Dartmouth Health

Project ECHO

WELCOME to
Palliative Care ECHO 4.0

Improving Care for those with Serious Illness

October 2024 – June 2025

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Dartmouth Health

Project ECHO®

Trauma-Informed Approach to Serious Illness

Sarah E. Guarda, MSW, LICSW

Palliative Care Echo Session #1 October 1, 2024

Learning Objectives

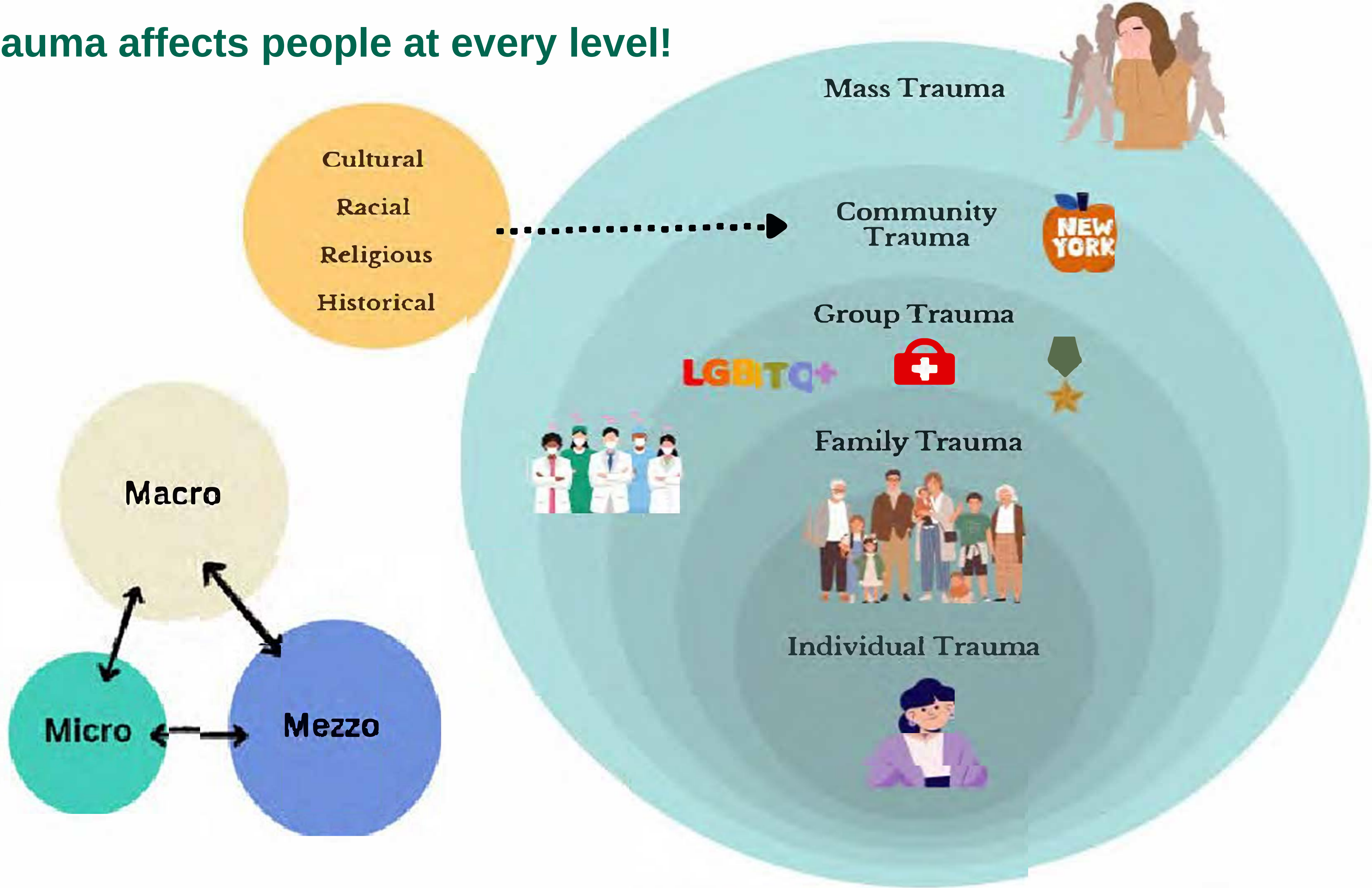
By the end of this session, ECHO participants will be able to:

- 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 → EXPERIENCES → EFFECTS

Trauma affects people at every level!



Cultural

Racial

Religious

Historical

Mass Trauma

Community Trauma

Group Trauma

Family Trauma

Individual Trauma

Macro

Micro

Mezzo

TRAUMA CAUSES PHYSICAL AND MENTAL ILLNESS.

EMOTIONAL & INTERPERSONAL

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

BEHAVIORAL

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

PHYSICAL

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

COGNITIVE

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

SPIRITUAL

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

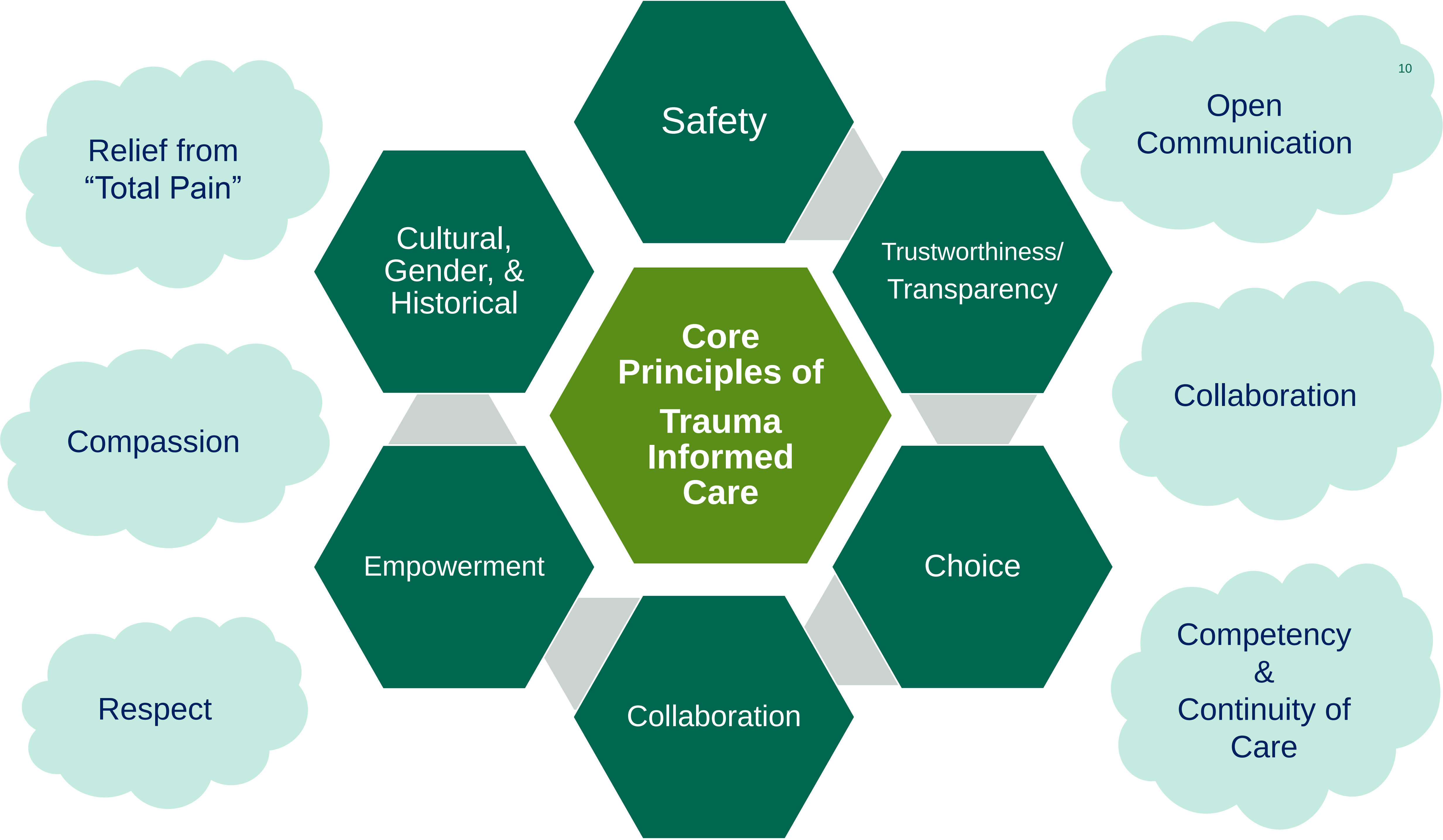
Trauma-informed approach is defined as:

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

SAMHSA
Substance Abuse and Mental Health Services Administration

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

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



Core Principles of Trauma Informed Care

Safety

Trustworthiness/ Transparency

Choice

Collaboration

Empowerment

Cultural, Gender, & Historical

Relief from “Total Pain”

Compassion

Respect

Open Communication

Collaboration

Competency & Continuity of Care

Ask questions to assess an individual’s trauma history.

Childhood and Family experiences

Distressing Events

Triggers and Unsafe Situations

Losses and Bereavements

Coping & Resilience

Privacy and Confidentiality

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

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

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

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

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

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

Closing Reflections:

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

Please type your answers in the chat!

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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 Care Planning Guide

Foundation for Healthy Communities


New Hampshire Advance Directive Form

<u>Advance Directives (AD’s) are not available</u>

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

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

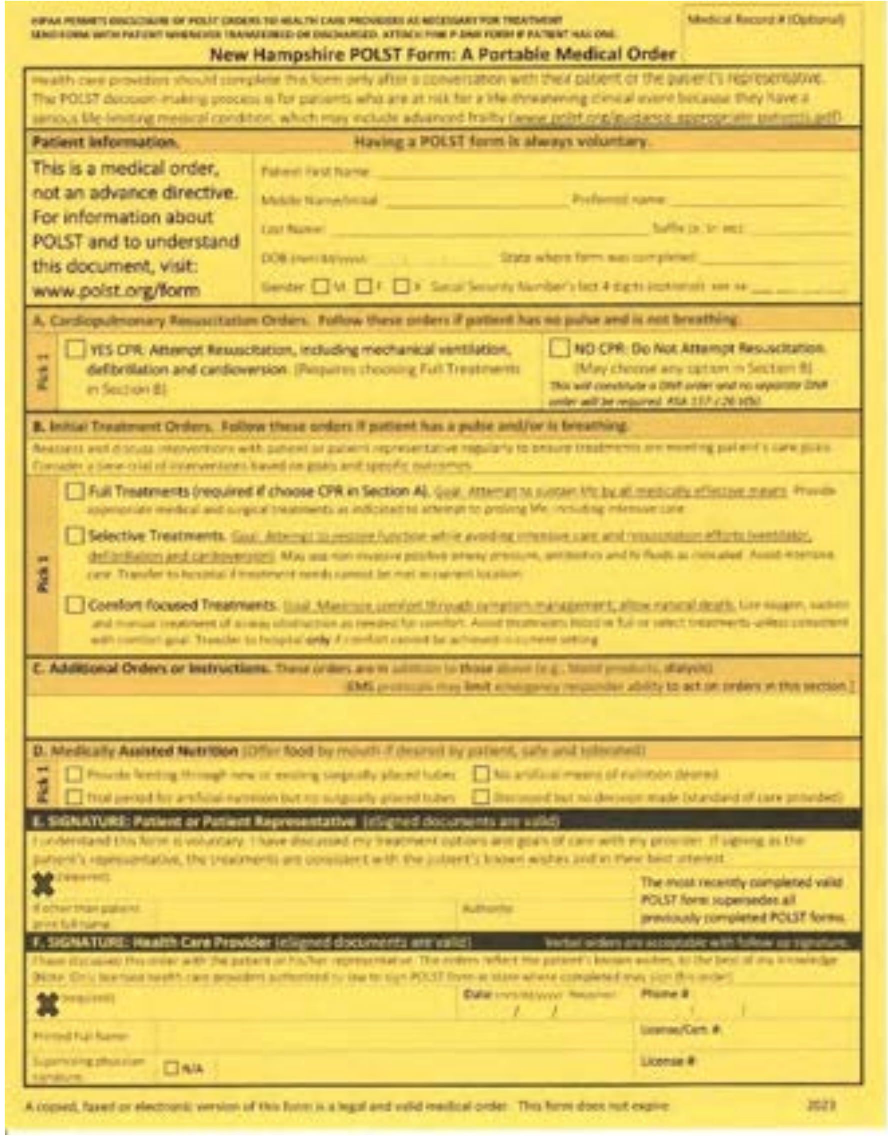
- @10% of elderly ill patients in ED are asked about AD’s
- @80% thought ED providers should be aware
- <40% expressed desire to discuss goals of care

*References in chat


Portable Do Not Attempt Resuscitation (P-DNR) Order


New Hampshire POLST Form: A Portable Medical Order

What PC Providers can offer the ED



Medical Record # (Optional)

New Hampshire POLST Form: A Portable Medical Order

Patient Information. **Having a POLST form is always voluntary.**

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

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

Pick 1

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

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

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

Pick 1

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

☐ **Selective Treatments.**

☐ **Comfort-focused Treatments.**

C. Additional Orders or Instructions.

D. Medically Assisted Nutrition

Pick 1

☐

☐

☐

☐

E. SIGNATURE: Patient or Patient Representative

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

F. SIGNATURE: Health Care Provider

Date / /

Phone #

License/Cert. #

☐ 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

What PC Providers can offer the ED

New Hampshire Forms

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 Healthy Communities

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.)

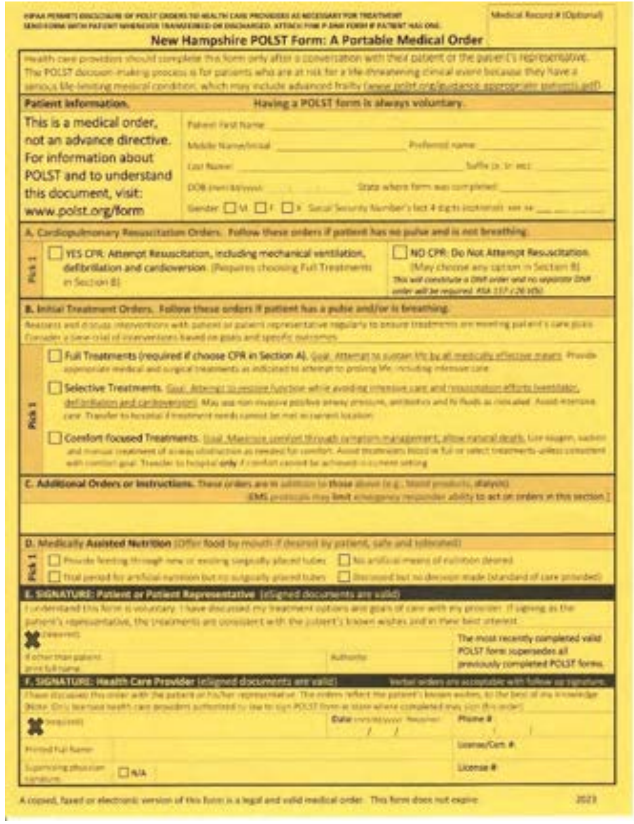
A. Choosing Your Agent:

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



New Hampshire POLST Form: A Portable Medical Order

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

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

☐ Selective Treatments.

☐ Comfort-focused Treatments.

C. Additional Orders or Instructions.

D. Medically Assisted Nutrition

E. SIGNATURE: Patient or Patient Representative

F. SIGNATURE: Health Care Provider

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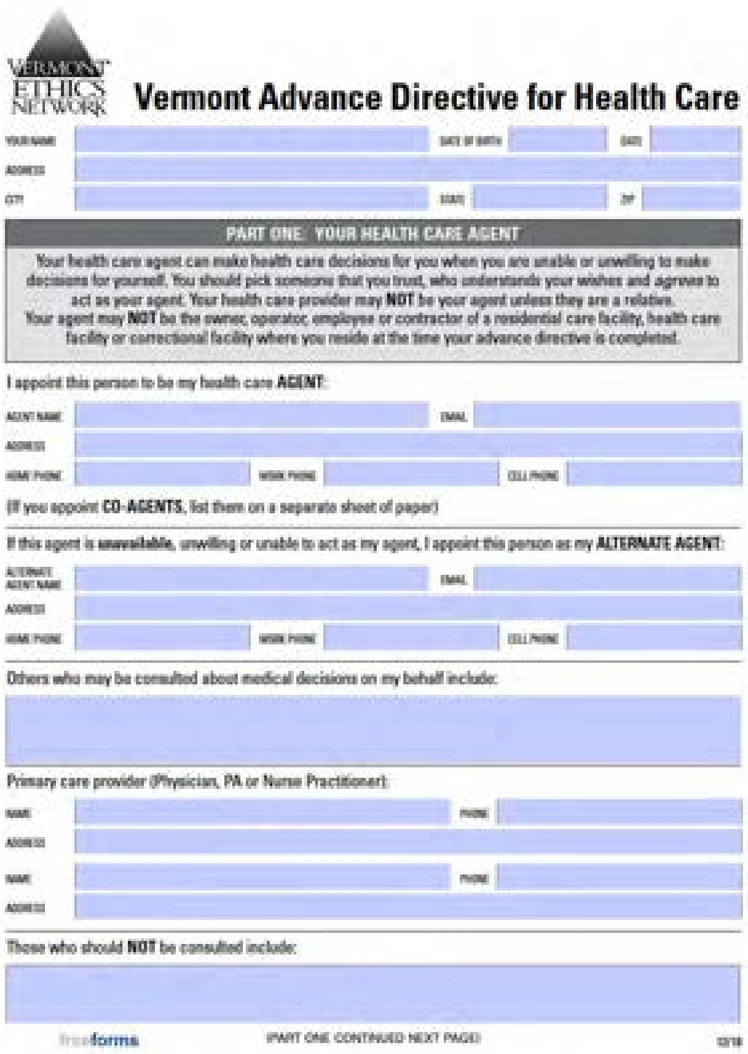
What PC Providers can offer the ED

Vermont Forms



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:

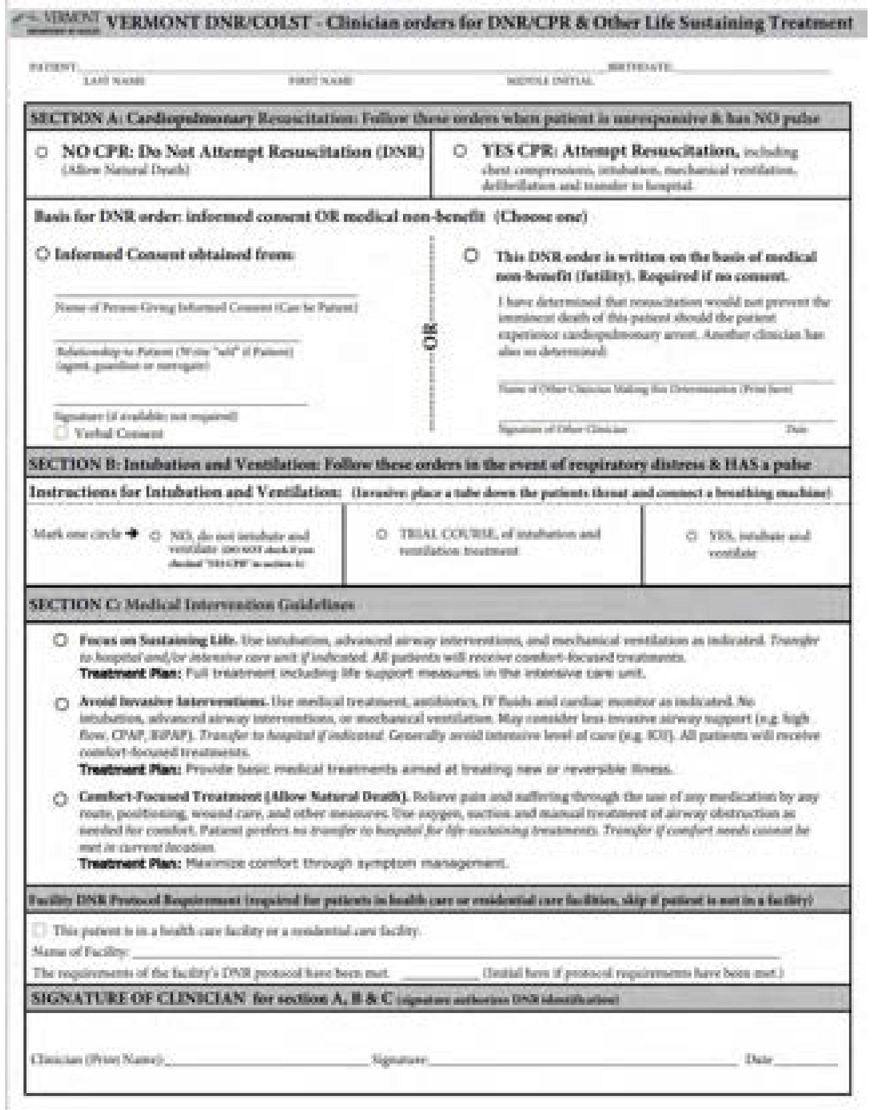
Primary care provider (Physician, PA or Nurse Practitioner):

NAME | PHONE
ADDRESS
NAME | PHONE
ADDRESS

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

freeforms (PART ONE CONTINUED NEXT PAGE) 12/18

- Short Form
- Long Form
- Registry
- COLST



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

PATIENT: LAST NAME FIRST NAME MIDDLE INITIAL BIRTHDATE:

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

Tools and Scripts

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

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Scripts: Our “surgical” Skills

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

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Communication Tools

Best Possible

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

Worst Possible

- "A prolonged dying process with suffering on machines"

Expected Outcomes

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

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What PC Providers can offer the ED

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

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

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

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

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Reasonable CPR outcome data

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

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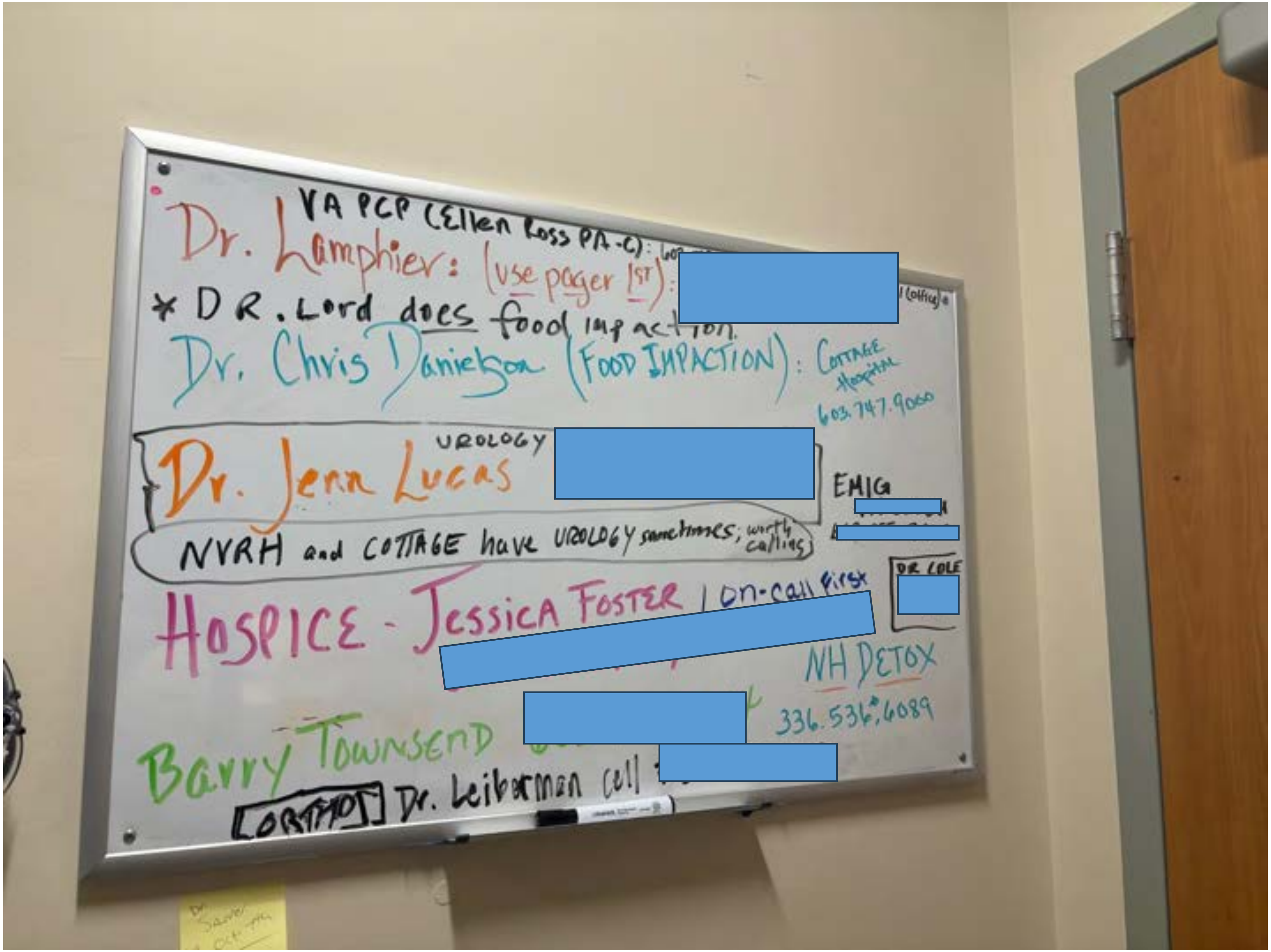
What PC Providers can offer the ED

Scripts to assist in demystifying hospice

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



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

Dr. Lamphier: (use pager 1ST): [redacted]

* DR. Lord does food impaction.

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

Dr. Jenn Lucas UROLOGY [redacted]

NVRH and COTTAGE have UROLOGY sometimes; worth calling

EMIG [redacted] [redacted]

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

DR COLE [redacted]

NH DETOX 336.536.6089

[redacted]

Barry Townsend

ORTHOS Dr. Leiberman cell [redacted]

What PC Providers can offer the ED

ED care of hospice patients:

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

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

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Models of Palliative Care in the ED

ED Nurse driven Goals of Care (GOC) discussions

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

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

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Models of Palliative Care in the ED

Quality Improvement strategies for early hospice referral

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

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

- Brigham and Womens, Boston

Models of Palliative Care in the ED

Embed Palliative Care Provider Services in ED

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

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

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Consultation in the ED

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

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

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

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Recommendations

1. 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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EMS

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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Where good health begins.

