

Palliative Care in Neurology

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Disclosures: None

Objectives

- Briefly review definitions, scope and history of palliative care (and hospice)
- Discuss neurology's role in palliative care
 - Prognostication
 - Identifying “end of life” phase of illness
 - Advanced Care Planning
 - Having the conversation
 - Types of ACP documents

Scope of Services for Palliative Care

Palliative care is the comprehensive care and management of the physical, psychological, functional, practical, emotional, and spiritual needs of patients and their families with serious and/or life-threatening illness(es).



Serious illness is defined as a "health condition that carries a high risk of mortality and either negatively impacts a person's daily function or quality of life or excessively strains their caregiver" (Kelley and Bollens-Lund, 2018).



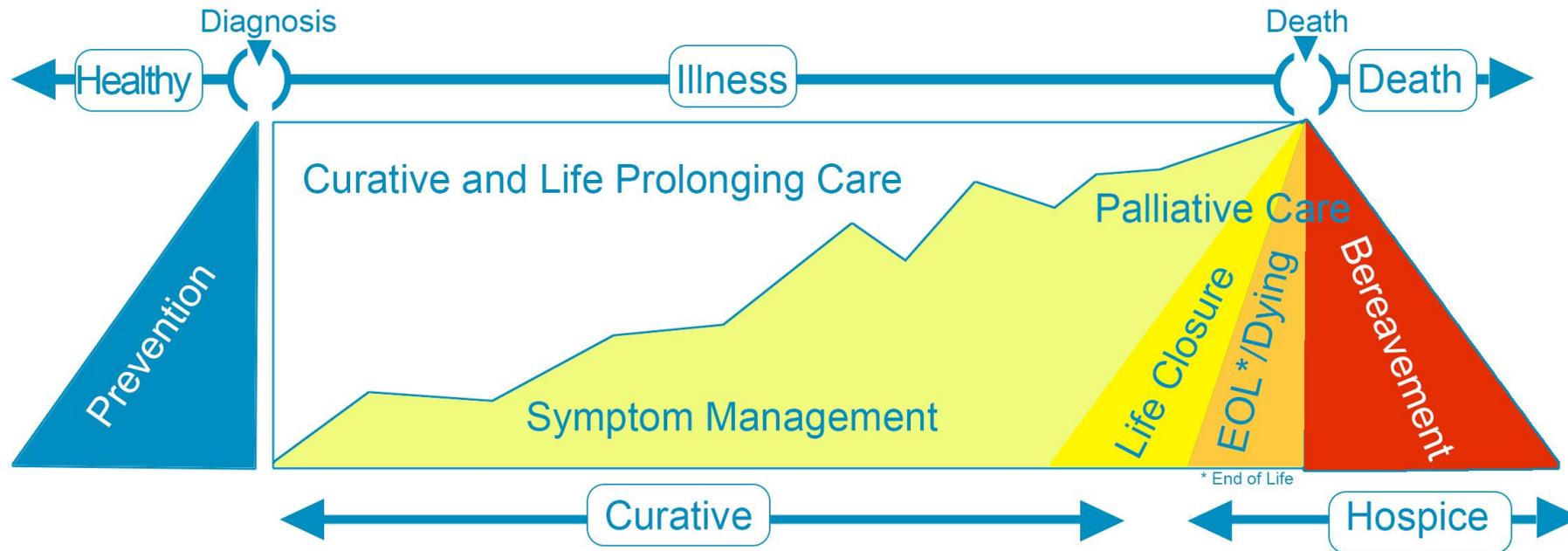
Illnesses in this population may include, but are not limited to, chronic and progressive disease such as end-stage organ failure, newly diagnosed or advanced malignancies, and/or sudden and catastrophic such as traumatic brain injury, large hemispheric or brain stem stroke

Definitions

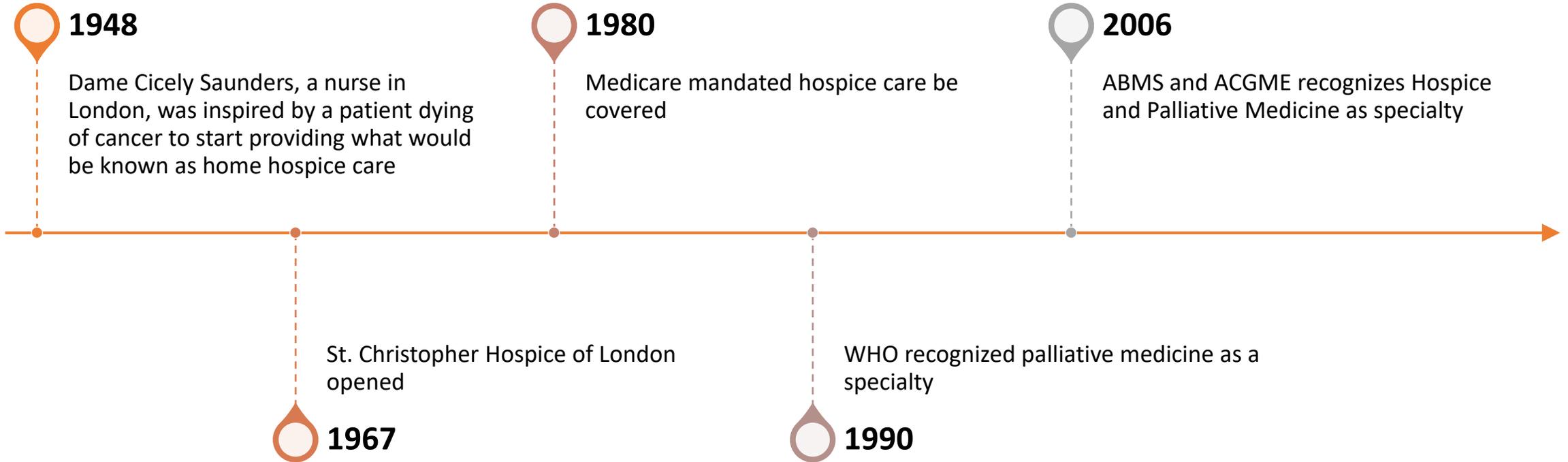
- Palliative Care actively focuses on relieving suffering and improving quality of life. Care can be offered at the same time as curative or disease-modifying treatment, distinguishing it from hospice care. Palliative care is interdisciplinary and integrates all needed services including pain and other symptom management, psychosocial and spiritual support.
- Palliative care is not:
 - Status of care
 - Hospice
 - No care or "giving up"

