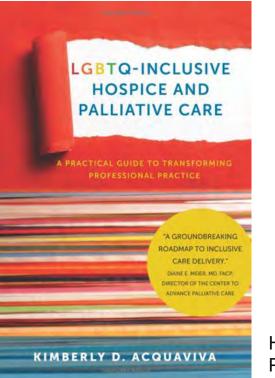


## **Additional Resources to Explore**

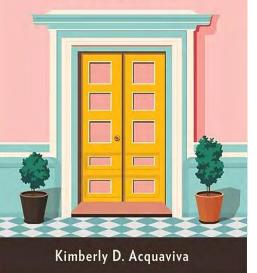


## **Additional Resources to Explore**

Two recent books have been published that take a deeper dive



Harrington Park Press Published: May 2017 The Handbook of LGBTQIA-Inclusive Hospice and Palliative Care



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



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





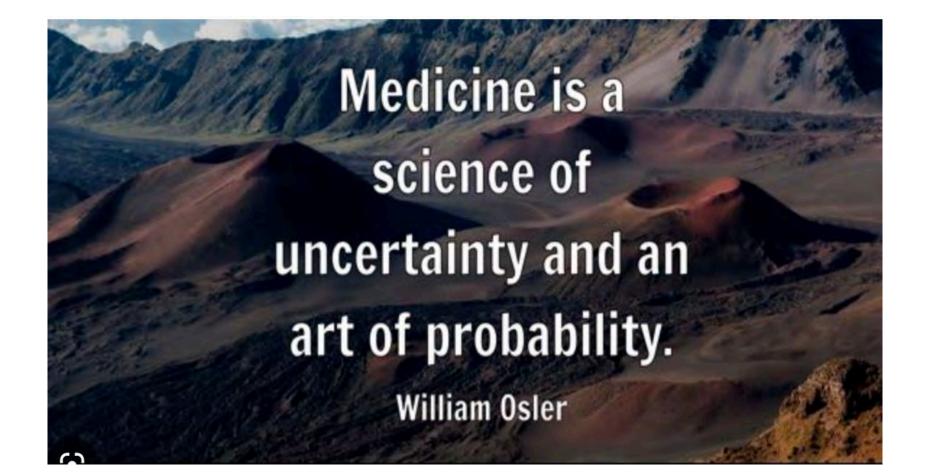
#### Describe Medical Aid in Dying (MAID) and eligibility criteria