Conclusions from research


Advance Care Planning Guide

Foundation for Healthy Communities

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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Where good health begins.

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**?

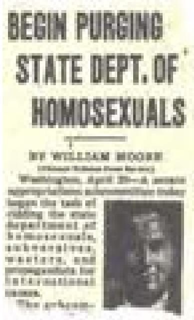
Meet Robert

- **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

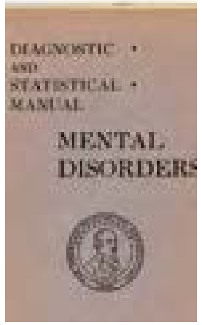
The Life of Robert

Born 1937 (age 87)

1950
Age 13
Lavender Scare



1952
Age 15
DSM Published



1969
Age 32
Stonewall Riots

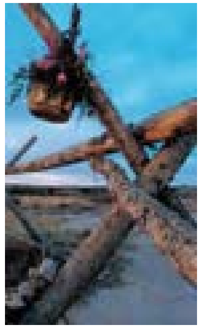
1978
Age 41
Harvey Milk Murdered

1982
Age 45
HIV/AIDS Epidemic

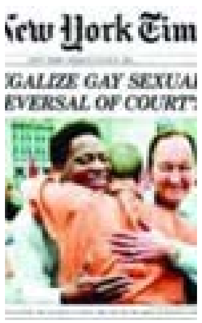
1993
Age 56
"Don't Ask, Don't Tell"

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

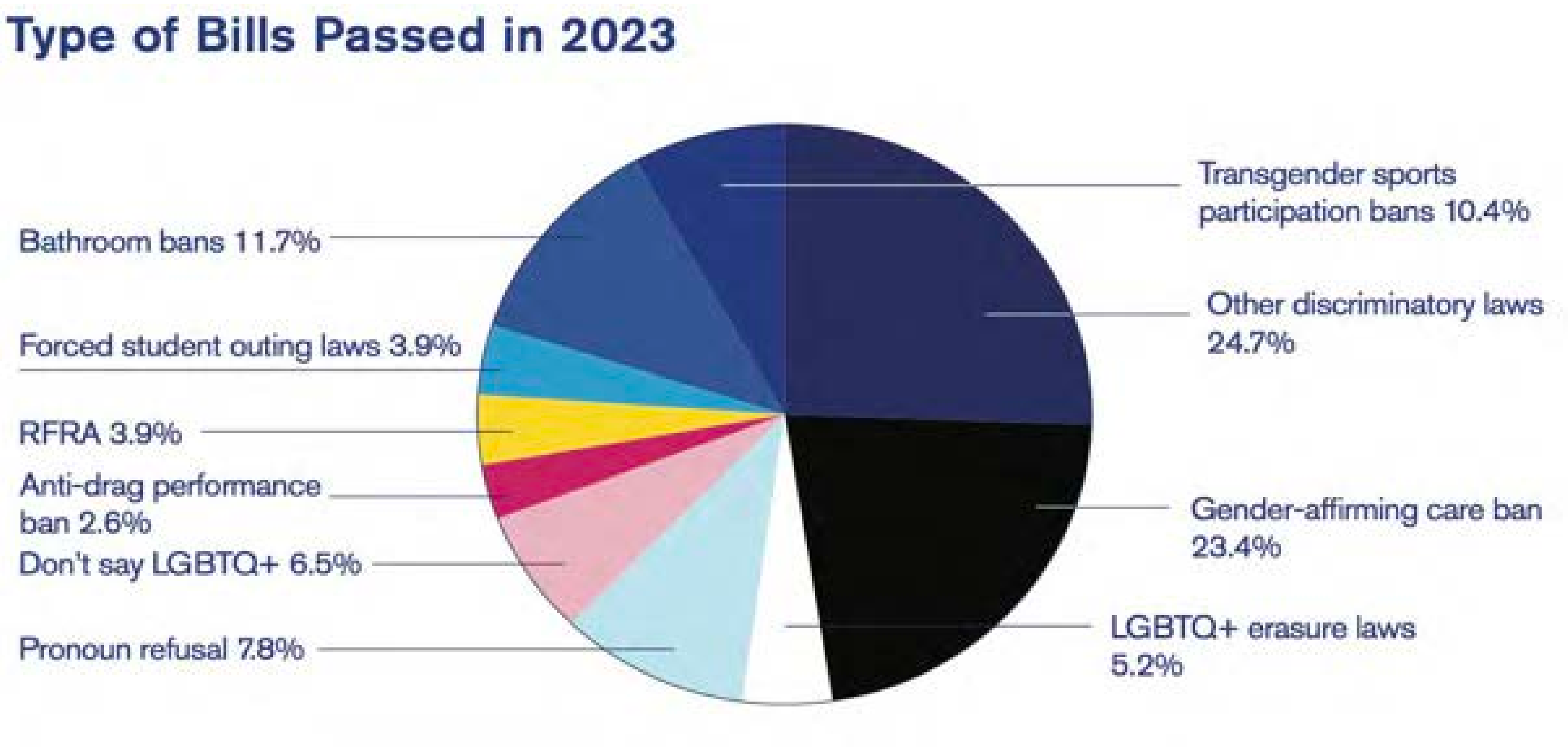
2020
Age 83
LGBTQ Workplace Rights

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.



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

HPM Professionals Identify LGBT Discrimination

54% Believed LGB Patients were more likely to experience discrimination

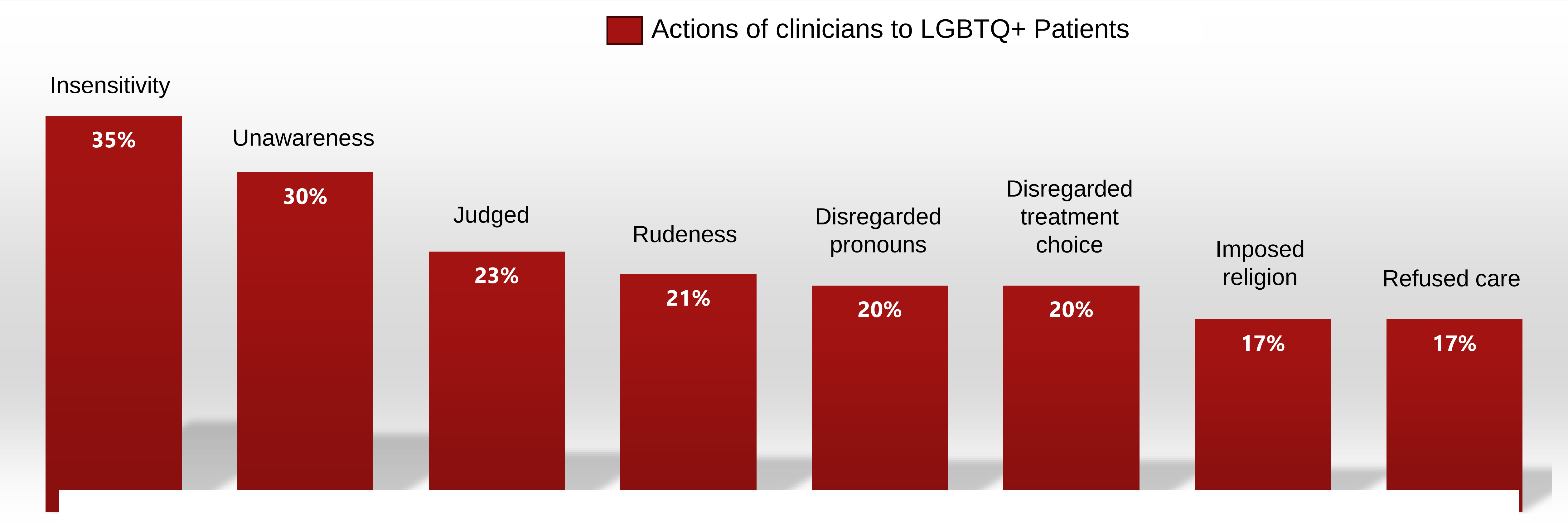
24% Observed discriminatory care toward LGB patients

33% Observed discrimination against LGBT patients’ spouses/partners

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

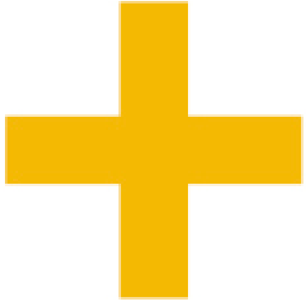
New Study Finds Seriously Ill LGBTQ+ Patients and Care Partners Experience Discrimination

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



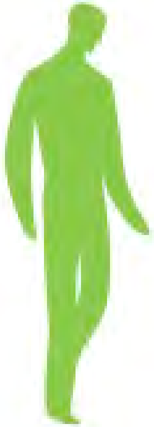
Stein et al., 2023, Health Affairs

Healthcare barriers that LGBTQIA+ patients may experience



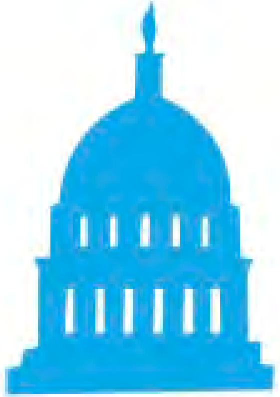
HEALTH CARE ORGANIZATIONS

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



INDIVIDUAL AND SOCIETAL

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

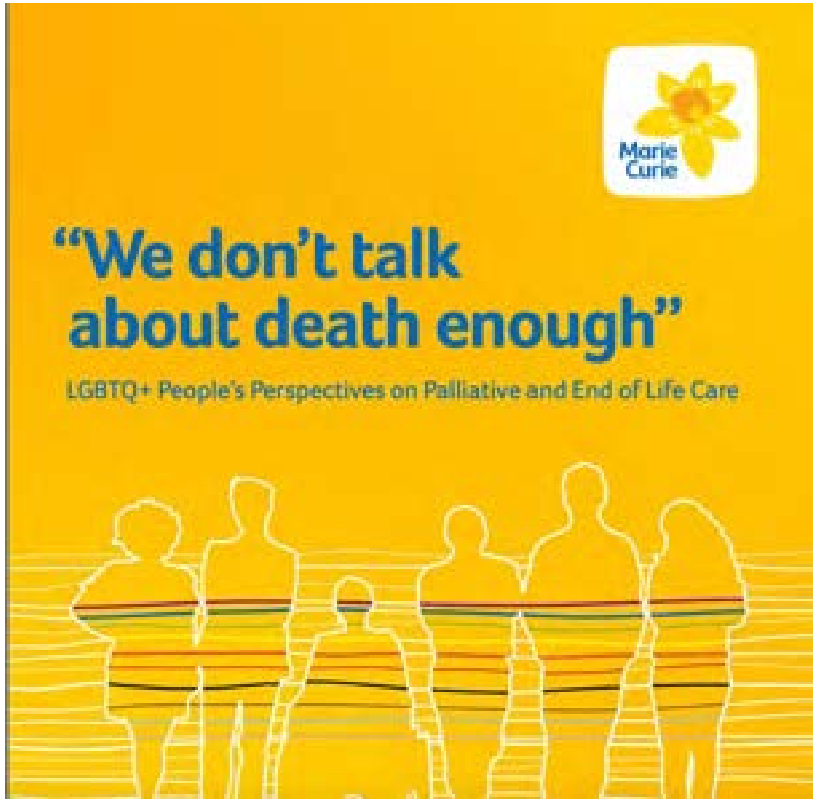


LEGAL AND SOCIAL SYSTEM

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

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

Key Problems at the End of Life



Marie Curie

"We don't talk about death enough"

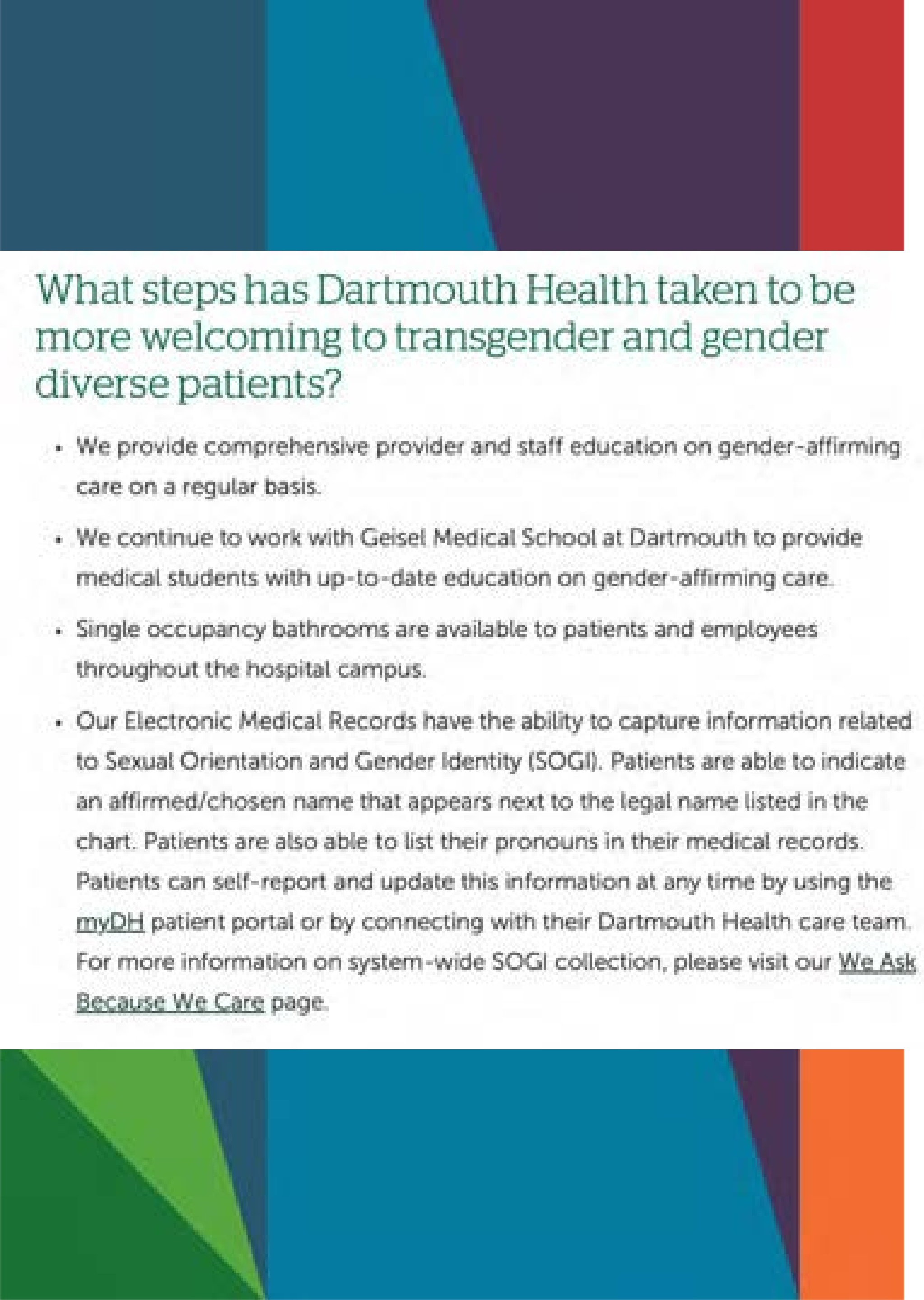
LGBTQ+ People's Perspectives on Palliative and End of Life Care

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

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

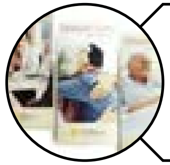
How can we **make palliative care more inclusive** to LGBTQIA+ patients and families?

Ideas to Consider

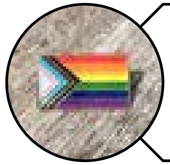


What steps has Dartmouth Health taken to be more welcoming to transgender and gender diverse patients?

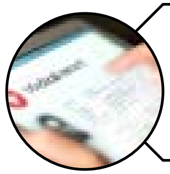
- We provide comprehensive provider and staff education on gender-affirming care on a regular basis.
- We continue to work with Geisel Medical School at Dartmouth to provide medical students with up-to-date education on gender-affirming care.
- Single occupancy bathrooms are available to patients and 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.



Diversity in materials that are distributed

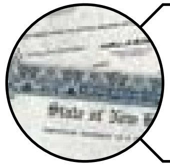


LGBTQIA+ visible signs of support

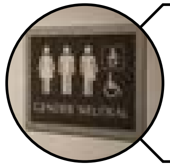


Patient forms contain inclusive, gender-neutral language that allows for self identification

Ensure that phrasing of questions we ask does not assume heterosexuality



Explore preferences specific to patients who are transgender



Gender neutral restrooms

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

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

National
LGBT
Cancer
Network

Support for Patients and Care Partners

Cancer Support Group

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

SUPPORT GROUPS

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

Additional Resources to Explore

aahpm
AMERICAN ACADEMY OF
HOSPICE AND PALLIATIVE MEDICINE

LGBT
Special Interest Group

LGBTQ+ Resource Guide

NHPCO

National
LGBT
Cancer
Network

HPNA
Hospice & Palliative Nurses Association
Advancing Expert Care in Serious Illness

LGBTQ
Special Interest Group

NATIONAL LGBTQIA+ HEALTH
EDUCATION CENTER
A PROGRAM OF THE FENWAY INSTITUTE

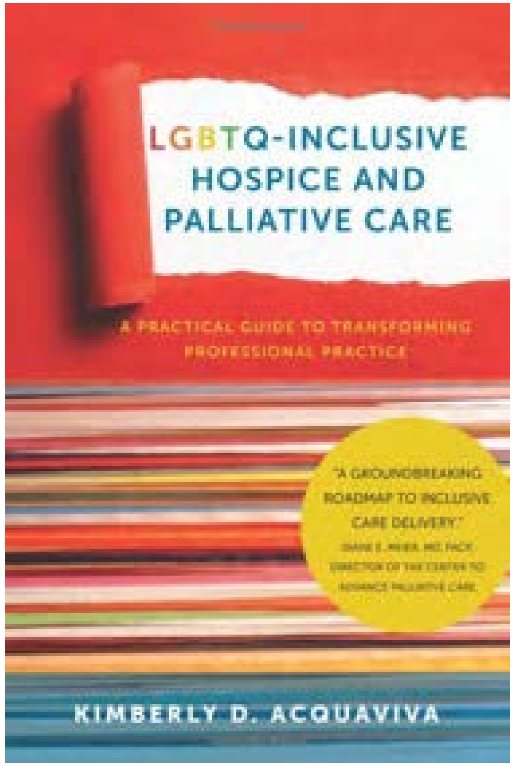
National LGBTQIA+
Health Education Center

capc

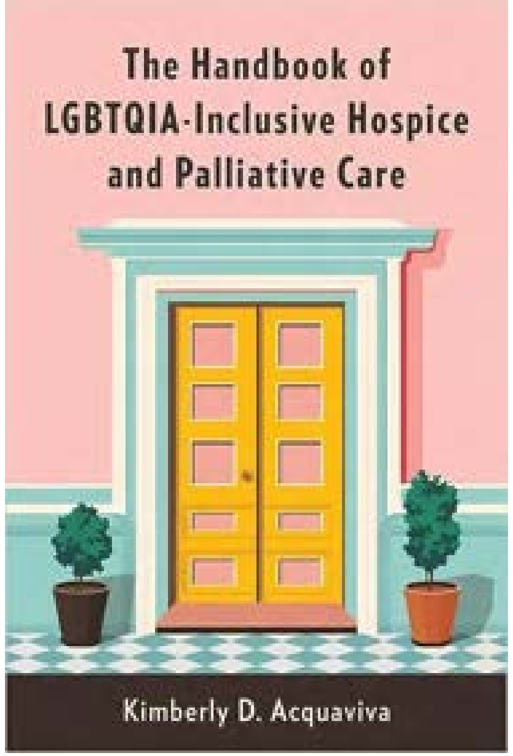
"Providing Inclusive and Affirmative Palliative Care for the LGBTQ+ Community"

Additional Resources to Explore

Two recent books have been published that take a deeper dive



Harrington Park Press
Published: May 2017



Columbia University Press
Published: October 2023

Resources

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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.