#### Explore motivation behind requests for MAID

#### Deepen awareness of multidimensional suffering

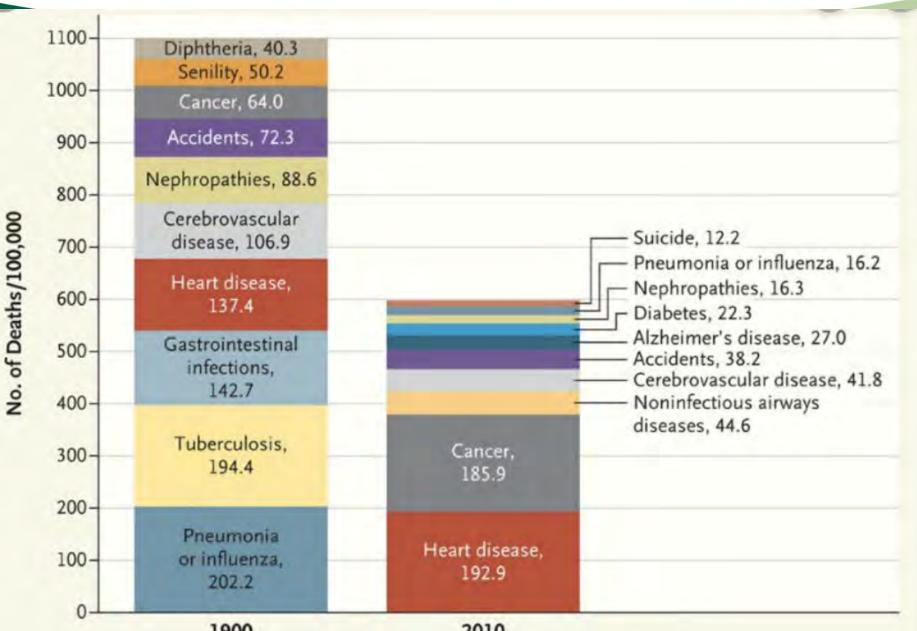


### William Osler, 1800s





#### Cause of Death 1900 vs. 2010





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** 





#### At home

#### Family/loved ones present

Comfortable



#### We all Die





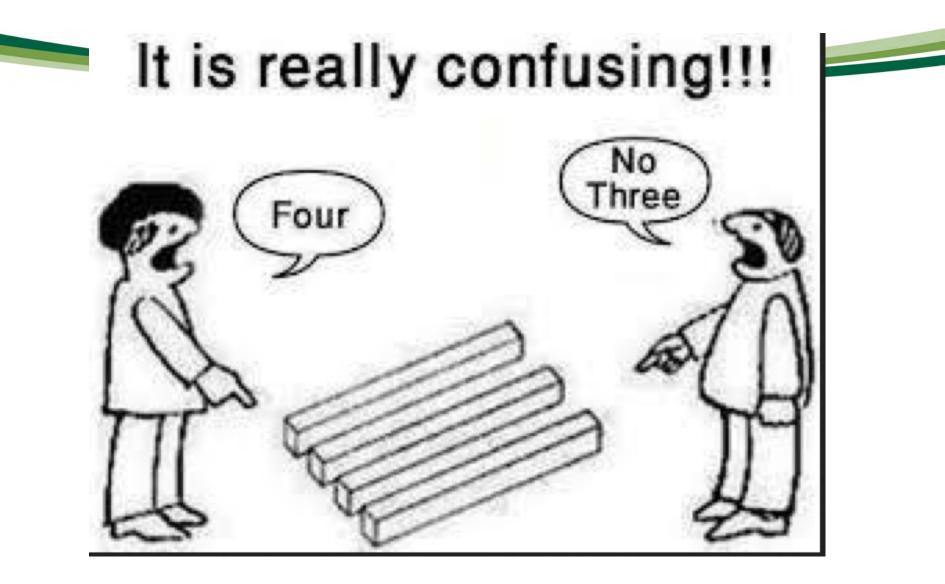
#### Experience in Oregon (27 years)

- Most common reasons for using MAID
  - Loss of autonomy

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- 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

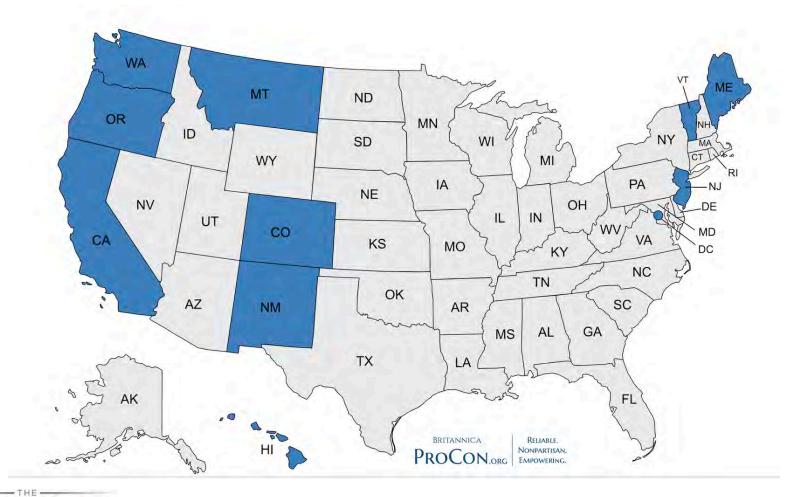
https://www.oregon.gov/oha/ph/providerpartnerresources/evaluationresearch/deat hwithdignityact/pages/ar-index.aspx