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THANK YOU

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

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

Disclosures

Will discuss off label use of FDA approved medications

I provide expert legislative testimony for access to MAID

I am occasionally reimbursed for testifying time
By Compassion and Choices

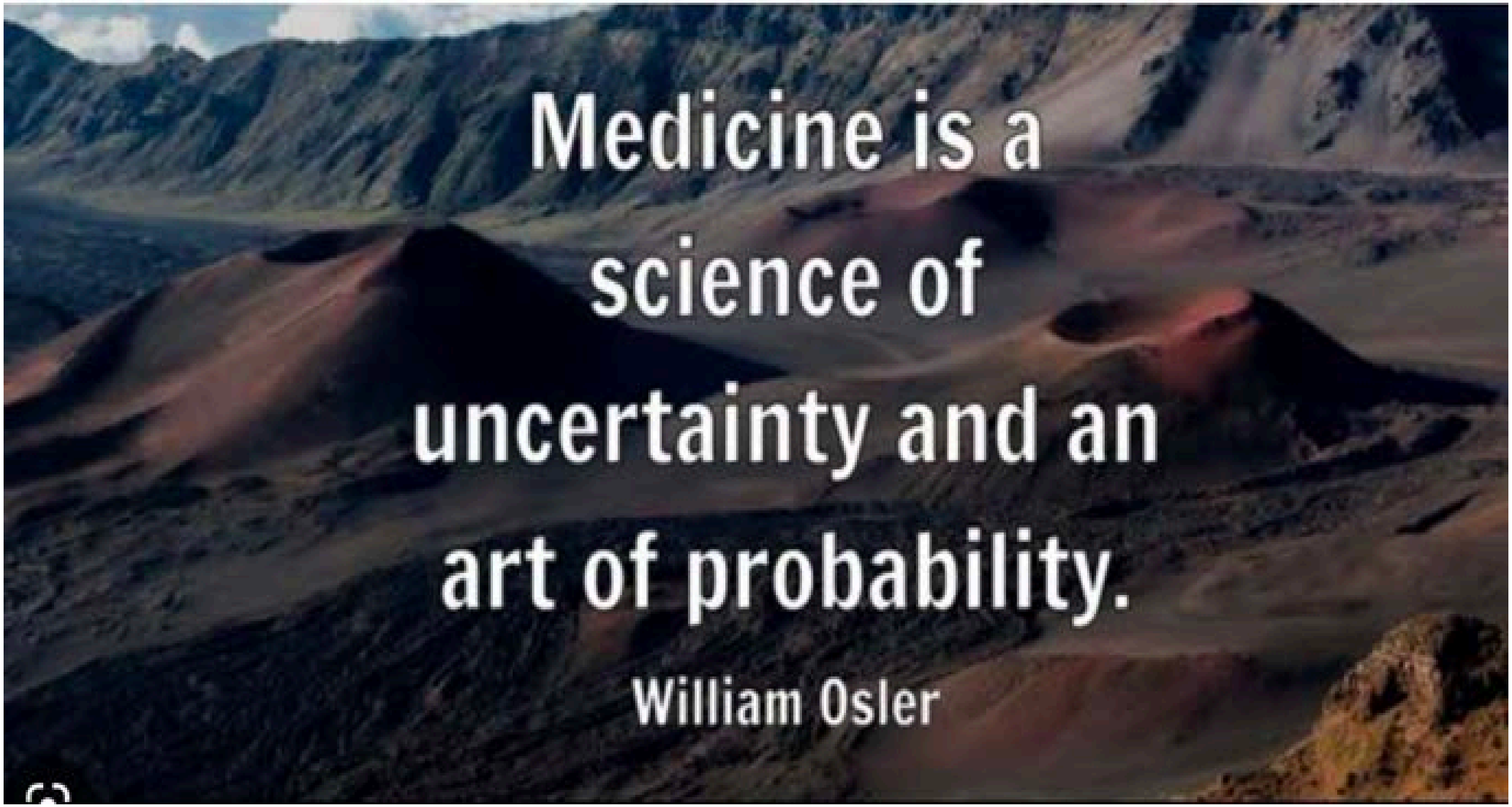
Objectives

Describe Medical Aid in Dying (MAID) and eligibility criteria

Explore motivation behind requests for MAID

Deepen awareness of multidimensional suffering

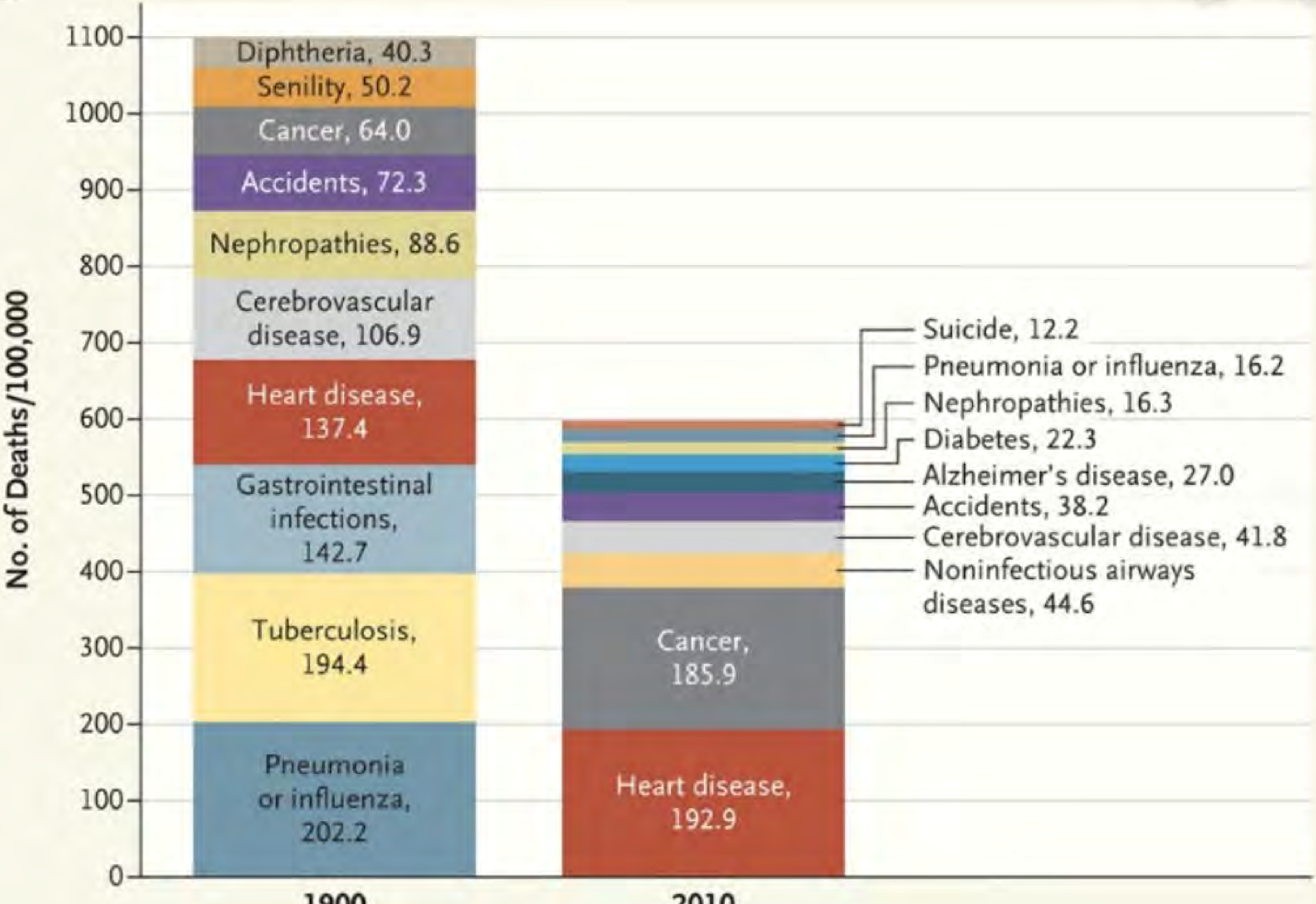
William Osler, 1800s



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

William Osler

Cause of Death 1900 vs. 2010



What IS Medical Aid in Dying

A practice that legally allows a physician

to prescribe a lethal dose of medication

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

for the purpose of *hastening death*

End of Life

Unique

Individual

Deeply Personal

Enduring Impact

Patient Preferences for end of life care

At home

Family/loved ones present

Comfortable

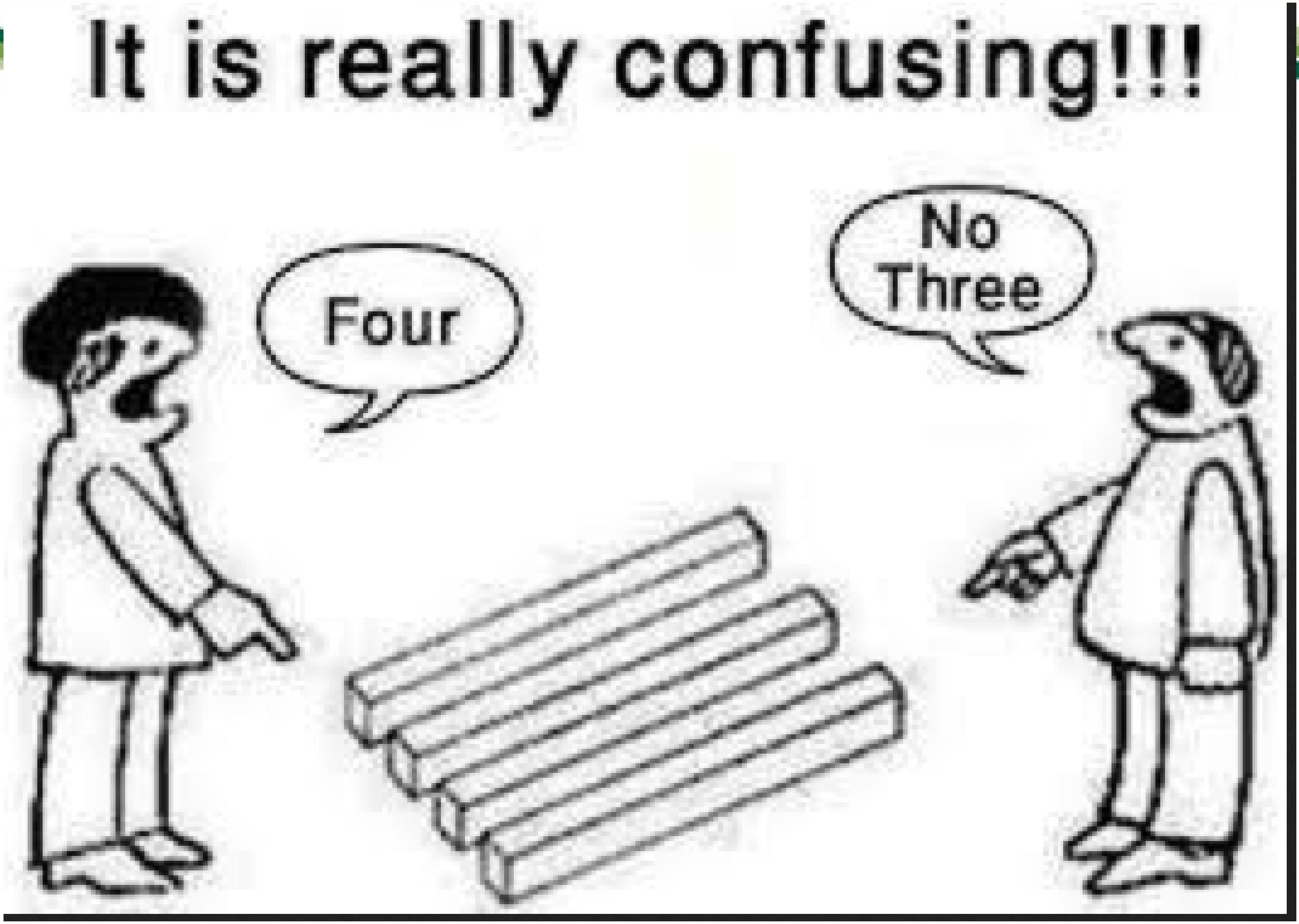
We all Die

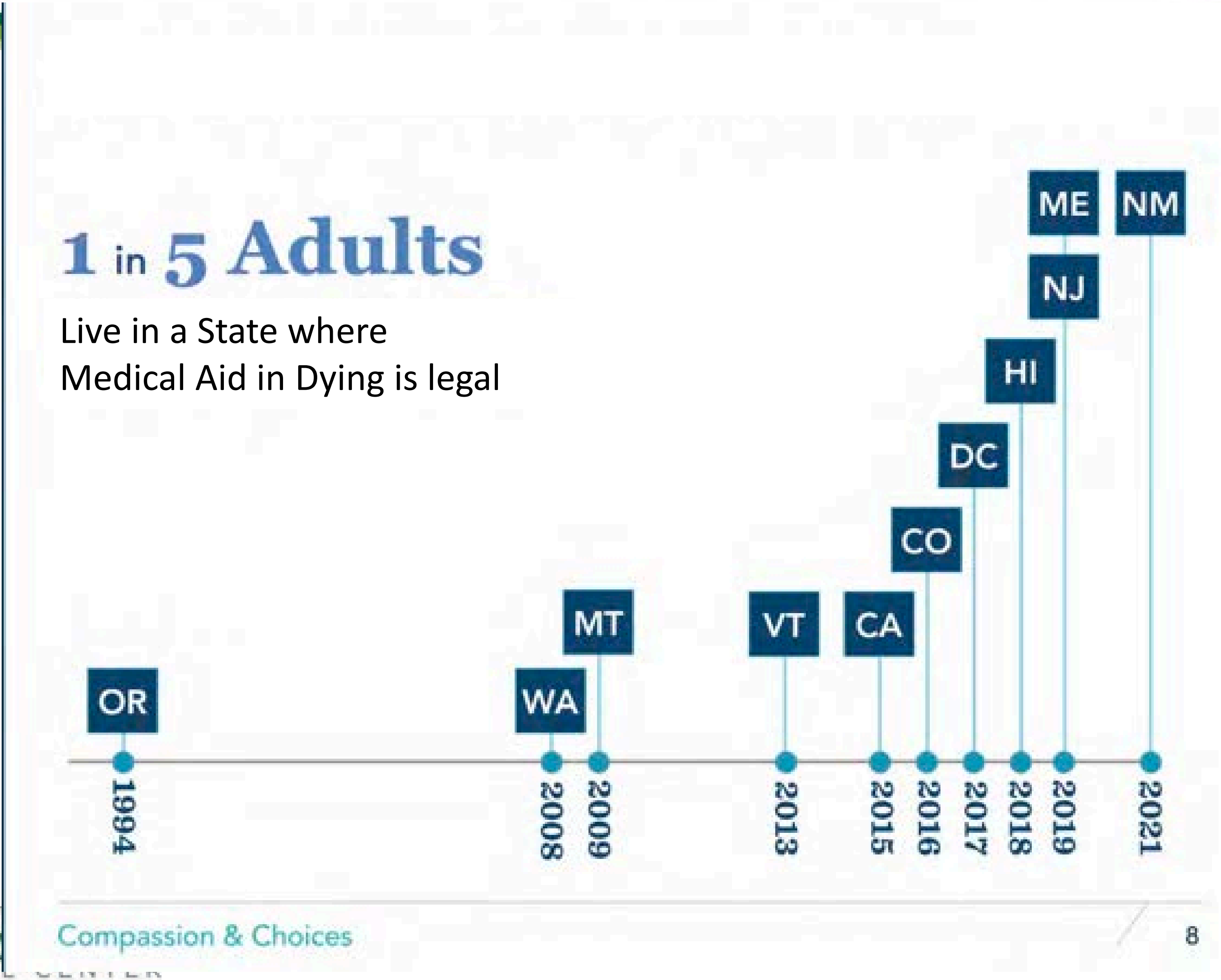
Experience in Oregon (27 years)

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

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

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


It is really confusing!!!
Four
No Three



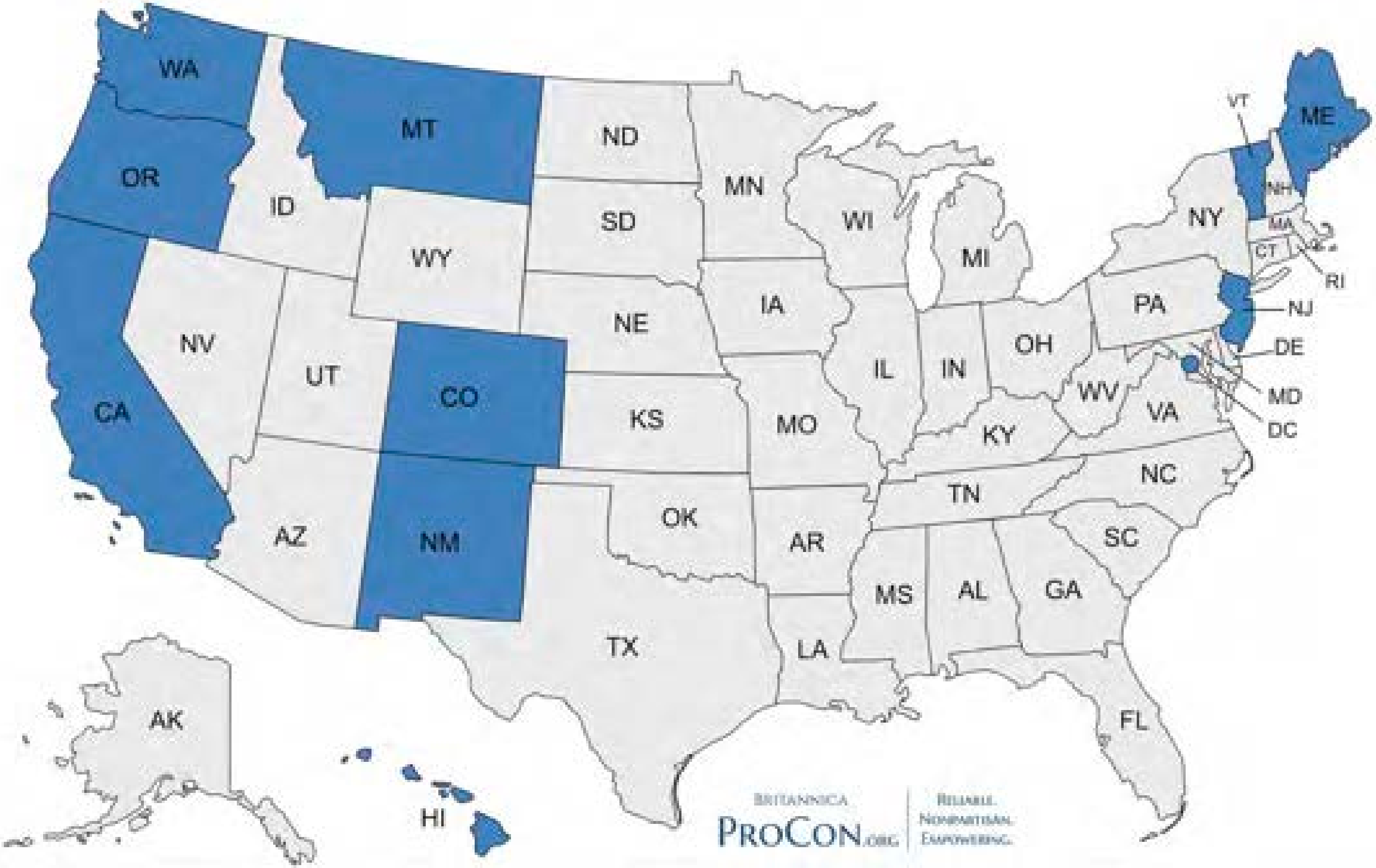
1 in 5 Adults

Live in a State where
Medical Aid in Dying is legal

Compassion & Choices

8

https://www.britannica.com/procon



Suffering- Dr. Eric Cassell, NEJM, 1982

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

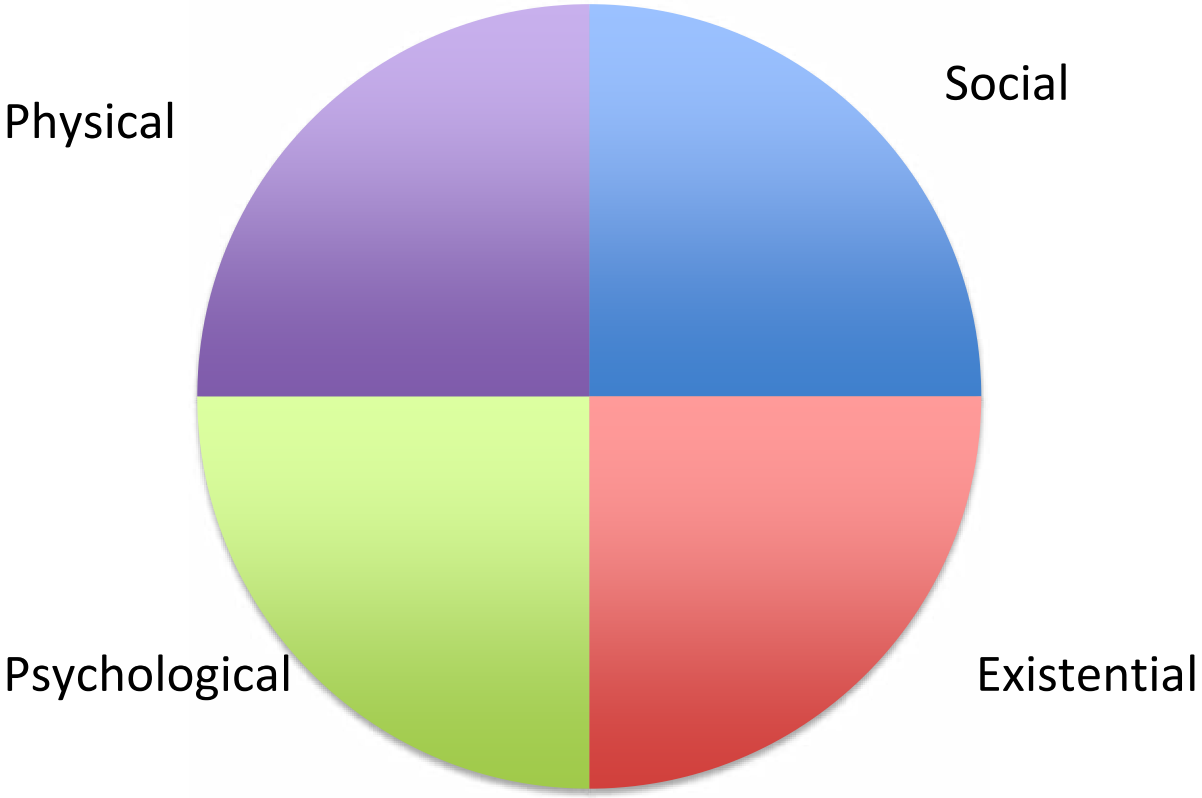
Suffering is experienced by persons, not merely by bodies, and has its source in challenges that threaten the intactness of the person as a complex social and psychological entity.

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

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

Total Suffering (adapted)

Dame Cicely Saunders



THE University of Vermont MEDICAL CENTER

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

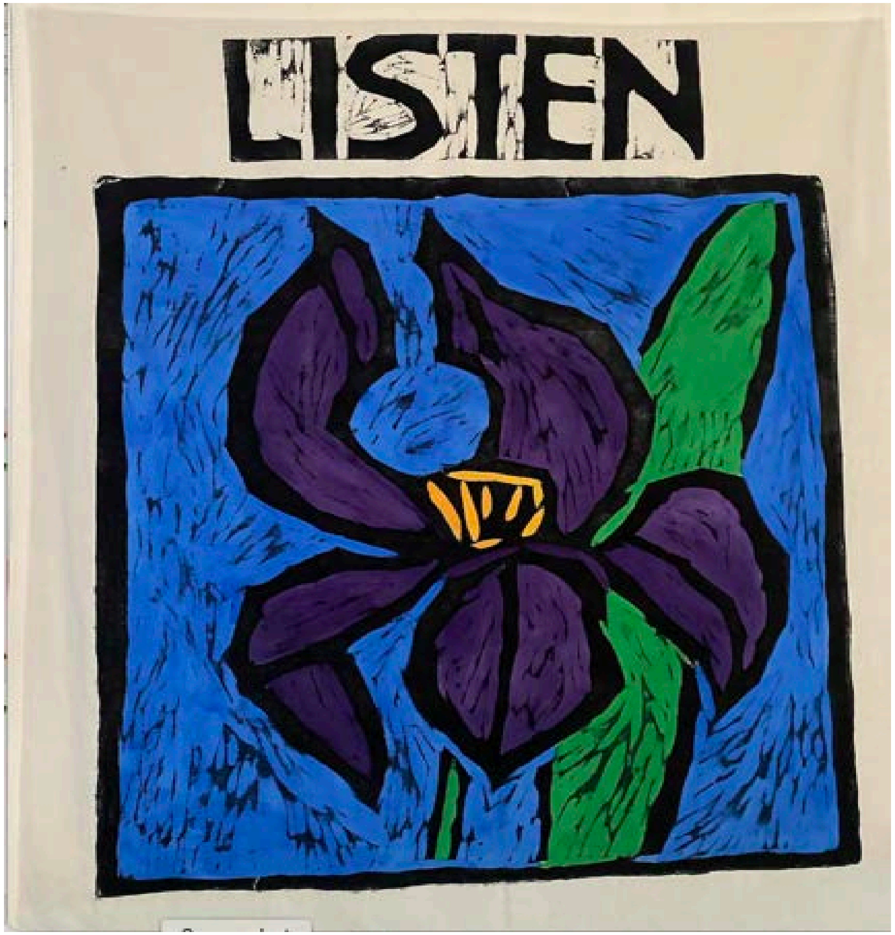
Prognostication

- 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

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

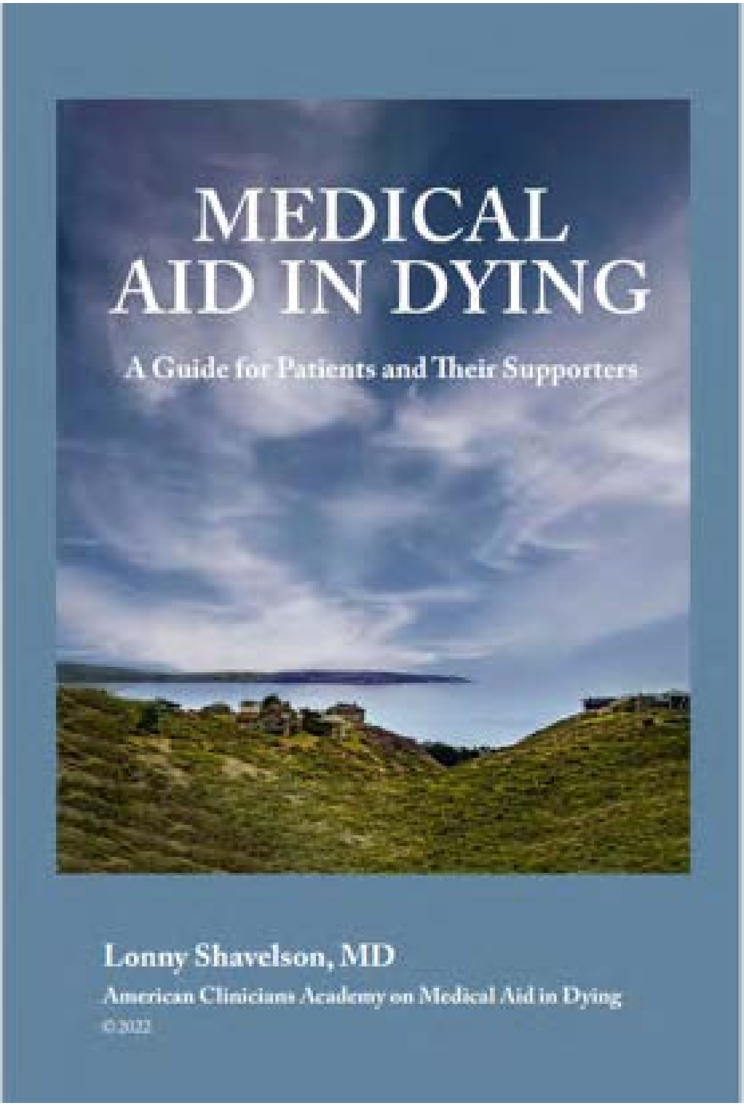
Non-Resident Checklist:

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

PCV Helpline:

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

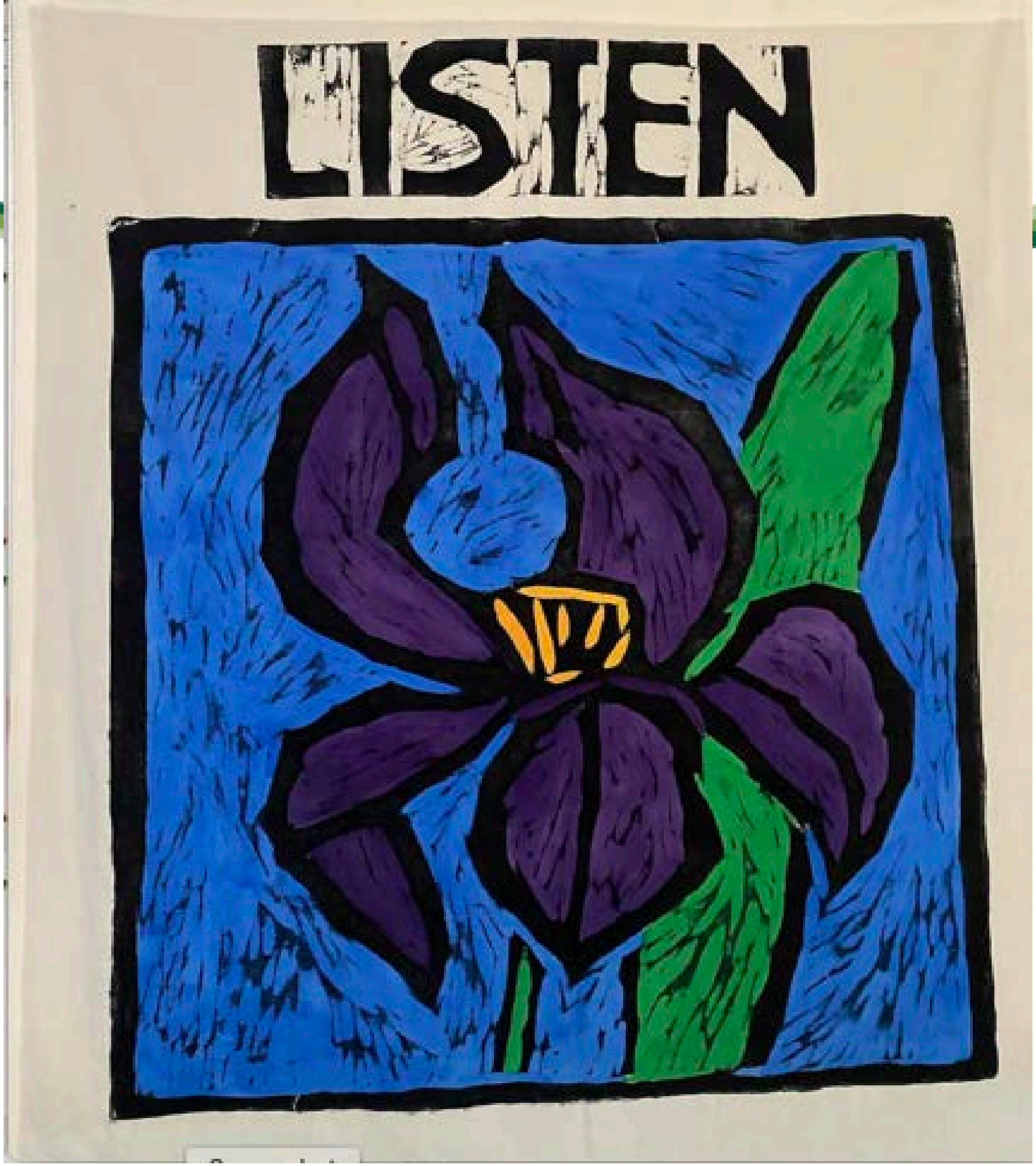
Aid-in-Dying-Patient-Guide.pdf (acamaid.org)



MEDICAL
AID IN DYING

A Guide for Patients and Their Supporters

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


LISTEN

References/Information

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

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

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

Vermont Ethics Network

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

- Oregon Health Authority

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

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

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

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

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

THE
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MEDICAL CENTER

Palliative ECHO: Severe Mental Illness and Palliative Care

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Dartmouth-Health, Department of Psychiatry

Disclosures

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

Objectives

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

Definitions

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

Palliative Care and Psychiatry

- Similarities/Overlap
- Differences
- Palliative Psychiatry?

Severe Persistent Mental Illness (SPMI)

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

Morbidity and Mortality for People with SPMI

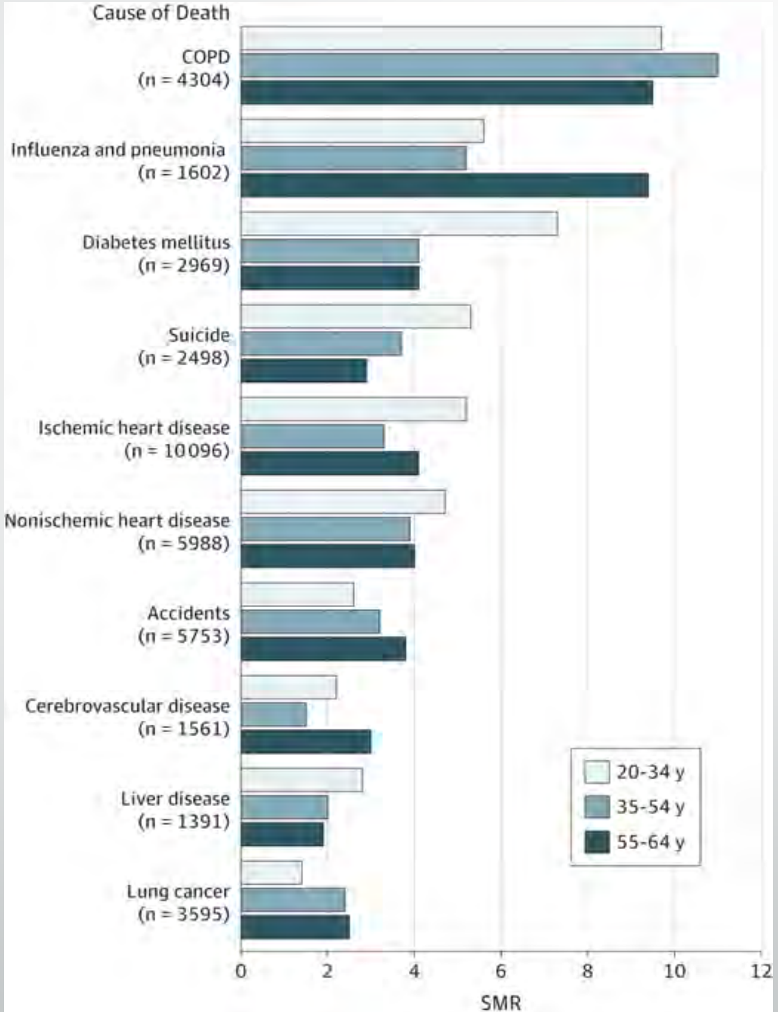


Figure. Standardized Mortality Ratios of Adult Medicaid Beneficiaries Diagnosed as Having Schizophrenia for 10 Common Causes of Death by Age Group (January 1, 2001, to December 31, 2007)

Decision Making Capacity

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

https://vtethicsnetwork.org/

Decision Making Capacity – "Sliding Scale"

Levels of Capacity

The ability to…

- …reach a reasonable decision (reasonable person standard)
- …give risk/benefit-related reason
- …give a rational reason
- …give a reason
- …understand relevant information
- …understand one's situation and its consequences
- …express or communicate a preference or choice

https://vtethicsnetwork.org/

Decision Making Capacity – Continued

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

Advanced Care Planning

- Who makes decisions?

Health Care Equity/Access to Care

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

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

Health Care Equity/Access to Care

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

Challenges for patients and providers

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

Challenges for patients and providers

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

Specific Mental Health Issues

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

Tips

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

Riordan et al. J Pall Med. 2018.

Trauma-Informed Care

Trauma-Informed Care (TIC)

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

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

5 KEY PRINCIPALS:

Safety
Creating areas that are calm & comfortable

Trust
Providing clear and consistent information

Choice
Providing an individual options in their treatment

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

Empowerment
Noticing capabilities in an individual

UNIVERSAL SCREENING

Prevents misdiagnosis and inappropriate treatment planning

THE FOUR R'S OF TIC

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

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

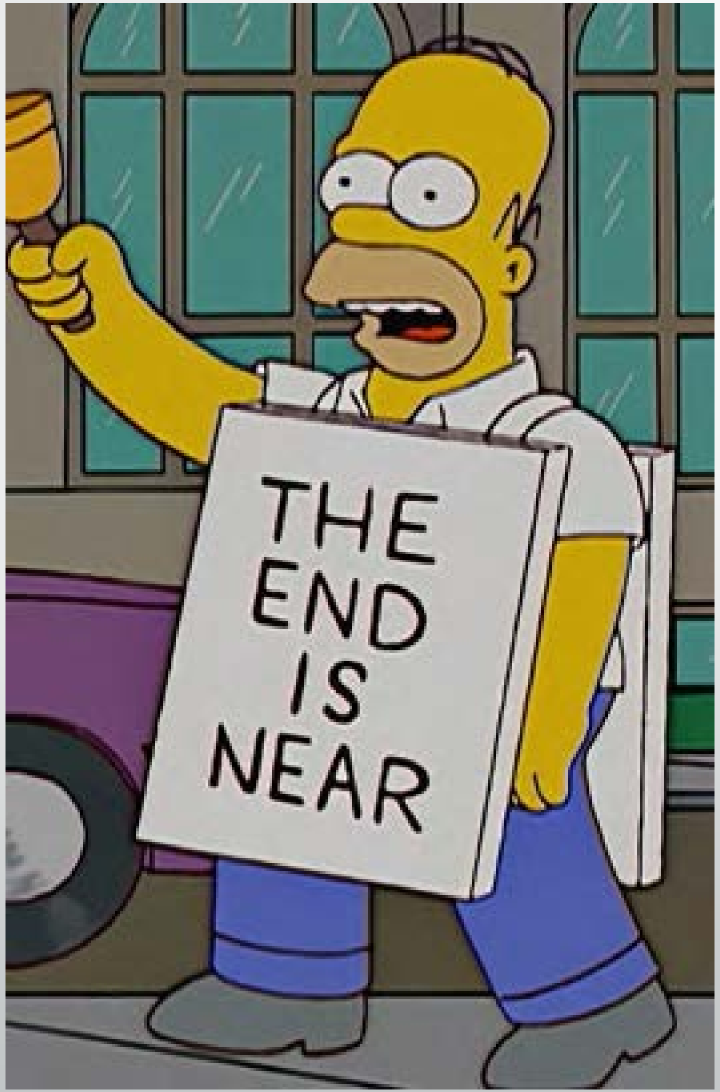
RECOGNISE
People within organisations are able to recognise the signs and symptoms of trauma

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

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

Sandra Bloom, Creator of the Sancturay Model

Final Thoughts and Tips/Recommendations



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

Amelia Cullinan, MD

March 4, 2025

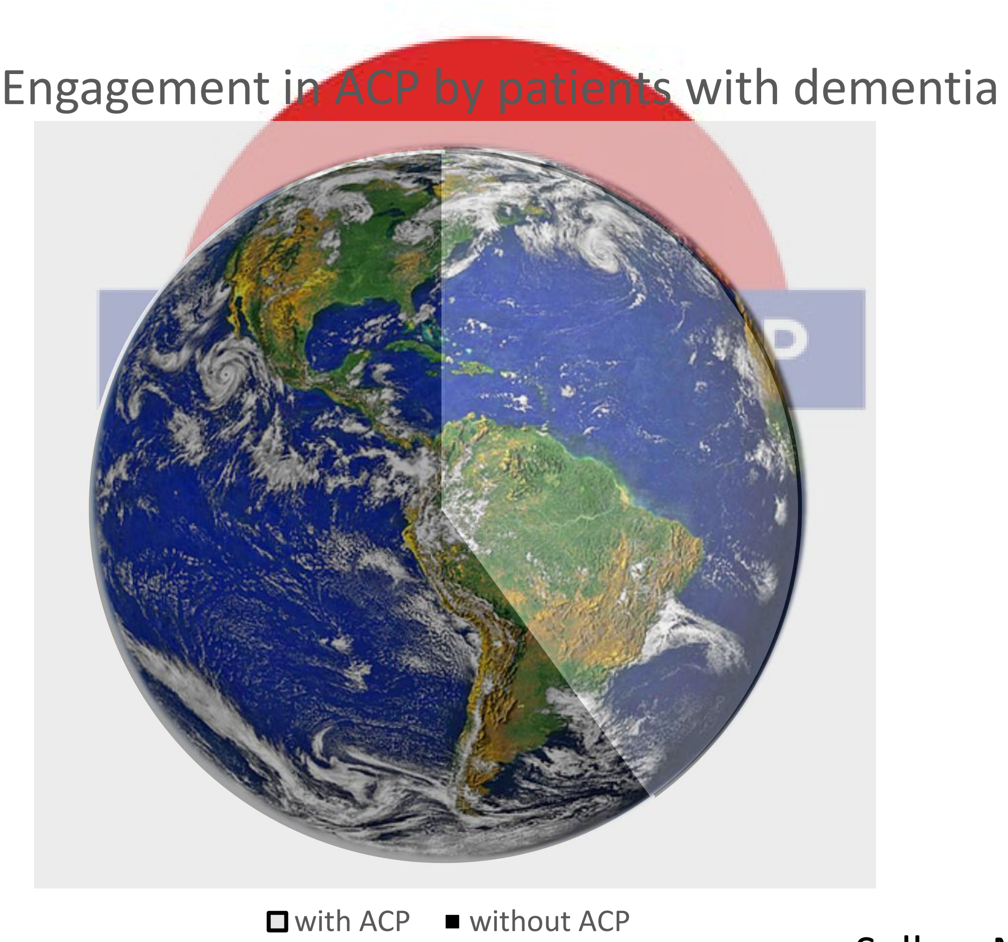
I have no disclosures!

Learning Objectives

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

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

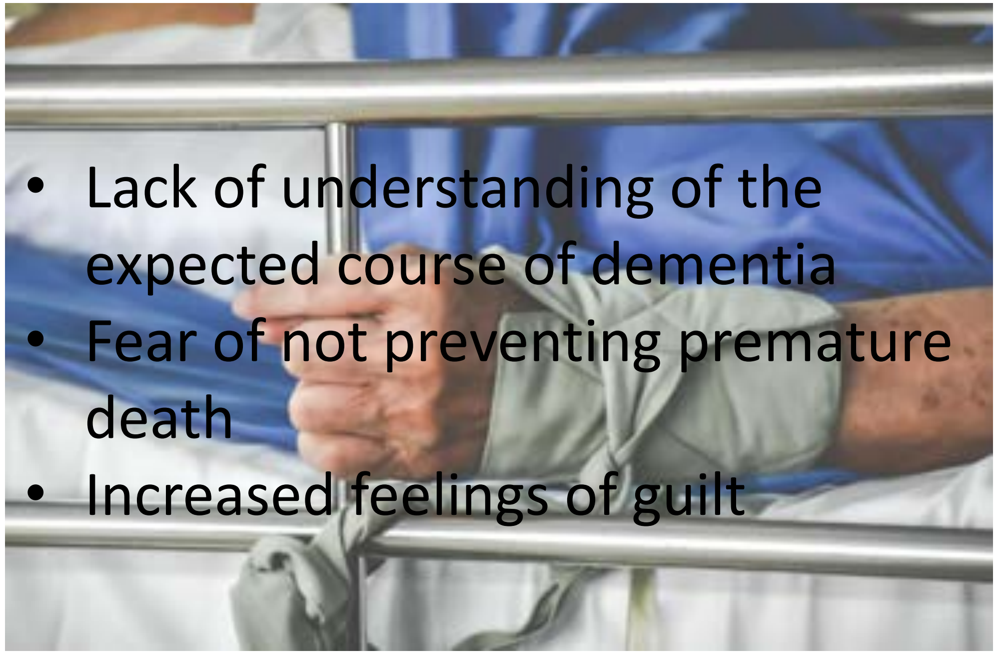
Let’s talk about the gap: dementia is prevalent and not enough patients have engaged in advance care planning (ACP)



47 million
worldwide,
and rising

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

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



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

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

Why do so few patients with dementia engage in ACP?

Patient and care partner (CP) barriers to ACP

Care Partners (CP)

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

William Utermohlen

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

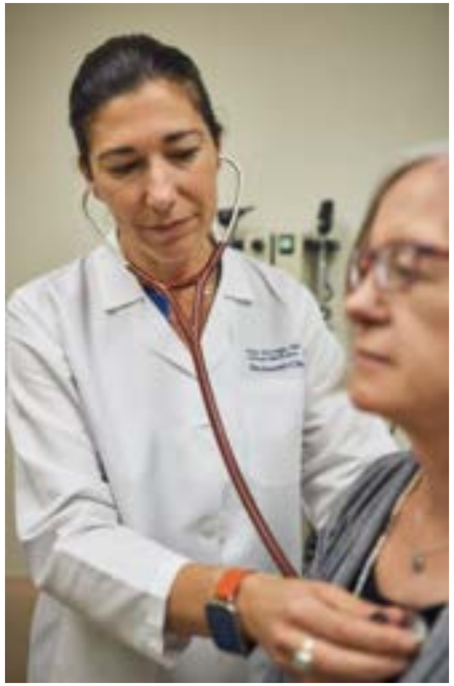
Healthcare professionals’ barriers to ACP

Too early:

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

Too late:

- Concern that patients lack capacity to discuss it



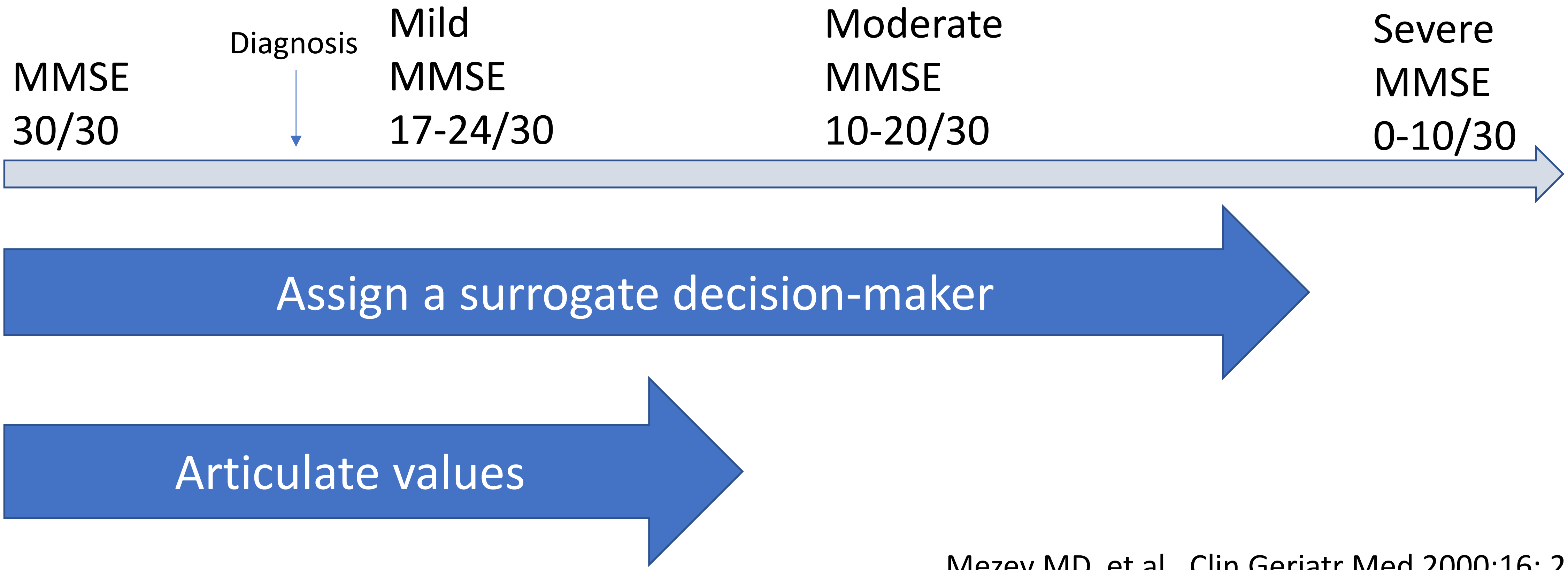
Lack of time for conversations

Fear

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

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

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



MMSE
30/30

Diagnosis

Mild
MMSE
17-24/30

Moderate
MMSE
10-20/30

Severe
MMSE
0-10/30

Assign a surrogate decision-maker

Articulate values

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

ACP benefits both patients with dementia and their CPs

Patients with dementia

↑
- Death in preferred place
- Coping

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

Care Partners

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

↓
- Feeling of responsibility for death
- Depression
- Anxiety

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

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


Review Article

PALLIATIVE MEDICINE

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

Palliative Medicine
2019, Vol. 33(3) 274–290
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Marcus Sellars[1,2], Olivia Chung[3], Linda Nolte[1], Allison Tong[3], Dimity Pond[4], Deirdre Fetherstonhaugh[5], Fran McInerney[6], Craig Sinclair[7] and Karen M Detering[1,8]

Education about what to expect

Iterative conversations

Recommendations from clinicians they trust

Best practices for ACP for patients with dementia

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

Start early, revisit often

Listen for cues

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

Best practices for ACP for patients with dementia

Patient Clinician Care Pa

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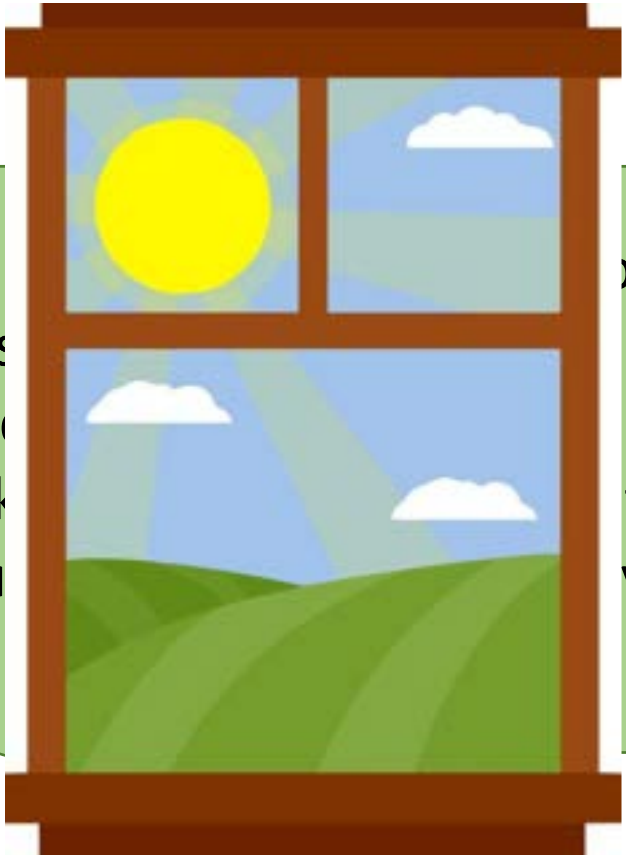

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Optimize conditions

Assume capacity and empower HCP

Start early, revisit often

Listen for cues

Mezey MD, et al. Clin Geriatr Med 2000;16: 255-268
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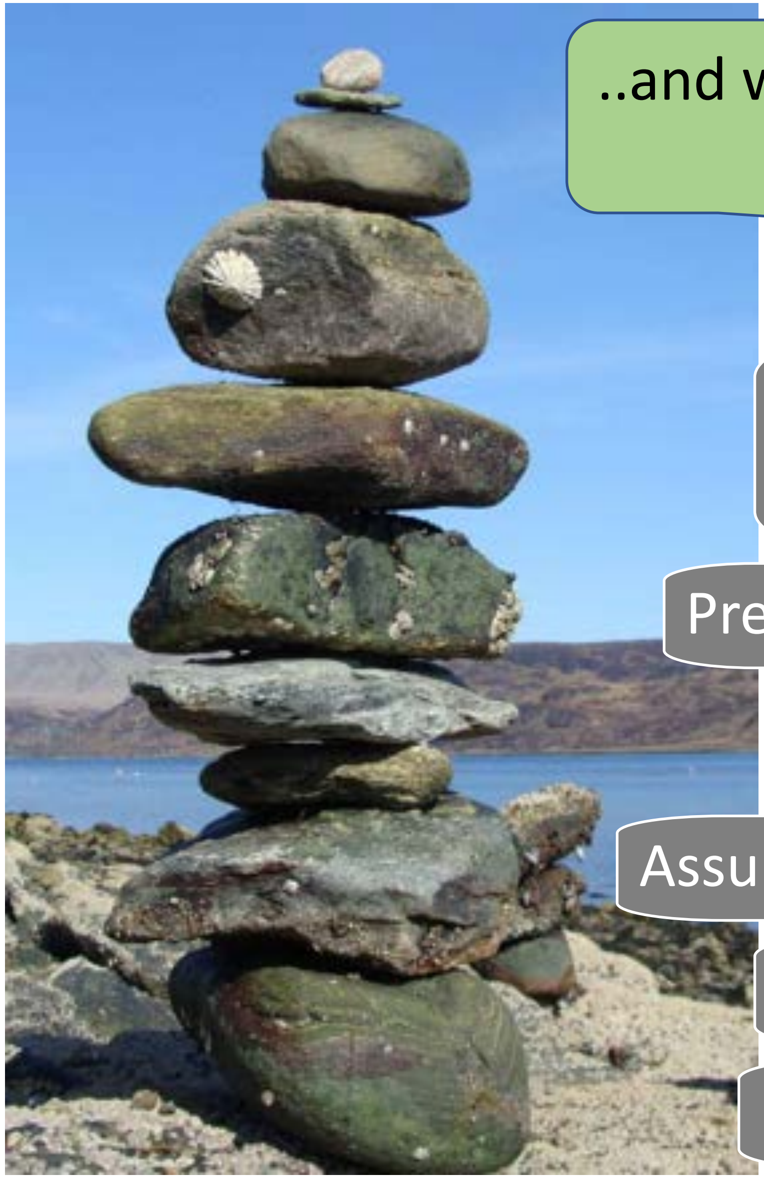
Best practices for ACP for patients with dementia



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

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

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

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

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

Best practices for ACP for patients with dementia

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

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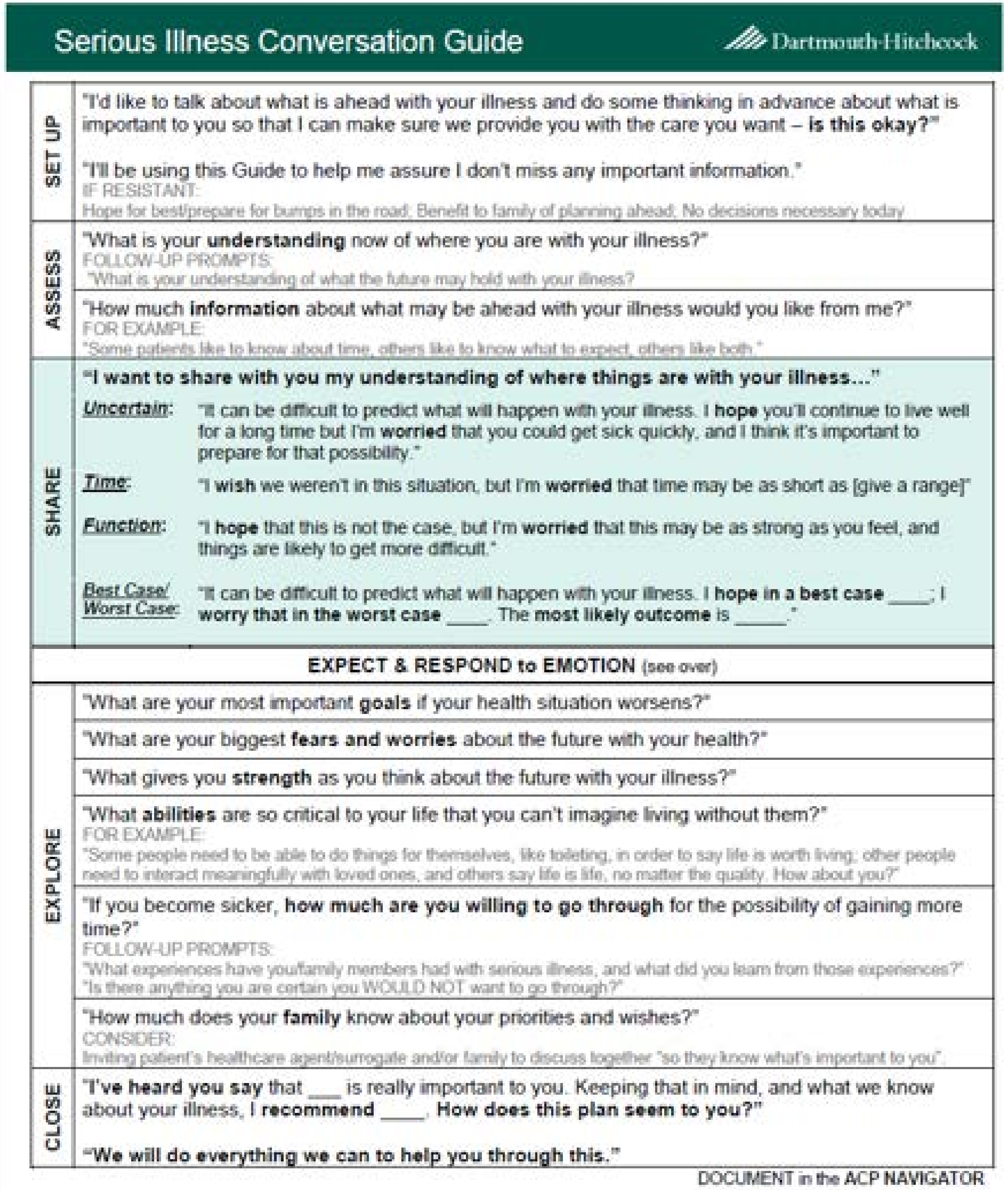
The Serious Illness Conversation

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



Serious Illness Conversation Guide

Dartmouth-Hitchcock

SET UP

"I'd like to talk about what is ahead with your illness and do some thinking in advance about what is important to you so that I can make sure we provide you with the care you want – **is this okay?"**

"I'll be using this Guide to help me assure I don't miss any important information."
IF RESISTANT:
Hope for best/prepare for bumps in the road; Benefit to family of planning ahead; No decisions necessary today

ASSESS

"What is your **understanding** now of where you are with your illness?"
FOLLOW-UP PROMPTS:
"What is your understanding of what the future may hold with your illness?