#### https://www.britannica.com/procon



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

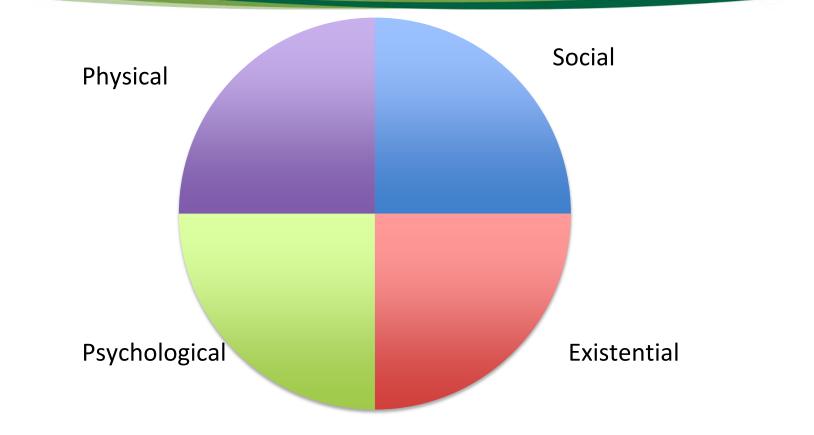
Suffering is experienced by persons, not merely by bodies, and has its source in challenges that threaten the intactness of the person as a complex social and psychological entity.

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 (<u>www.acamaid.org</u>)

- 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)

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# Data collection

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

#### 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



#### Clinician's Guide to Medical Aid in Dying:

https://www.patientchoices.org/clinicians-guide.html

Patient Choices Vermont

#### **Non-Resident Checklist:**

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

#### **PCV Helpline:**

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



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

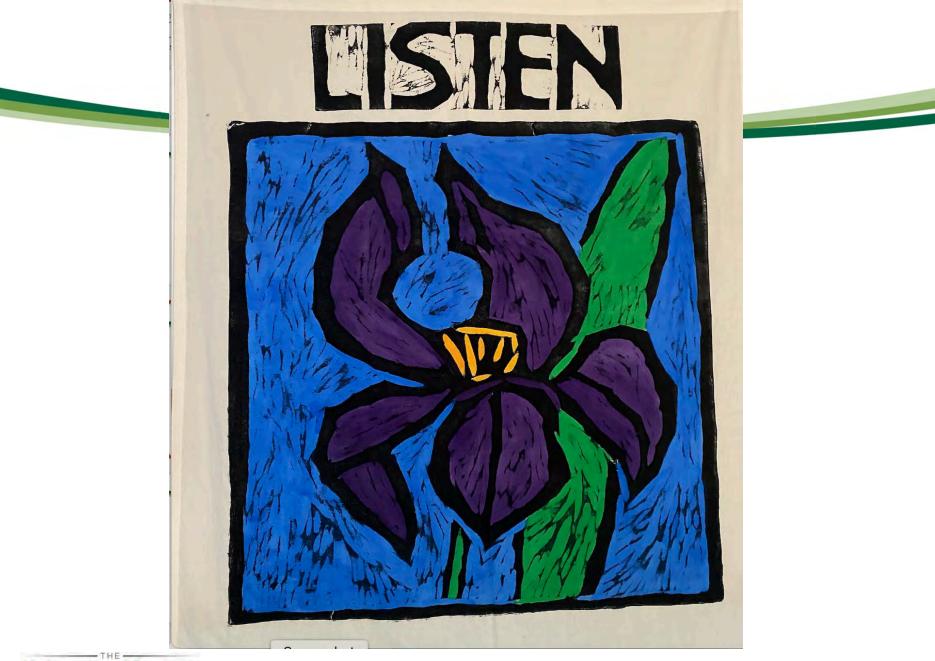
#### MEDICAL AID IN DYING

A Guide for Patients and Their Supporters



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





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#### **References/Information**

- Patient Choices Vermont <u>https://www.patientchoices.org</u>
- American Academy of Medical Aid in Dying <u>https://www.acamaid.org/</u>
- Vermont Department of Health

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

Vermont Ethics Network

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

• Oregon Health Authority

<u>Oregon Health Authority : Oregon's Death with Dignity Act : Death with</u> <u>Dignity Act : State of Oregon</u>

Compassion and Choices

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





Clinical Criteria for Physician Aid in Dying; Journal of Palliative Medicine Volume 19, Number 3, 2016; Mary Ann Liebert, Inc.; DOI:10.1089/jpm.2015.0092

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