"How much **information** about what may be ahead with your illness would you like from me?"
FOR EXAMPLE:
"Some patients like to know about time, others like to know what to expect, others like both."

SHARE

"I want to share with you my understanding of where things are with your illness..."

Uncertain: "It can be difficult to predict what will happen with your illness. I **hope** you'll continue to live well for a long time but I'm **worried** that you could get sick quickly, and I think it's important to prepare for that possibility."

Time: "I **wish** we weren't in this situation, but I'm **worried** that time may be as short as [give a range]"

Function: "I **hope** that this is not the case, but I'm **worried** that this may be as strong as you feel, and things are likely to get more difficult."

Best Case/ Worst Case: "It can be difficult to predict what will happen with your illness. I **hope in a best case** ____; I **worry that in the worst case** ____. The **most likely outcome** is _____."

EXPECT & RESPOND to EMOTION (see over)

EXPLORE

"What are your most important **goals** if your health situation worsens?"

"What are your biggest **fears and worries** about the future with your health?"

"What gives you **strength** as you think about the future with your illness?"

"What **abilities** are so critical to your life that you can't imagine living without them?"
FOR EXAMPLE:
"Some people need to be able to do things for themselves, like toileting, in order to say life is worth living; other people need to interact meaningfully with loved ones, and others say life is life, no matter the quality. How about you?"

"If you become sicker, **how much are you willing to go through** for the possibility of gaining more time?"
FOLLOW-UP PROMPTS:
"What experiences have you/family members had with serious illness, and what did you learn from those experiences?"
"Is there anything you are certain you WOULD NOT want to go through?"

"How much does your **family** know about your priorities and wishes?"
CONSIDER:
Inviting patient's healthcare agent/surrogate and/or family to discuss together "so they know what's important to you".

CLOSE

"**I've heard you say** that ___ is really important to you. Keeping that in mind, and what we know about your illness, I **recommend** ____. **How does this plan seem to you?"**

"We will do everything we can to help you through this."

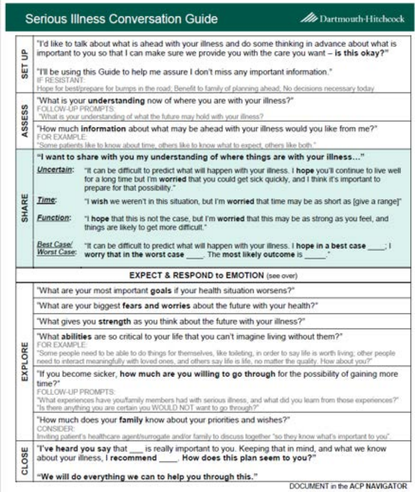
DOCUMENT in the ACP NAVIGATOR

Adapting the Serious Illness Conversation Guide for Dementia Care

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

DOI: 10.1177/10499091231200214
com/home/ajh

Charlotte E. Berry, BA[1]
Robert Santulli, MD[1], ar

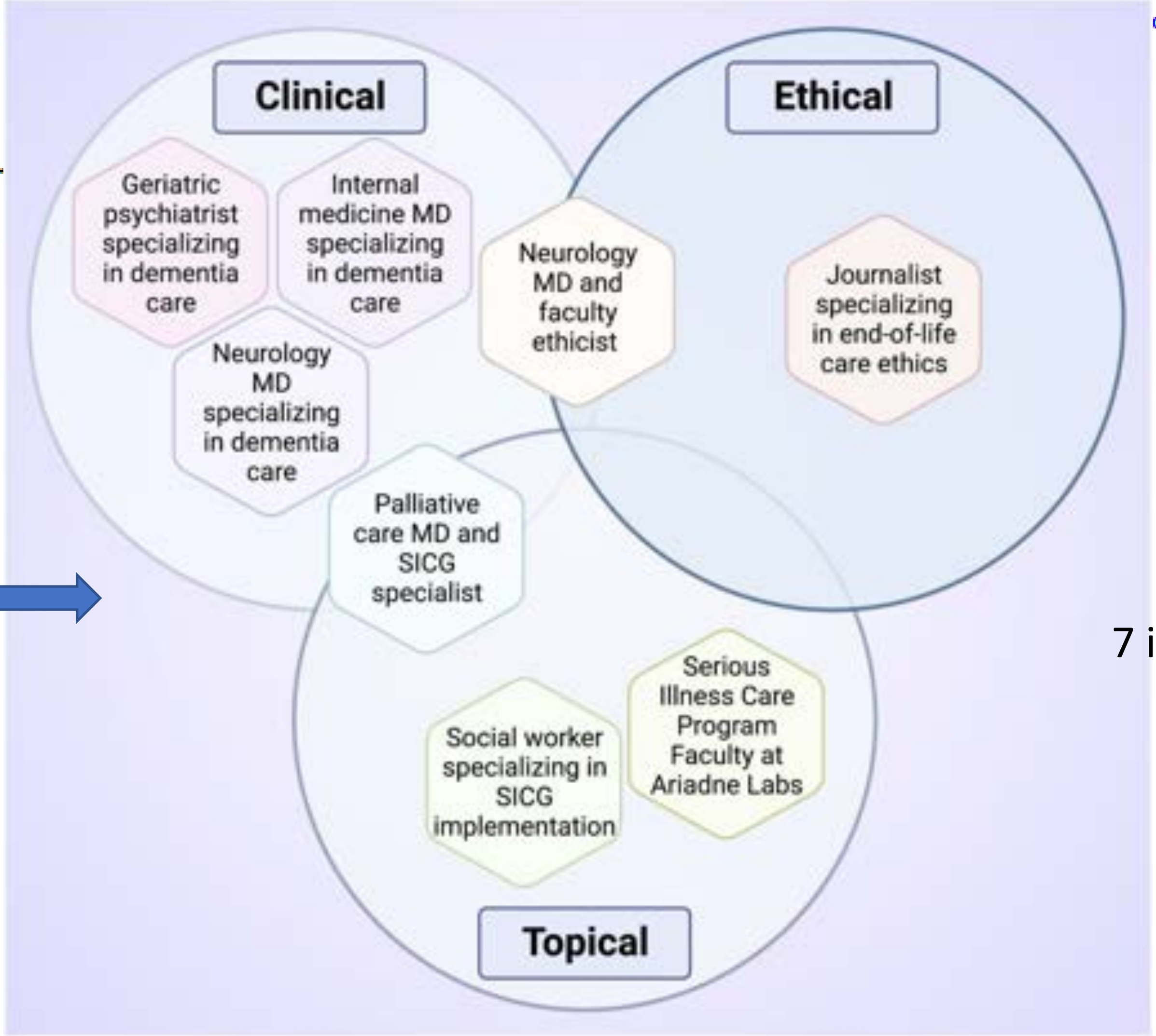


Serious Illness Conversation Guide Dartmouth-Hitchcock

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

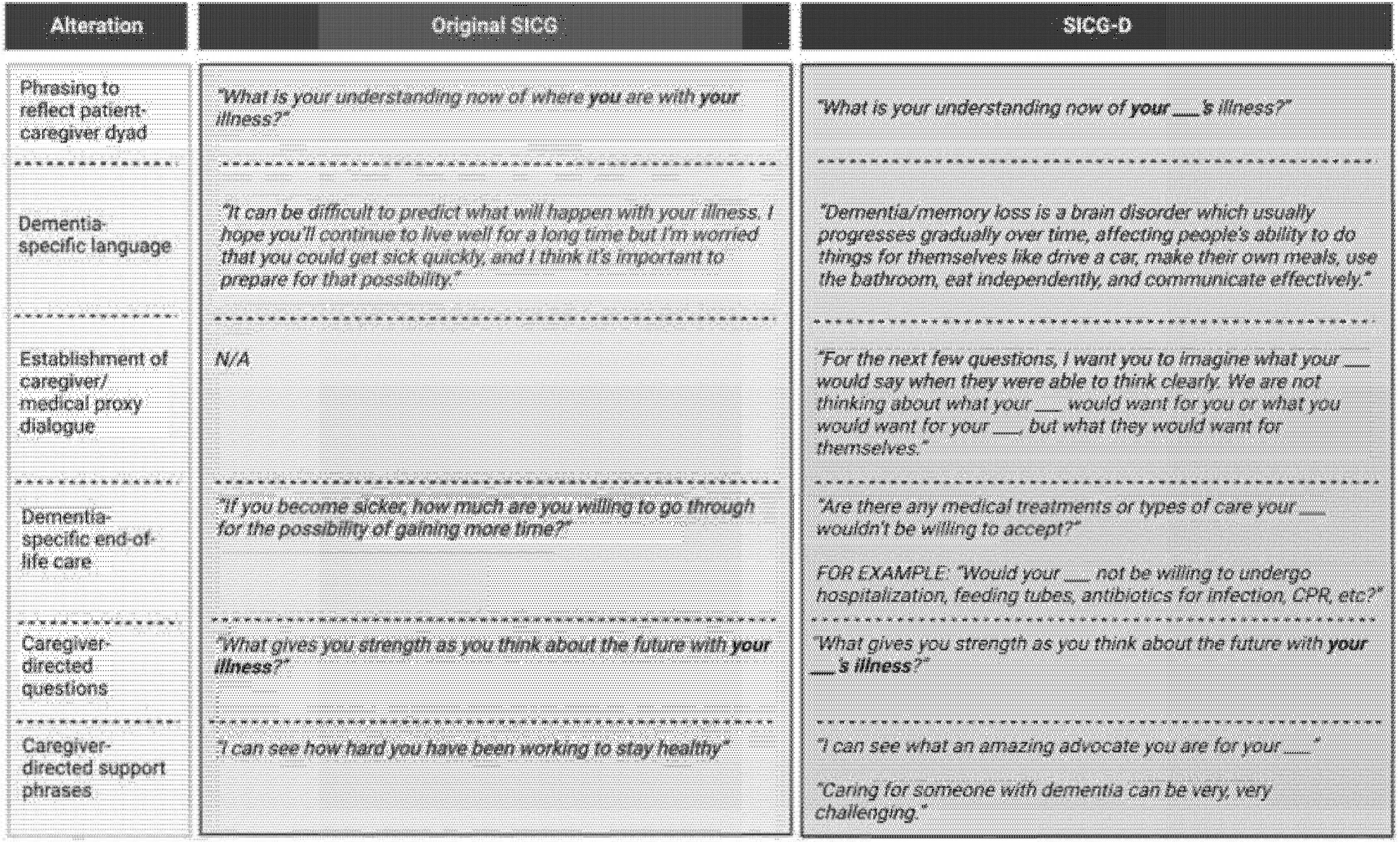
DOCUMENT in the ACP NAVIGATOR

SIC - Original



7 iterations

SIC-Dementia



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

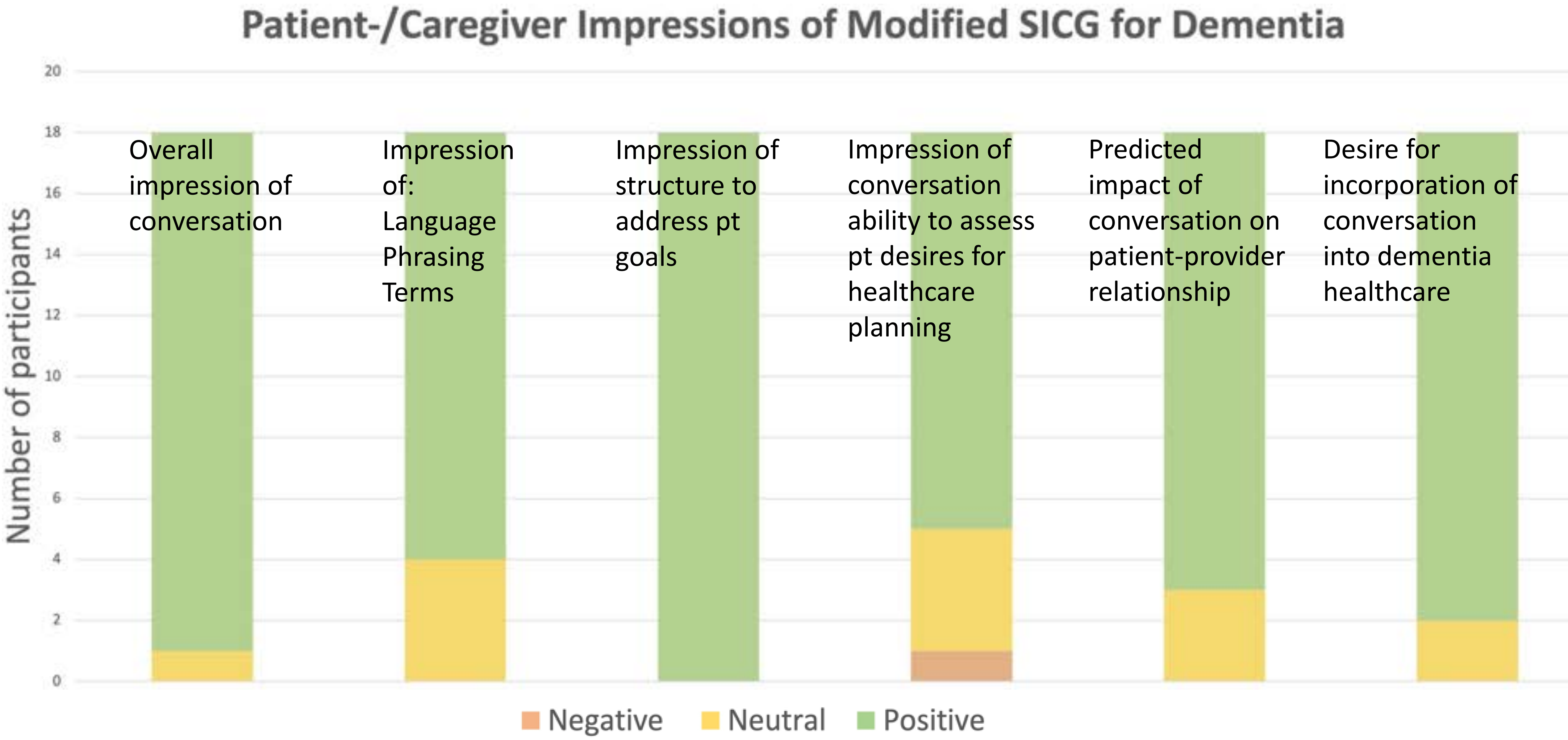
14 people with dementia
18 care partners

Thematic analysis

Anonymous quantitative survey

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

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



Overall impression of conversation

Impression of: Language Phrasing Terms

Impression of structure to address pt goals

Impression of conversation ability to assess pt desires for healthcare planning

Predicted impact of conversation on patient-provider relationship

Desire for incorporation of conversation into dementia healthcare

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

Closing Pearls

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

Spirituality and Cultural Sensitivity in Serious Illness

Connolly Huddleston, MAPS, BCC
April 1, 2025
ECHO 4.0

THE
University of Vermont
MEDICAL CENTER

I have no disclosures!

What’s your experience?

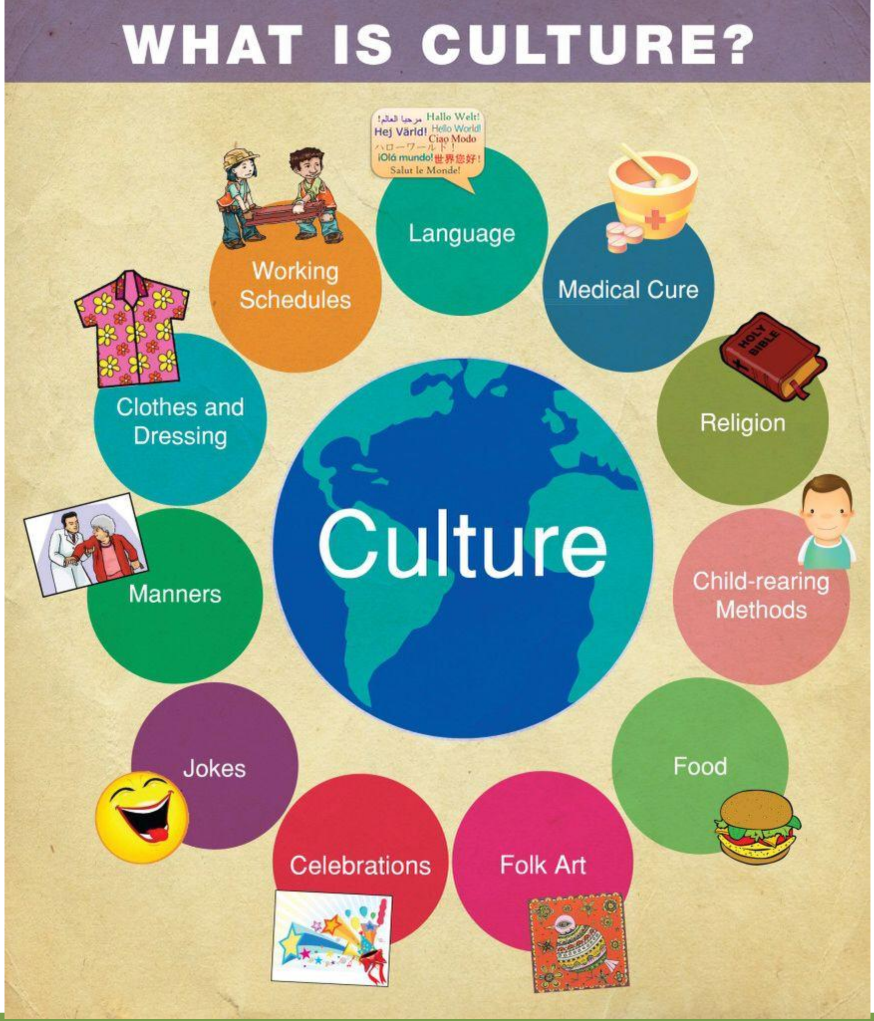
Takeaways

- Define spiritualty and culture
- Defining and attending to spiritual/existential distress- theirs and *yours*
- Tools to step into “courageous conversations” and seek to understand

Spirituality…

*…the aspect of humanity that refers to the way individuals **seek and express meaning and purpose** and the way they **experience their connectedness** to the moment, to self, to others, to nature, and to the significant or sacred.*

PUCHALSKI, C., & FERRELL, B. (2010). MAKING HEALTH CARE WHOLE: INTEGRATING SPIRITUALITY INTO PATIENT CARE. WEST CONSHOHOCKEN, PA: TEMPLETON PRESS.



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Serious illness is a ground shaker

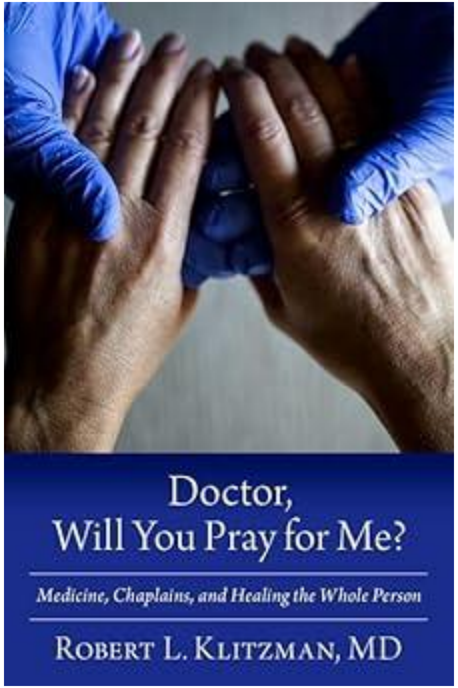
INDONESIA’S AMBON- EARTH QUAKE STRIKES ONE DEAD – THE HERALD

Spiritual/Existential Distress

- A feeling of mental turmoil that can occur when people confront the reality of their existence, circumstance, life change, etc.

Barriers to addressing spiritual distress

- **62%** of doctors (medical providers) reported a lack of training as a barrier
- Lack of private office space
- Personal discomfort talking about spiritual issues
- Belief that patients do not want these conversations
- Worry that patient will feel uncomfortable
- Feeling uncomfortable engaging with patients who have religious beliefs different than their own



KLITZMAN, R. DOCTOR WITH YOU PRAY WITH ME? RESPONDING TO PATIENTS' RELIGIOUS AND SPIRITUAL CONCERNS. ACAD MED. 2021 MARCH 01; 96(3): 349–354. HTTPS://DOI:10.1097/ACM.0000000000003765

Seeking to Understand: a courageous conversation with others

- **Empathic listening**
- **Curiosity-**
  - “Tell me more…”
  - Reflective statements: “That’s a really good question. What do you think?” Or “What does your faith/life experiences tell you about that?”
  - How would you like to receive information?
- **Humility**
- **Educate** yourself!

Seeking to Understand Others cont.

- **Authenticity**
  - “Will you pray with me?”
    - “I hear prayer is important to you and a source of strength. I’d be happy to sit with you while you pray.”
    - “I will be sending you good thoughts/energy.”
    - “Would it be helpful to have a visit with the chaplain?”
- **Validate and affirm**
  - “I hear that you hope for a miracle. We will not get in the way of God doing what God does AND it would be helpful for us to talk about the ‘what ifs.’”
- Involve **chaplains**!

Seeking to Understand: a courageous conversation *with yourself*

- **Curiosity**
- **Self-awareness**
  - Where is this coming from?
  - What is it about this case that is challenging me?
- **Humility**
- **Education**
- **Validate and affirm**
- **Hold own beliefs lightly and uphold other beliefs**
- **Talk it out**
- **Empathy**

Thank you!

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UVMHealth.org/MedCenter

THE University of Vermont MEDICAL CENTER

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Palliative ECHO:
Impact of Neurological Diseases on the Care Partner

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Dartmouth Health

Dartmouth
GEISEL SCHOOL OF
MEDICINE

Conflicts of Interest/Disclosures

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

Care partners are a **critical resource** in the care of individuals with neurological disorders

About 29% of US population serves as care partner

- About two-thirds are **women**
- **About 20 hours per week** spent on caregiving tasks, on average
- **Generally unpaid**

Physical, financial, emotional, and social challenges can increase the risk for fatigue and burnout

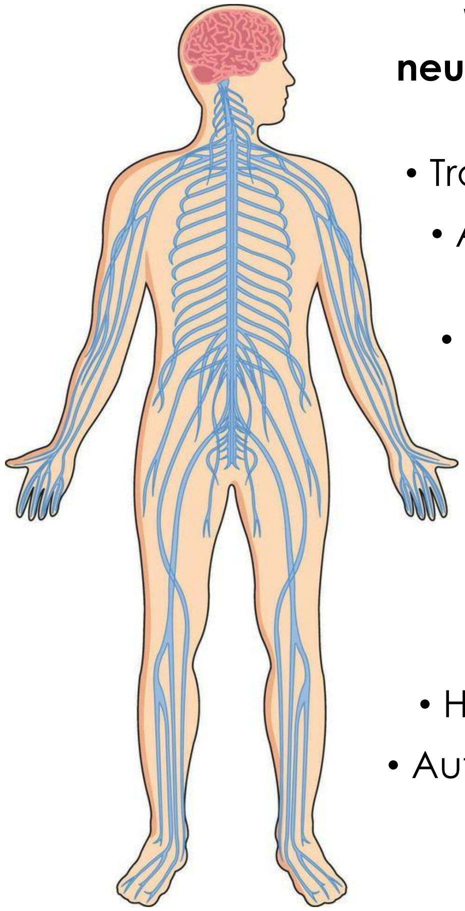
Decreased **health-related quality of life**

Elevated rates of **depression and anxiety**

Impaired **cognition** compared to age-matched peers

Treasure (2004) EMBH; Harrad & Sulla (2018) AB

Disease-related **variation** can present challenges



WIDE variety of neurological disorders

- Traumatic brain injury
- Amyotrophic lateral Sclerosis (ALS)
- Alzheimer's disease
- Parkinson's/plus
- Brain tumor
- Epilepsy
- Stroke
- Multiple Sclerosis
- Huntington's disease
- Autoimmune disorders

- **Dramatic variances** in symptoms, impact on function, and prognosis
- **Frequent misunderstanding** about natural history and overall trajectory of neurological disorders
  - By patients, families…AND healthcare providers
- **"Siloed" care may prevent familiarity** with what progression of neurodegenerative diseases looks like
- **"Prognosis paralysis" delays implementation** of measures to promote quality of life
  - Course is often protracted and relatively unpredictable
- **Disjointed care delivery** for advanced neurological disorders speaks to the need for increased collaboration across specialties

Traditional models of care **miss opportunities!**

Traditional model of care is DICHOTOMOUS:

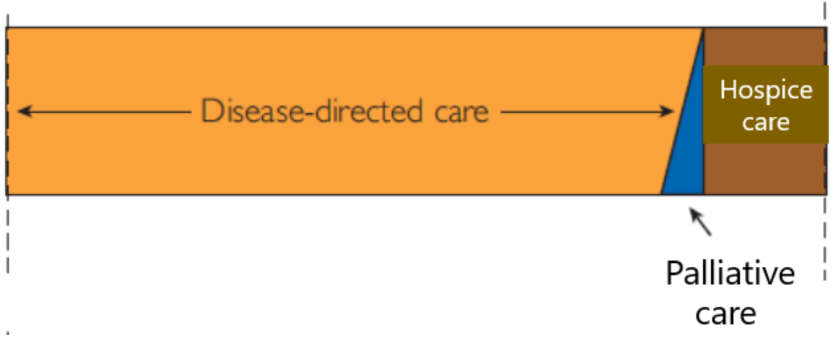
- **Curative or disease-modifying treatment** is offered at the ***outset*** of an illness
- **Palliative and hospice** care generally offered ***only*** *when/if curative or disease modifying measures are no longer appropriate*

Most neurologic illnesses and care goals do NOT lend themselves to this model

- A convincing argument could be made that ***ALL care*** for those with neurodegenerative disorders is palliative

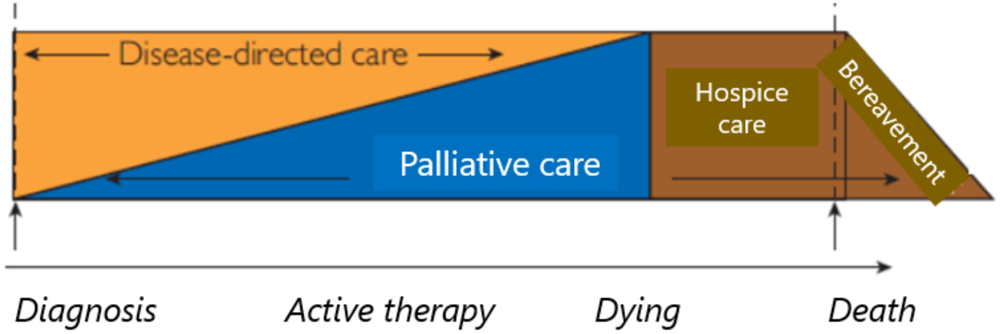
Traditional

Palliative care as "brink of death" care

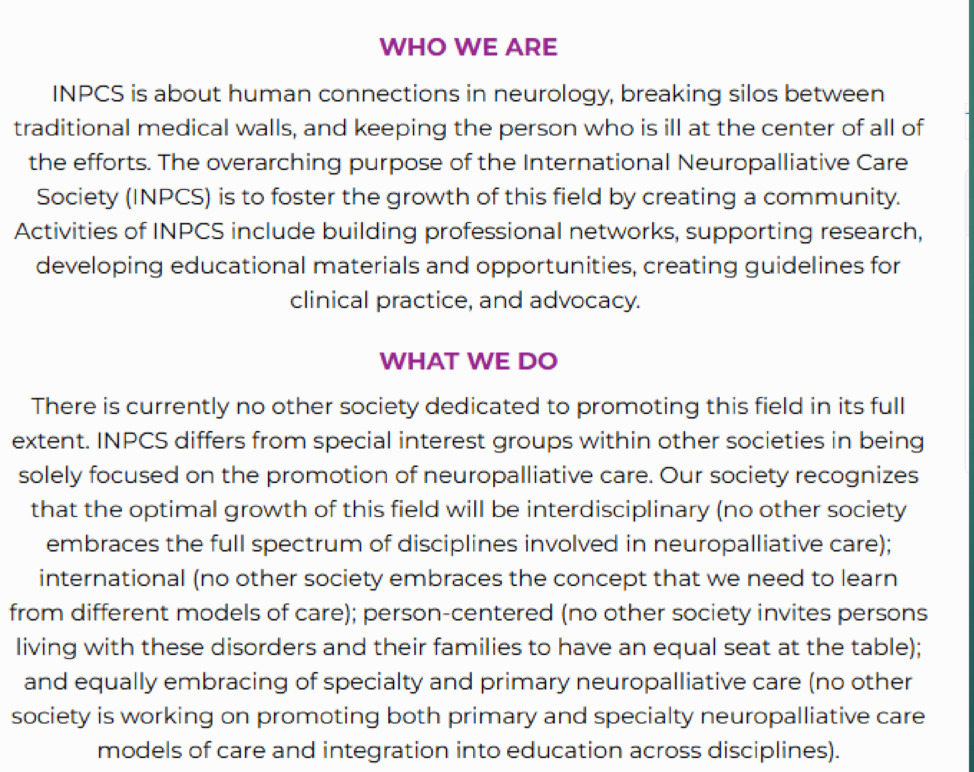


IDEAL

Palliative care as "quality of life" care



International Neuropalliative Care Society (founded in 2020)



WHO WE ARE

INPCS is about human connections in neurology, breaking silos between traditional medical walls, and keeping the person who is ill at the center of all of the efforts. The overarching purpose of the International Neuropalliative Care Society (INPCS) is to foster the growth of this field by creating a community. Activities of INPCS include building professional networks, supporting research, developing educational materials and opportunities, creating guidelines for clinical practice, and advocacy.

WHAT WE DO

There is currently no other society dedicated to promoting this field in its full extent. INPCS differs from special interest groups within other societies in being solely focused on the promotion of neuropalliative care. Our society recognizes that the optimal growth of this field will be interdisciplinary (no other society embraces the full spectrum of disciplines involved in neuropalliative care); international (no other society embraces the concept that we need to learn from different models of care); person-centered (no other society invites persons living with these disorders and their families to have an equal seat at the table); and equally embracing of specialty and primary neuropalliative care (no other society is working on promoting both primary and specialty neuropalliative care models of care and integration into education across disciplines).

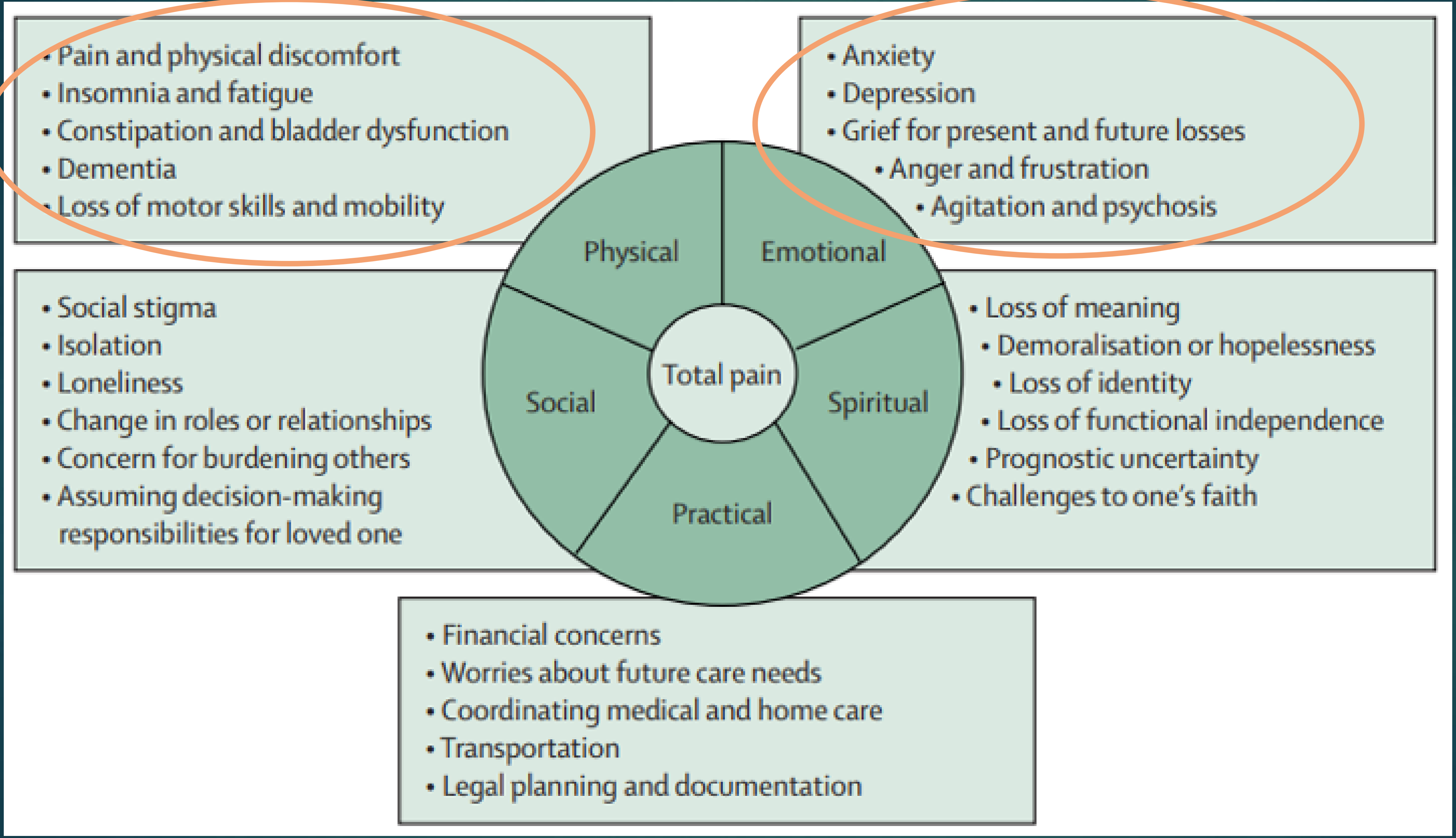
Goals…

- "to **unite** patients, families, health-care providers, and researchers across a wide range of specialties and disciplines (e.g. medicine, nursing, social work, and spiritual care)
- to **promote** educational, research, clinical, and advocacy efforts
- to **improve** palliative care for people with neurological conditions"

Suffering

- **Progressive neurological disorders are among the most dreaded illnesses** because they directly affect multiple aspects of personhood including consciousness, agency, and identity
- **Suffering is a fundamental concern** of medicine
  - Conceptualized as the **TOTAL PAIN of serious illness**, spanning multiple dimensions beyond just physical pain, including psychological, social, and spiritual distress
- **Building on the total pain model**, care for advanced and/or progressive neurological disorders can be re-conceptualized to address common sources of suffering

A MODEL of TOTAL PAIN for neurological disease



- Pain and physical discomfort
- Insomnia and fatigue
- Constipation and bladder dysfunction
- Dementia
- Loss of motor skills and mobility

- Anxiety
- Depression
- Grief for present and future losses
- Anger and frustration
- Agitation and psychosis

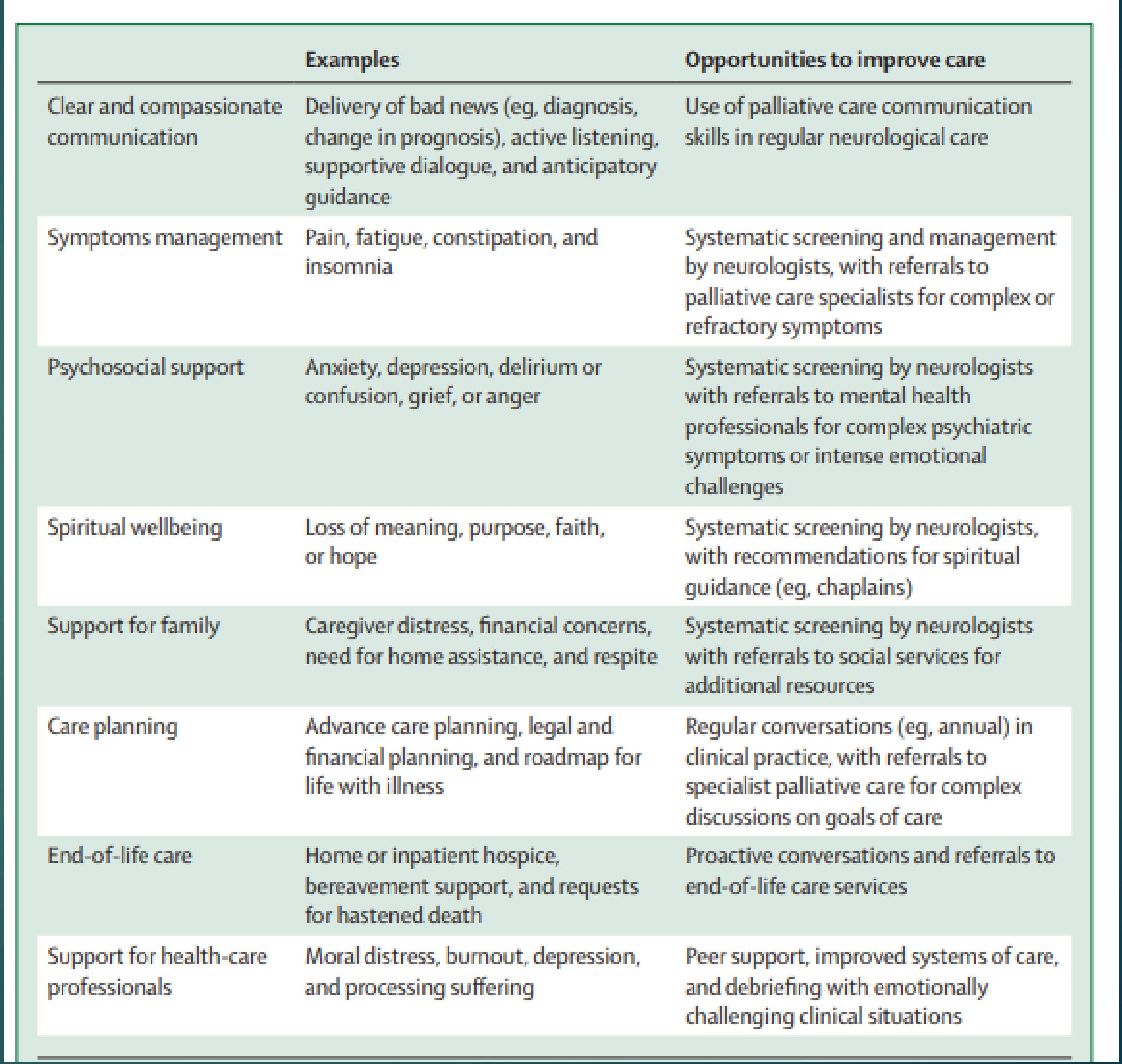
- Social stigma
- Isolation
- Loneliness
- Change in roles or relationships
- Concern for burdening others
- Assuming decision-making responsibilities for loved one

- Loss of meaning
- Demoralisation or hopelessness
- Loss of identity
- Loss of functional independence
- Prognostic uncertainty
- Challenges to one's faith

- Financial concerns
- Worries about future care needs
- Coordinating medical and home care
- Transportation
- Legal planning and documentation

Kluger et al. (2023) Lancet Neurology

Palliative care NEEDS of people with neurological disease and their carers



	Examples	Opportunities to improve care
Clear and compassionate communication	Delivery of bad news (eg, diagnosis, change in prognosis), active listening, supportive dialogue, and anticipatory guidance	Use of palliative care communication skills in regular neurological care
Symptoms management	Pain, fatigue, constipation, and insomnia	Systematic screening and management by neurologists, with referrals to palliative care specialists for complex or refractory symptoms
Psychosocial support	Anxiety, depression, delirium or confusion, grief, or anger	Systematic screening by neurologists with referrals to mental health professionals for complex psychiatric symptoms or intense emotional challenges
Spiritual wellbeing	Loss of meaning, purpose, faith, or hope	Systematic screening by neurologists, with recommendations for spiritual guidance (eg, chaplains)
Support for family	Caregiver distress, financial concerns, need for home assistance, and respite	Systematic screening by neurologists with referrals to social services for additional resources
Care planning	Advance care planning, legal and financial planning, and roadmap for life with illness	Regular conversations (eg, annual) in clinical practice, with referrals to specialist palliative care for complex discussions on goals of care
End-of-life care	Home or inpatient hospice, bereavement support, and requests for hastened death	Proactive conversations and referrals to end-of-life care services
Support for health-care professionals	Moral distress, burnout, depression, and processing suffering	Peer support, improved systems of care, and debriefing with emotionally challenging clinical situations

Kluger et al. (2023) Lancet Neurology;
Toze et al. (2020) Palliative Med

CONCERNS of carers of people with neurological disease

Themes	Key concepts within theme
Future (un)certainties	Certainty of death
	Uncertainty over speed of progression, symptom progression
Information paradox	Diversity of information needs
	Importance of sensitive and timely conveyance of information
Access to support	Barriers to accessing support
	Medicalisation of support
	Lack of access to emotional support (including bereavement
Taking decisions	Desire for loved one to take own decisions (but often being expected to do so)
	Decisions being overturned by professionals
Continuity, change and disruption	Maintaining a sense of normality and challenges to that
	Emotional commitment
	Loss and bereavement

Kluger et al. (2023) Lancet Neurology; Toze et al. (2020) Palliative Med

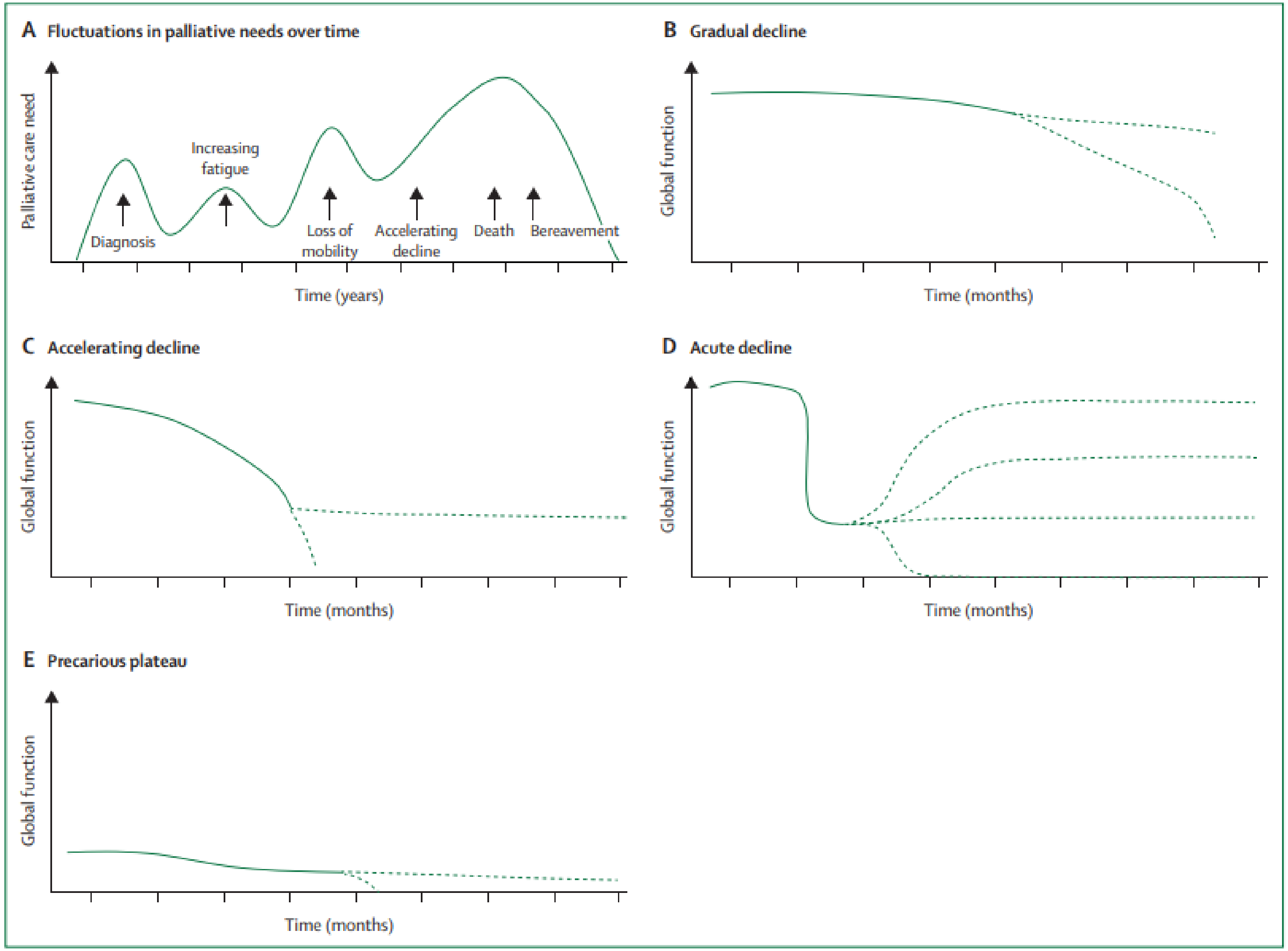
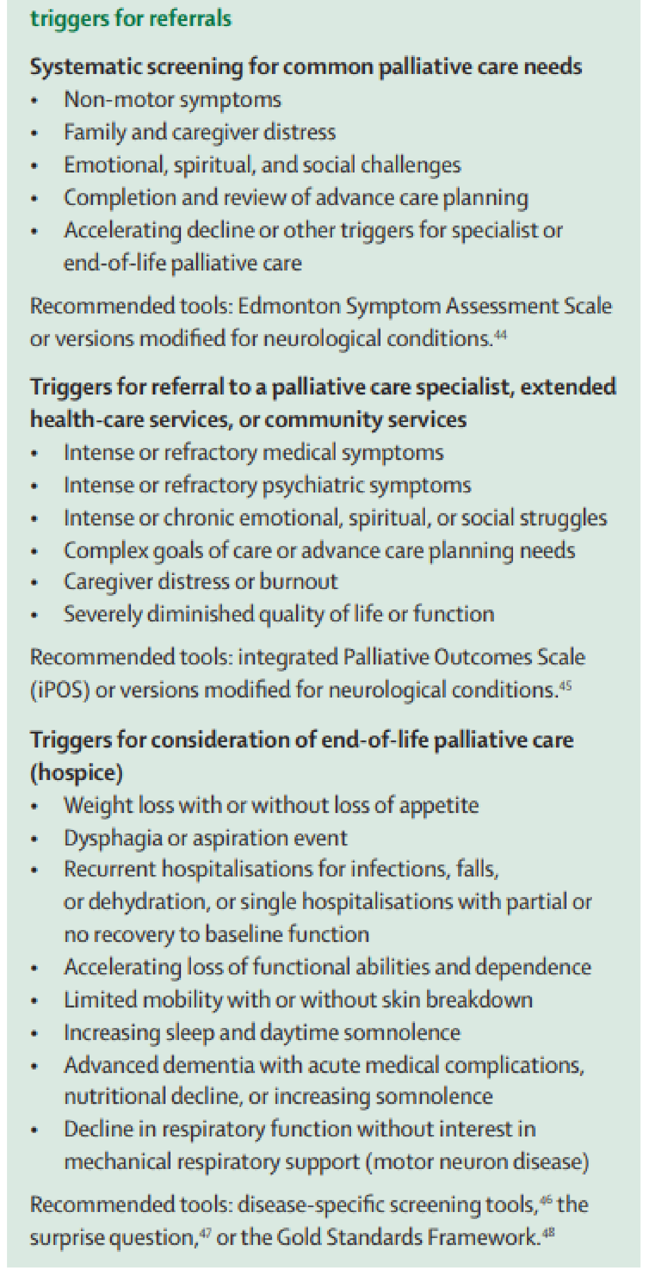


***Figure 2*: Common trajectories of palliative care needs and functional decline in neurological illness**

(A) The palliative care needs of an individual will fluctuate over the course of their illness based on events, symptoms, changes in function, and stage of the illness. In this example, an individual with a neurodegenerative disease has fluctuating needs over many years. (B–E) It is important that clinicians recognise possible outcomes (dotted lines) following key inflection points along the illness trajectory (solid lines). In these graphs, global function ranges on the y-axis from full function (top) to death (bottom) with varying degrees of mild, moderate, and severe disability in between. Common trajectories include: (B) gradual decline (can be followed by slow decline or a change in trajectory); (C) accelerating decline (can continue at accelerated pace or plateau); (D) acute change (can be followed by complete, partial, or limited recovery, or continued decline to death); and (E) precarious plateau (abrupt decline to death or a continued low functioning plateau).

Common trajectories of palliative care **needs** and functional **decline** in neurological illness

Kluger et al. (2023) Lancet Neurology



Panel 2: **Screening domains for palliative care needs and triggers for referrals**

Systematic screening for common palliative care needs

- Non-motor symptoms
- Family and caregiver distress
- Emotional, spiritual, and social challenges
- Completion and review of advance care planning
- Accelerating decline or other triggers for specialist or end-of-life palliative care

Recommended tools: Edmonton Symptom Assessment Scale or versions modified for neurological conditions.[44]

Triggers for referral to a palliative care specialist, extended health-care services, or community services

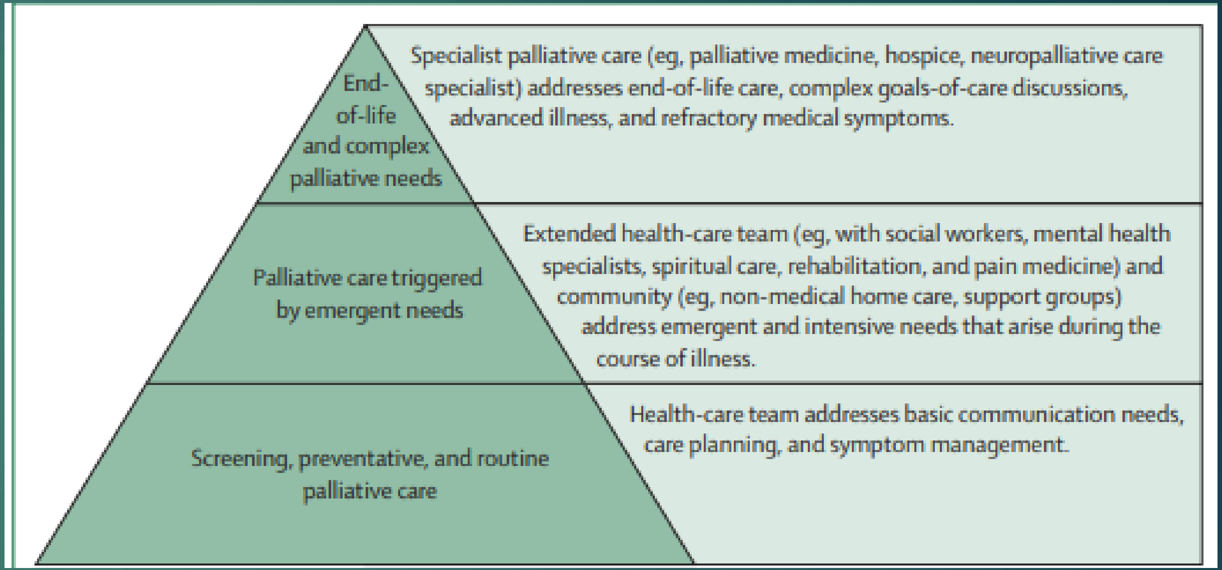
- Intense or refractory medical symptoms
- Intense or refractory psychiatric symptoms
- Intense or chronic emotional, spiritual, or social struggles
- Complex goals of care or advance care planning needs
- Caregiver distress or burnout
- Severely diminished quality of life or function

Recommended tools: integrated Palliative Outcomes Scale (iPOS) or versions modified for neurological conditions.[45]

Triggers for consideration of end-of-life palliative care (hospice)

- Weight loss with or without loss of appetite
- Dysphagia or aspiration event
- Recurrent hospitalisations for infections, falls, or dehydration, or single hospitalisations with partial or no recovery to baseline function
- Accelerating loss of functional abilities and dependence
- Limited mobility with or without skin breakdown
- Increasing sleep and daytime somnolence
- Advanced dementia with acute medical complications, nutritional decline, or increasing somnolence
- Decline in respiratory function without interest in mechanical respiratory support (motor neuron disease)

Recommended tools: disease-specific screening tools,[46] the surprise question,[47] or the Gold Standards Framework.[48]



End-of-life and complex palliative needs

Specialist palliative care (eg, palliative medicine, hospice, neuropalliative care specialist) addresses end-of-life care, complex goals-of-care discussions, advanced illness, and refractory medical symptoms.

Palliative care triggered by emergent needs

Extended health-care team (eg, with social workers, mental health specialists, spiritual care, rehabilitation, and pain medicine) and community (eg, non-medical home care, support groups) address emergent and intensive needs that arise during the course of illness.

Screening, preventative, and routine palliative care

Health-care team addresses basic communication needs, care planning, and symptom management.

Kluger et al. (2023) Lancet Neurology

Screening domains for palliative care needs… and **triggers** for referrals

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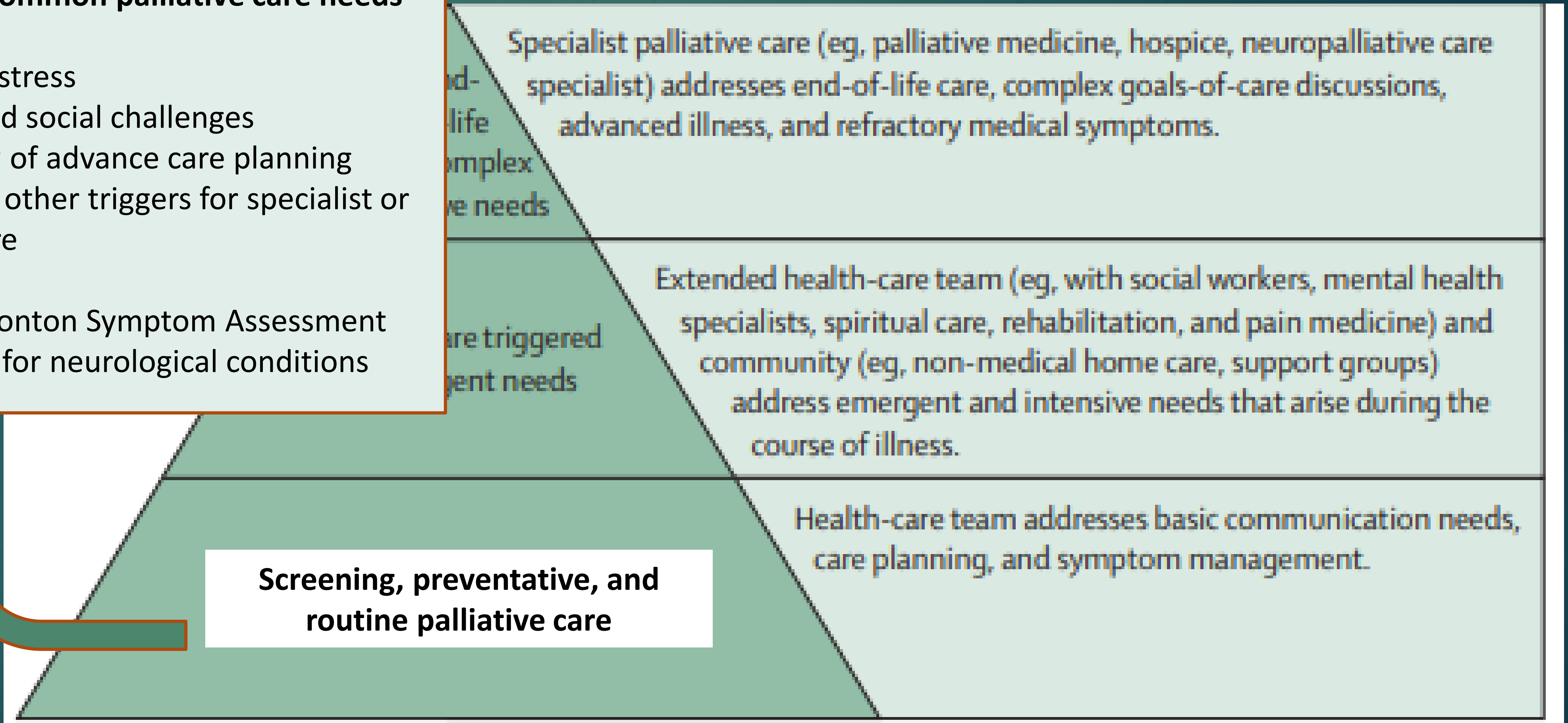

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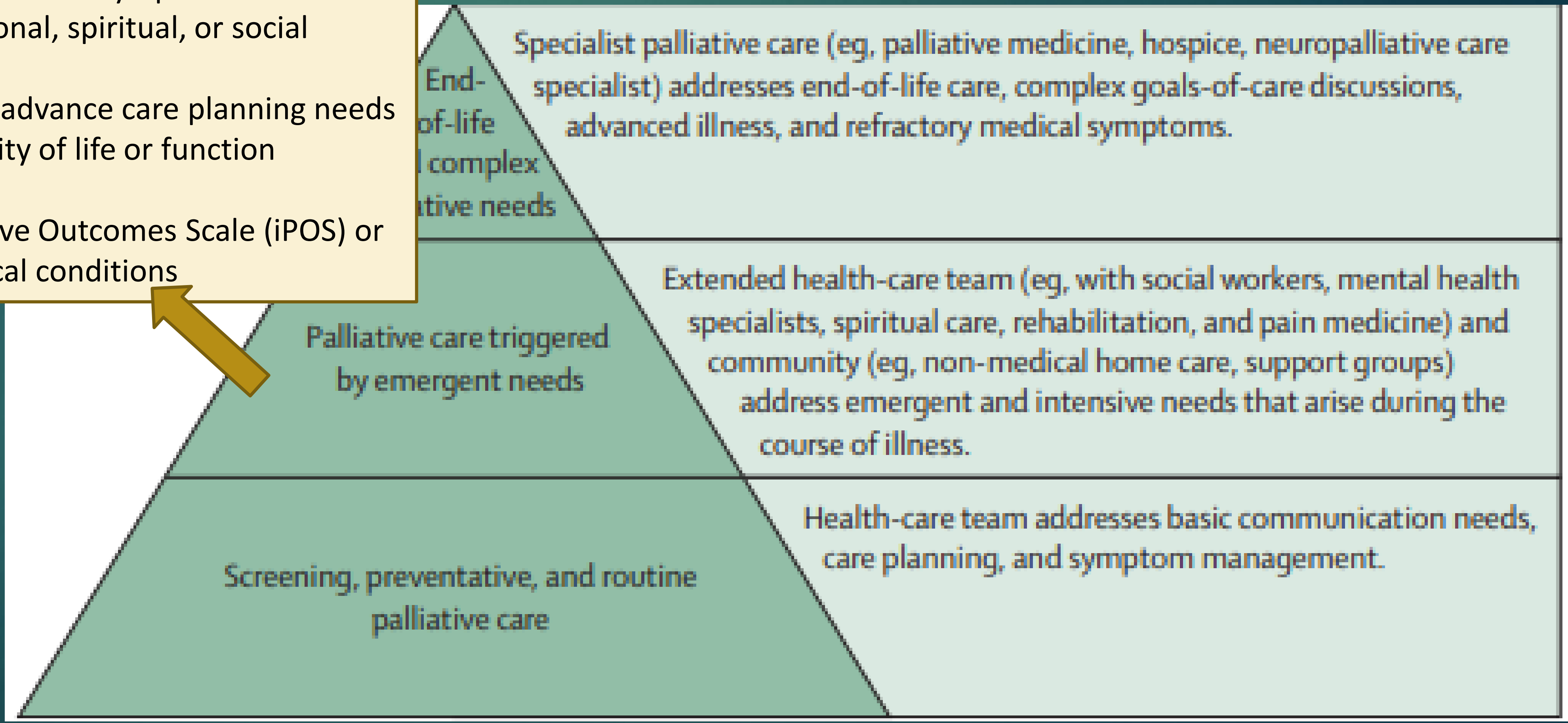

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Screening domains for palliative care needs… and **triggers** for referrals

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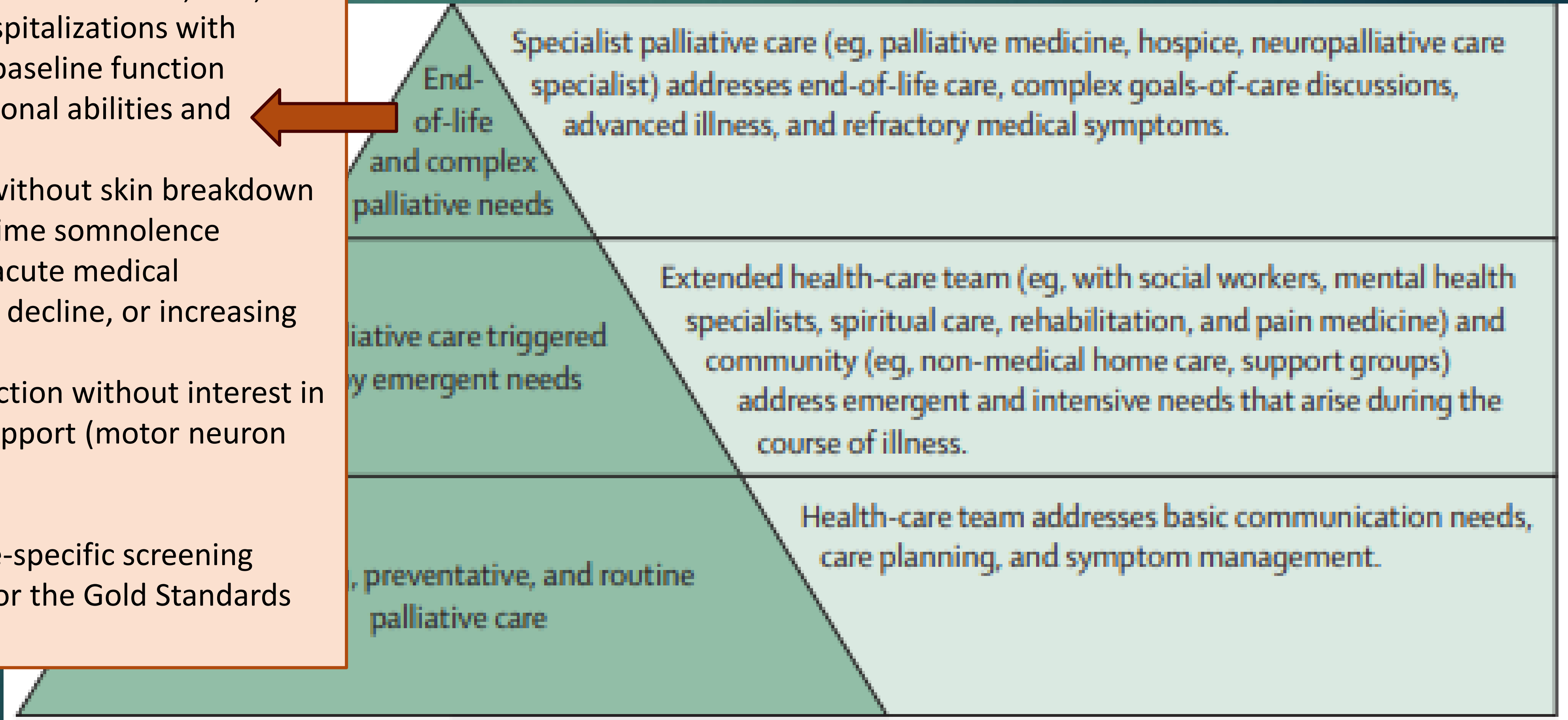

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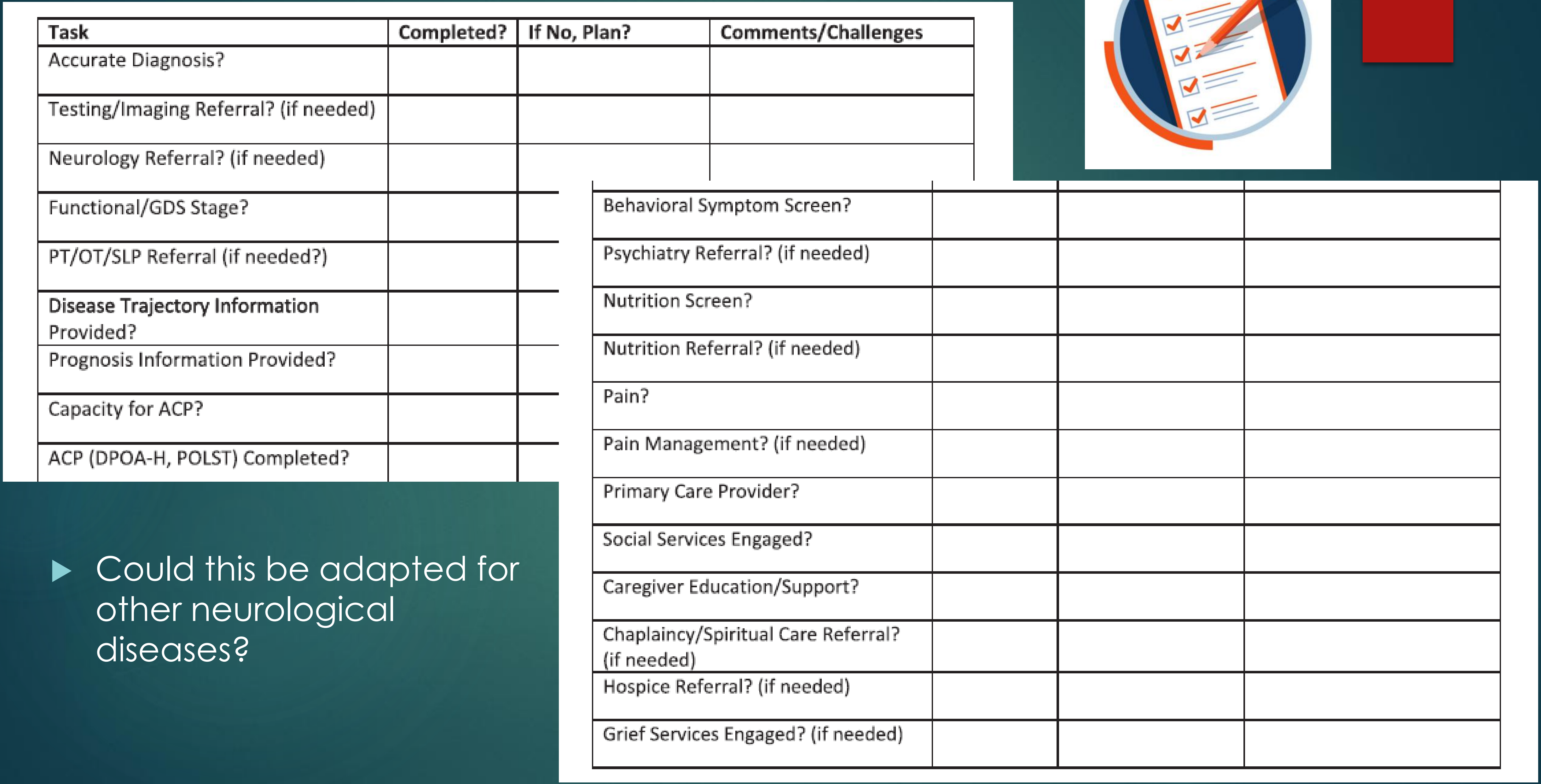
Health-care team addresses basic communication needs, care planning, and symptom management.

Coordination of care in dementia **CHECKLIST**

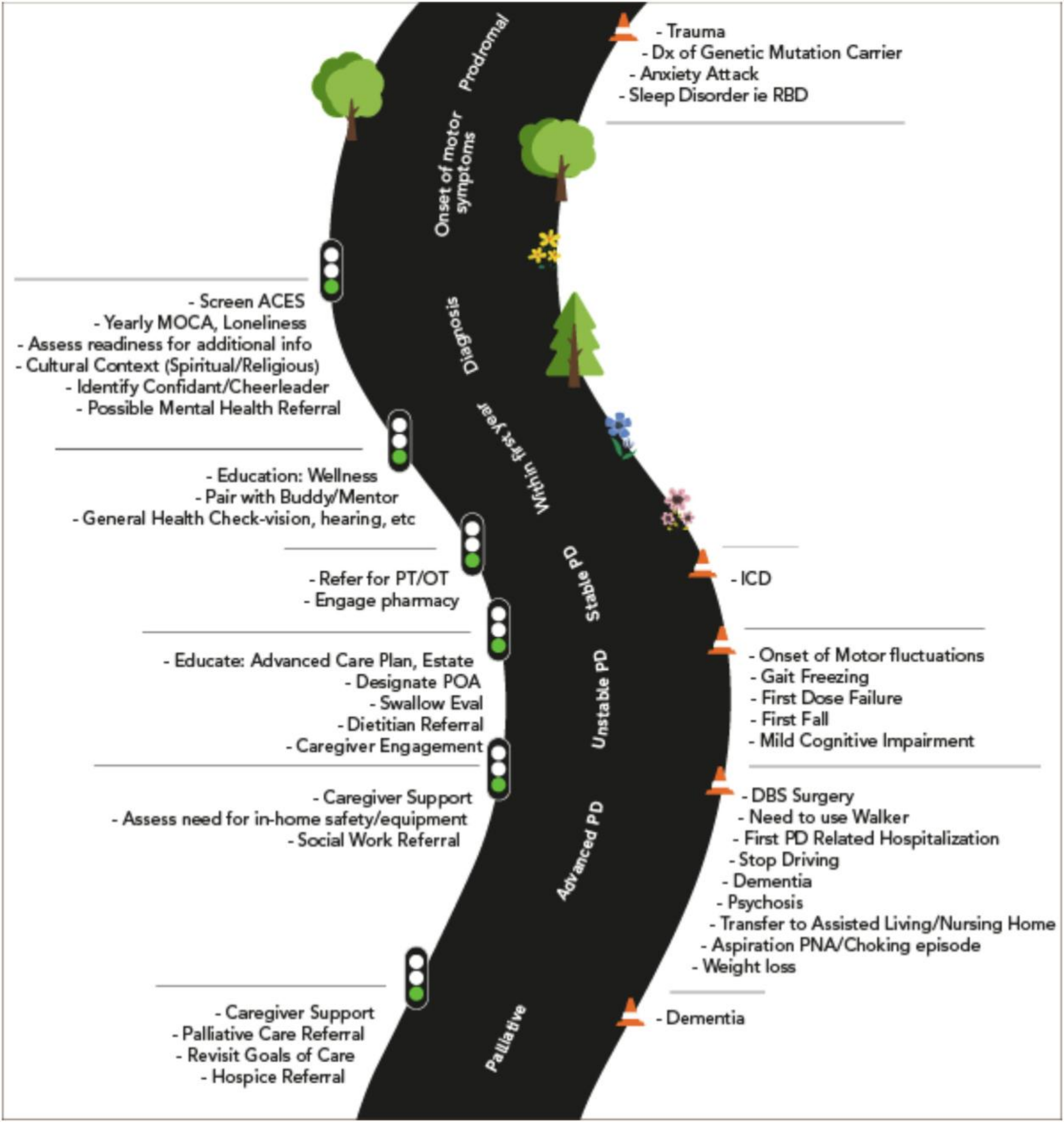


Task	Completed?	If No, Plan?	Comments/Challenges
Accurate Diagnosis?			
Testing/Imaging Referral? (if needed)			
Neurology Referral? (if needed)			
Functional/GDS Stage?			
PT/OT/SLP Referral (if needed?)			
Disease Trajectory Information Provided?			
Prognosis Information Provided?			
Capacity for ACP?			
ACP (DPOA-H, POLST) Completed?			
Behavioral Symptom Screen?			
Psychiatry Referral? (if needed)			
Nutrition Screen?			
Nutrition Referral? (if needed)			
Pain?			
Pain Management? (if needed)			
Primary Care Provider?			
Social Services Engaged?			
Caregiver Education/Support?			
Chaplaincy/Spiritual Care Referral? (if needed)			
Hospice Referral? (if needed)			
Grief Services Engaged? (if needed)			

- Could this be adapted for other neurological diseases?

Volle (2022) AJGP

YES!



- Trauma
- Dx of Genetic Mutation Carrier
- Anxiety Attack
- Sleep Disorder ie RBD

- Screen ACES
- Yearly MOCA, Loneliness
- Assess readiness for additional info
- Cultural Context (Spiritual/Religious)
- Identify Confidant/Cheerleader
- Possible Mental Health Referral

- Education: Wellness
- Pair with Buddy/Mentor
- General Health Check-vision, hearing, etc

- Refer for PT/OT
- Engage pharmacy

- ICD

- Educate: Advanced Care Plan, Estate
- Designate POA
- Swallow Eval
- Dietitian Referral
- Caregiver Engagement

- Onset of Motor fluctuations
- Gait Freezing
- First Dose Failure
- First Fall
- Mild Cognitive Impairment

- Caregiver Support
- Assess need for in-home safety/equipment
- Social Work Referral

- DBS Surgery
- Need to use Walker
- First PD Related Hospitalization
- Stop Driving
- Dementia
- Psychosis
- Transfer to Assisted Living/Nursing Home
- Aspiration PNA/Choking episode
- Weight loss

- Caregiver Support
- Palliative Care Referral
- Revisit Goals of Care
- Hospice Referral

- Dementia

Pontone et al., AJGP, 2023

Care Partner Support

- **Individualized** and **targeted** at specific challenges
- **Avoid adding to overall burden**
  (multiple appointments, travel time, costs...)
- **Requires additional healthcare resources**
  (trained and available staff, system-level understanding of benefit)
- **Community support** offerings can vary dramatically
- **Patients & care partners** may have to actively advocate for additional support

Care Partner Support

- Primary Care Provider (especially social workers or nurse care managers)
- Neurologist
- Palliative Care
- Connect Care Share
- Psychiatry and/or psychotherapy
- Aging Resource Center at Dartmouth
- National organizations
- Local support groups
- Veteran's Healthcare Administration
- Senior centers
- Community nurses
- Spiritual support
- Meals on wheels
- Respite grants

Conclusions

- **Neurological disorders are becoming more common** as our population ages!

- Most care is **provided by unpaid family care partners**

- **Care partner fatigue and burnout are impactful**
  - Adversely effect the quality of care that patients receive
  - Can directly harm the care partner

- **Difficulties with activities of daily living** and **neuropsychiatric symptoms** are among the most challenging aspects of care

- **Data supports impact of robust care partner education and support**
  - Improves quality of life for both patients and care partners

- **This is worth addressing aggressively!**

Comments? Questions?

Thank you!

An Introduction to Pediatric Palliative Care

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Jennifer Ebbitt, RN CHPN CHPPN
Dartmouth Health, Section of Palliative Medicine

We have no conflicts to disclose.

Objectives

- Identify three parties involved in providing goal-aligned care for children living with life-limiting illness
- Describe the pediatric concurrent care model
- Identify one difference between pediatric and adult palliative care
- Recognize potential barriers *and* facilitators that could impact delivery of Pediatric Palliative Care in the region

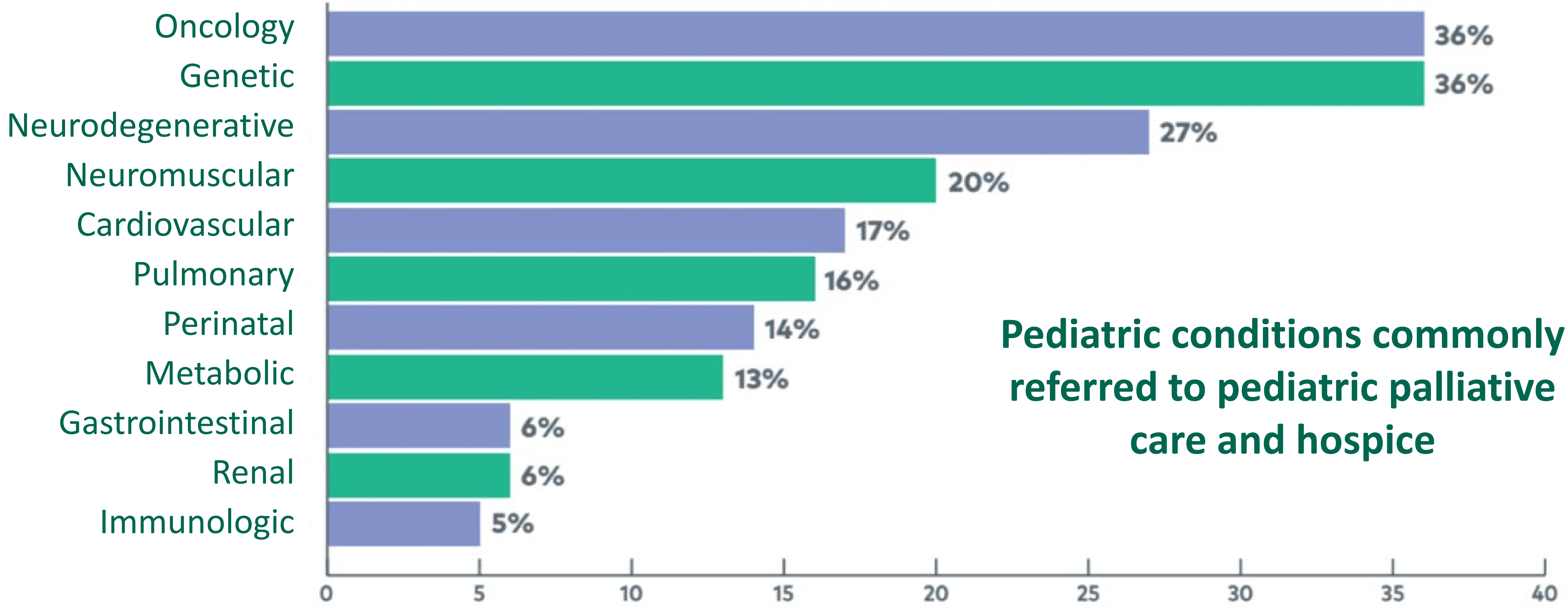
What is Pediatric Palliative Care?

- We strive to provide holistic, compassionate care for children and families living with serious, life-limiting illnesses
- Pediatric Palliative Care is based on need, not prognosis
- Our primary goal is to construct a plan of care that centers on maximizing quality of life

“Making each day the best it can be”

- Symptom management
- Guidance around important decisions
- Enhancing communication between multiple specialists
- Age-appropriate help for the child (and siblings) in understanding and coping with illness
- Longitudinal support for family and child’s communities along the arc of illness
- Collaborate for hospice enrollment
- End-of-life care
- Support for the interprofessional team throughout the span of child’s care

Who receives Pediatric Palliative Care?



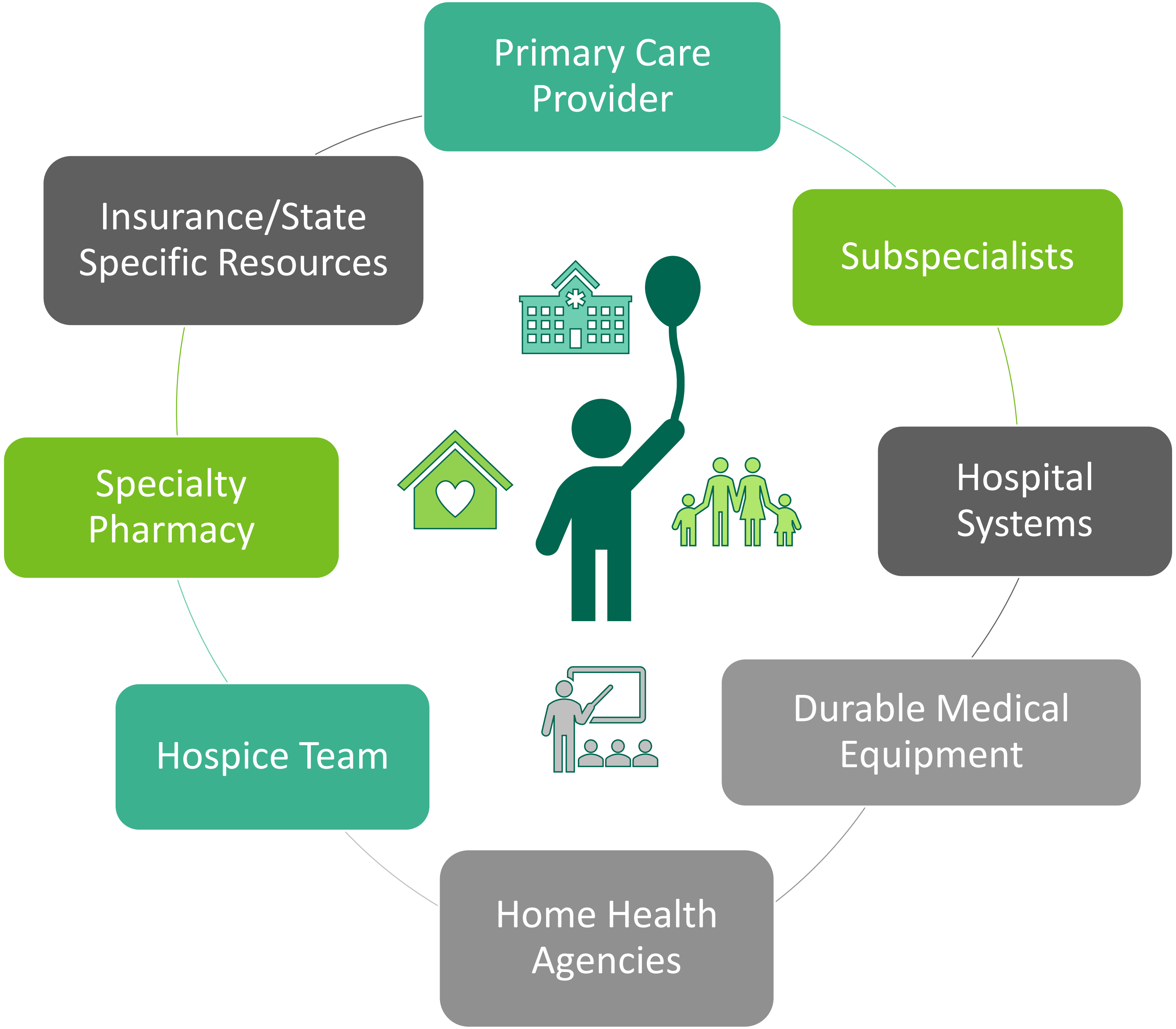
Pediatric conditions commonly referred to pediatric palliative care and hospice

Ref: NHPCO Pediatric Facts and Figures 2023

Who might we meet?

- 2 y/o girl with high-risk neuroblastoma: **Not responding to therapy as we hoped**
- 14 y/o male with Lennox-Gastaut syndrome characterized by developmental delay, seizure disorder, and severe scoliosis: **Family considering spinal surgery**
- 2-month-old boy, born full-term with severe hypoxic-ischemic encephalopathy and gastric-tube dependence: **High likelihood to develop infantile spasms**
- 13 y/o girl born prematurely: Progressive pulmonary hypertension, ventilator and gastric-tube dependent. **Mother grieving the death of her twin sister from the same condition**
- 31 y/o first time mother *and her baby* who was diagnosed prenatally with genetic differences: **Baby expected to survive days-weeks**

Who makes up a child’s care team?



Primary Care Provider

Subspecialists

Hospital Systems

Durable Medical Equipment

Home Health Agencies

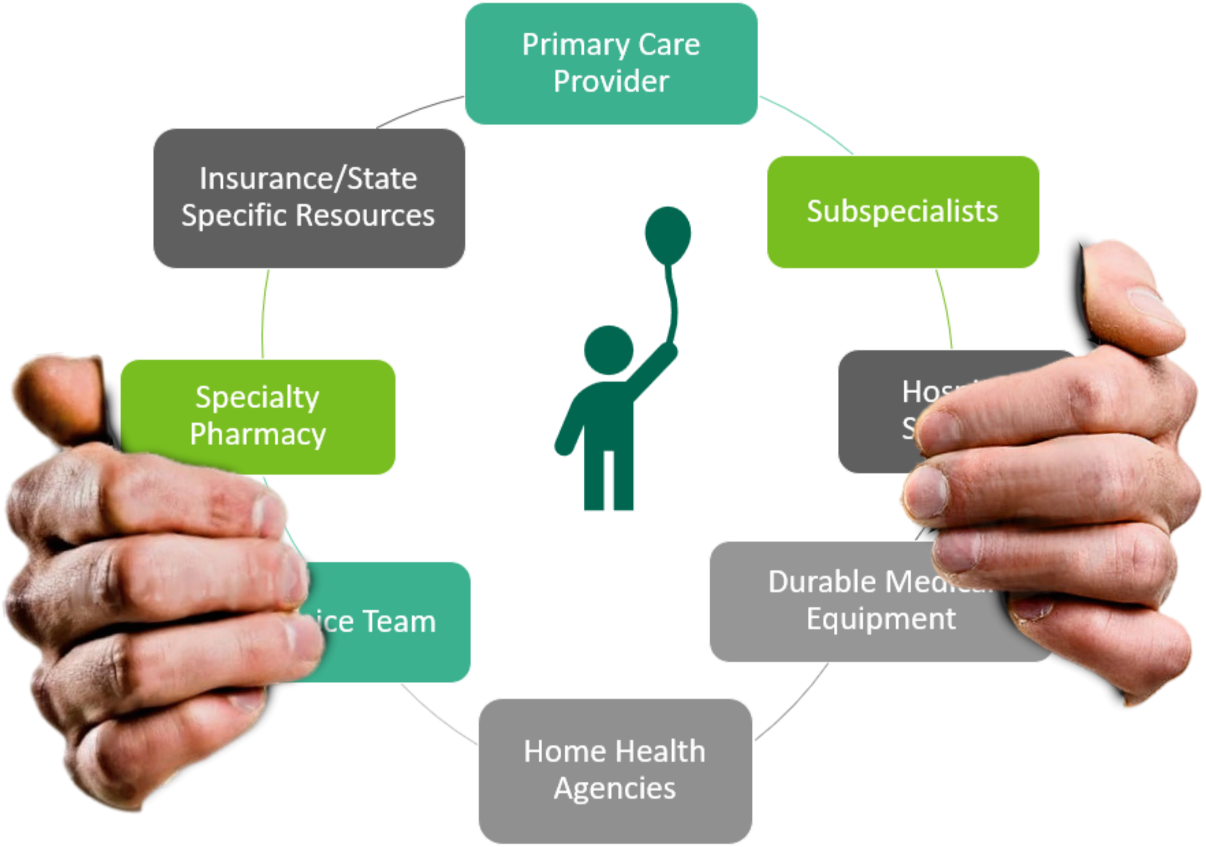
Hospice Team

Specialty Pharmacy

Insurance/State Specific Resources

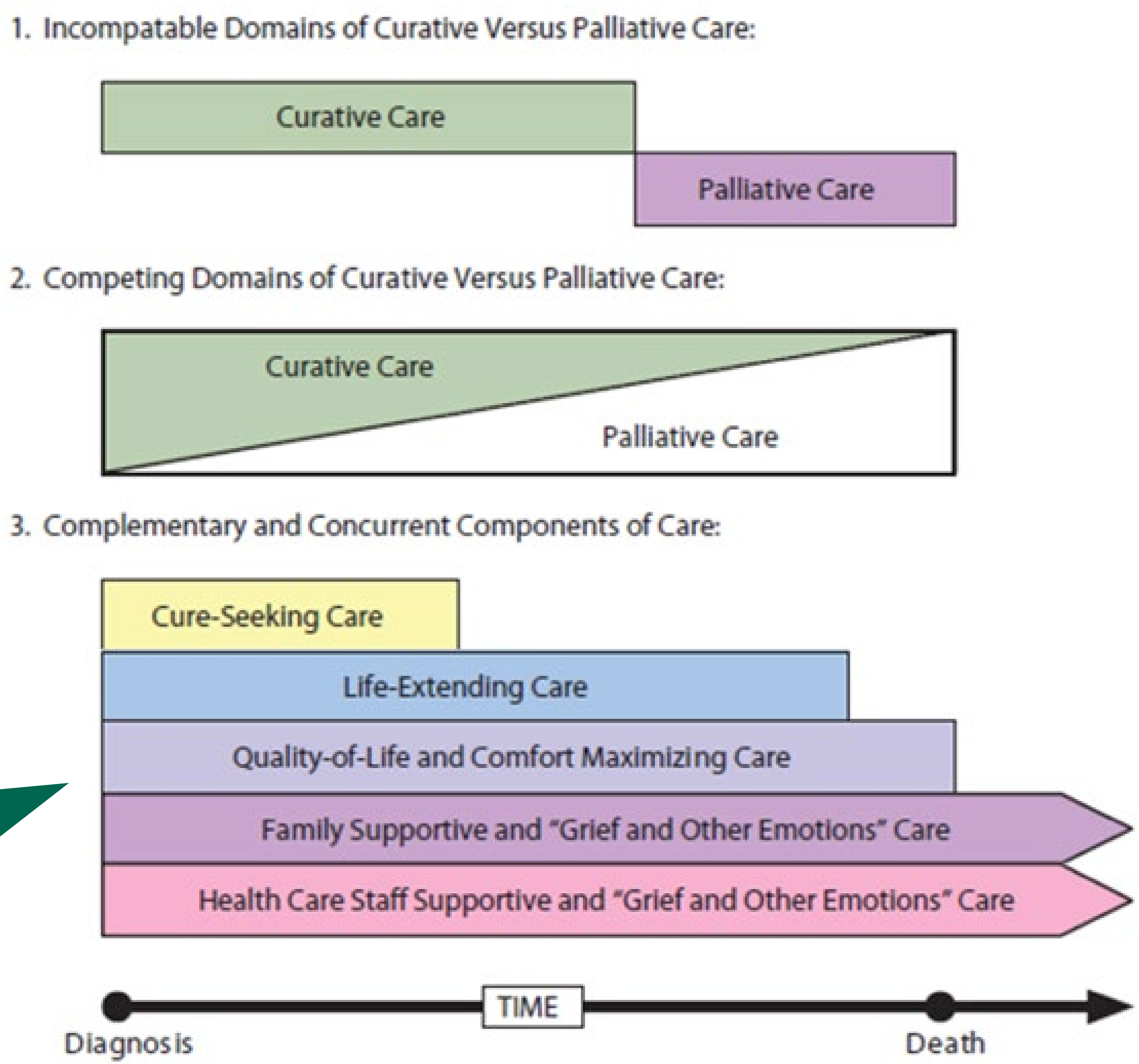
Pediatric Palliative Care provides…

- The “glue” to help hold it all together
- Stepping back to see the big picture
  - *Forest rather than the trees*
- Support when/as goals shift along a child’s illness trajectory
- Streamlined communication
  - *Translation to meaning*



When is the *'right time'* to consult?

Palliative care as patient-centered complementary and concurrent modes of care



1. Incompatable Domains of Curative Versus Palliative Care:

2. Competing Domains of Curative Versus Palliative Care:

3. Complementary and Concurrent Components of Care:

Ref: Committee on Approaching Death (Feudtner et al. 2015)

Pediatric and Adult Palliative Care Differ

- Diagnoses and disease trajectories
- Serious illness is never a “normal” part of childhood
  - Education/support needs of providers
- Complexities of collaboration with a child’s community
- Funding mechanisms

What is “Concurrent Care for Children”?

2010

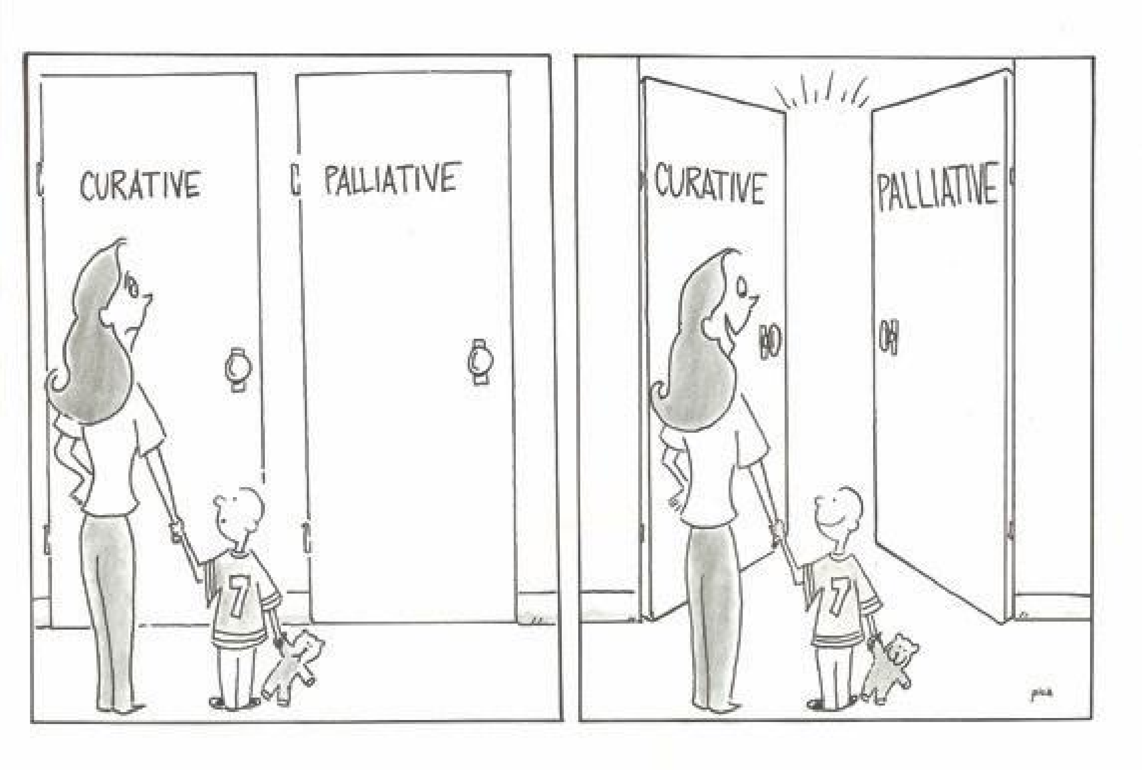
Disease-directed therapies *and* hospice services

Six-month prognosis

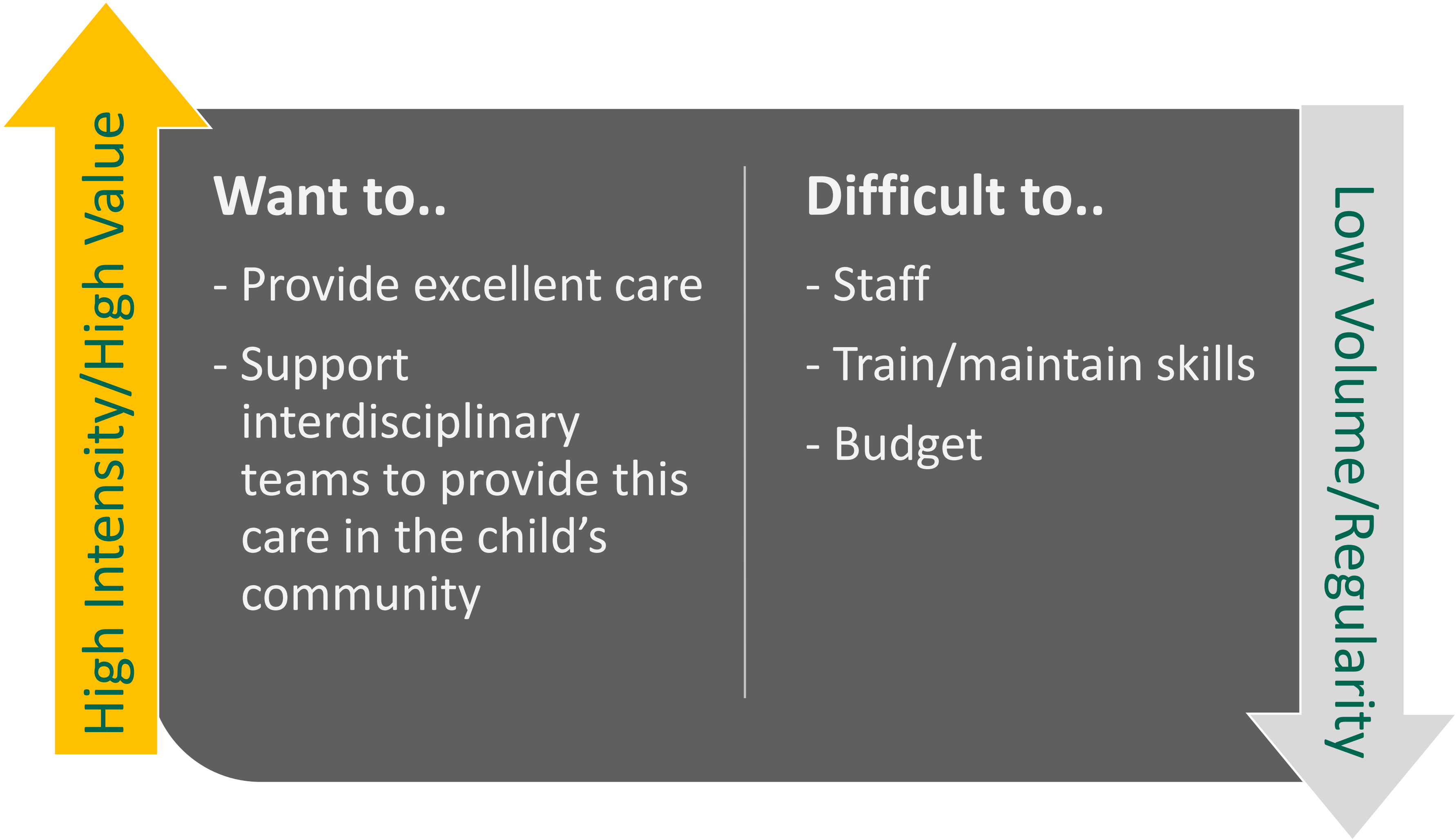
Medicaid or
Children’s Health Insurance Program (CHIP)
(most private insurances accommodate, too)

Age <21

Under concurrent care, children can continue disease-directed therapies AND block time nursing while receiving hospice care



Facilitators & Barriers to Providing Pediatric Palliative Care



High Intensity/High Value

Want to..

- Provide excellent care
- Support interdisciplinary teams to provide this care in the child's community

Difficult to..

- Staff
- Train/maintain skills
- Budget

Low Volume/Regularity

Barriers to Care and their Downstream Effects

700,000 children in the United States with serious illness

- High symptom burden
- High care needs

20% of children's hospitals with no formal PPC program

35% of programs with no outpatient services

~60% of programs with no home hospice services

>65% of programs with no home palliative care

Poor mental and physical health outcomes for family members

- These outcomes are amplified in historically marginalized groups.

Medically intense end-of-life care, often inconsistent with wishes

PPC: Pediatric Palliative Care
Ref: Boyden et al. 2024

Supporting Access to Care

- **Mobilize** champions within your institution and community.
- **Share** expertise through development of state, regional, and national coalitions.
- Stay current with legislative changes and **contribute** where you can.
- **Disseminate** primary pediatric palliative care skills through education.

Pediatric Palliative Care in the Region

Regional Resources

VERMONT
DEPARTMENT OF HEALTH

Friends of
Aine™
Center for Grieving Children & Families

NEW HAMPSHIRE
DHHS
DEPARTMENT OF
HEALTH & HUMAN SERVICES

empty arms
VERMONT

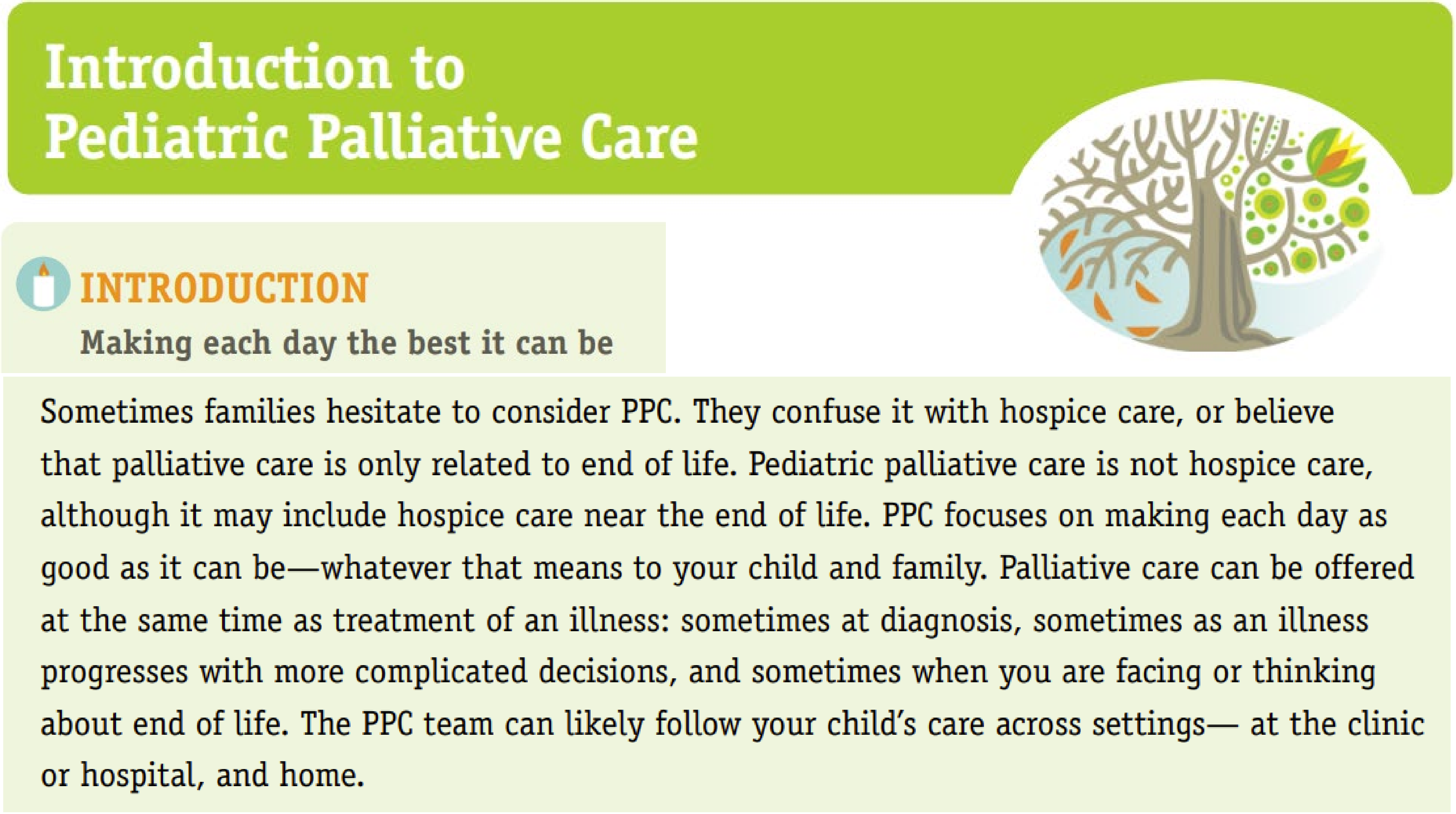
New Hampshire
FAMILY VOICES®

National Resources

COURAGEOUS PARENTS NETWORK
10
Celebrating 10 years
THIS SHARED JOURNEY

NACG
NATIONAL ALLIANCE FOR CHILDREN'S GRIEF

pediatric palliative
care coalition



Introduction to Pediatric Palliative Care

INTRODUCTION

Making each day the best it can be

Sometimes families hesitate to consider PPC. They confuse it with hospice care, or believe that palliative care is only related to end of life. Pediatric palliative care is not hospice care, although it may include hospice care near the end of life. PPC focuses on making each day as good as it can be—whatever that means to your child and family. Palliative care can be offered at the same time as treatment of an illness: sometimes at diagnosis, sometimes as an illness progresses with more complicated decisions, and sometimes when you are facing or thinking about end of life. The PPC team can likely follow your child's care across settings— at the clinic or hospital, and home.

Courageous Parents Network: CPN-Introduction-to-Pediatric-Palliative-Care_R2.pdf

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1. What is Pediatric Palliative Care?
2. NHPCO Pediatric Facts and Figures 2023 Edition (PDF)
3. Committee on Approaching Death: Addressing Key End of Life Issues; Institute of Medicine. Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life. Washington (DC): National Academies Press (US); 2015 Mar 19. Appendix F, Pediatric End-of-Life and Palliative Care: Epidemiology and Health Service Use. Available from: https://www.ncbi.nlm.nih.gov/books/NBK285690/#
4. Ernecoff NC, Anhang Price R. Concurrent Care as the Next Frontier in End-of-Life Care. *JAMA Health Forum.* 2023;4(8):e232603. doi:10.1001/jamahealthforum.2023.2603
5. Laird, Jessica, Melanie J. Cozad, Jessica Keim-Malpass, Jennifer W. Mack, and Lisa C. Lindley. "Variation In State Medicaid Implementation Of The ACA: The Case Of Concurrent Care For Children: Study examines state-level implementation of concurrent care for pediatric Medicaid beneficiaries." *Health Affairs* 39, no. 10 (2020): 1770-1775.
6. Boyden, Jackelyn Y., Puja J. Umaretiya, Louise D'Souza, and Emily E. Johnston. "Disparities in Pediatric Palliative Care: Where Are We and Where Do We Go from Here?." *The Journal of Pediatrics* 275 (2024).

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Thank you!

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