Palliative Care Timeline

Palliative Care and Hospice Care



History of Palliative Care and Hospice



Palliative Care Growth

- Palliative Care Programs in U.S. hospitals with 50 or more beds, 2000-2020
- 2000- 24.5%
- 2012- 69.6%
- 2020- 83.4%

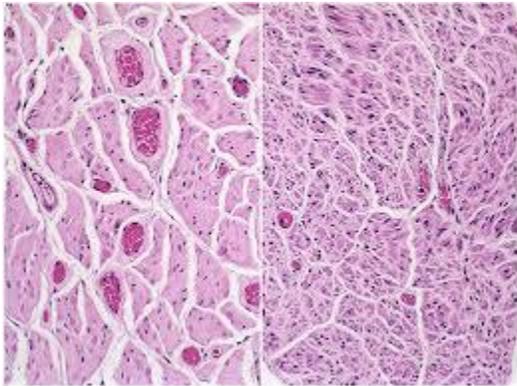
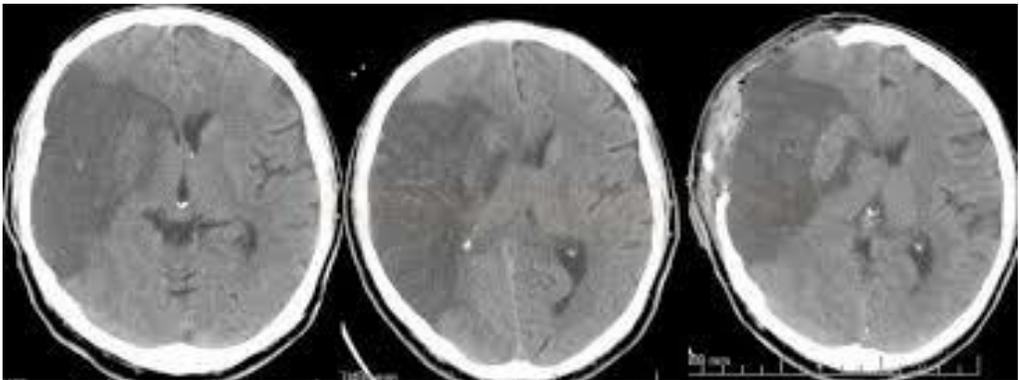
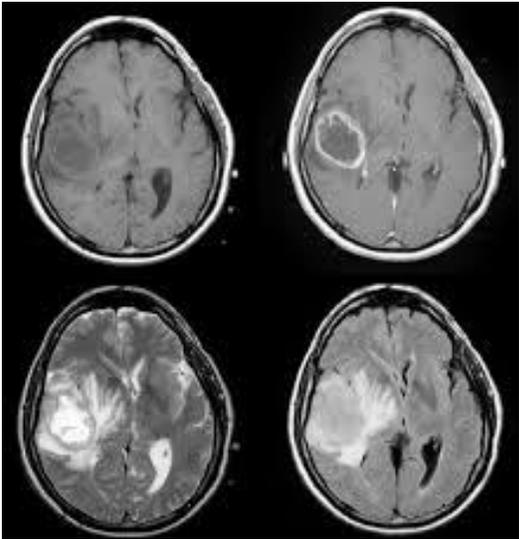
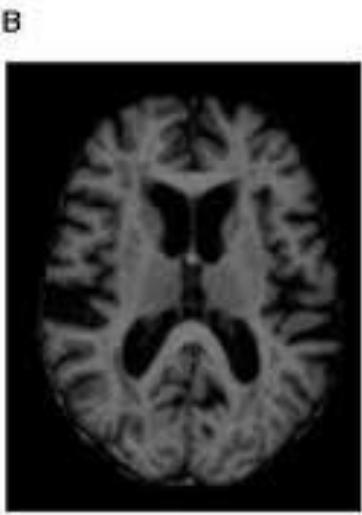
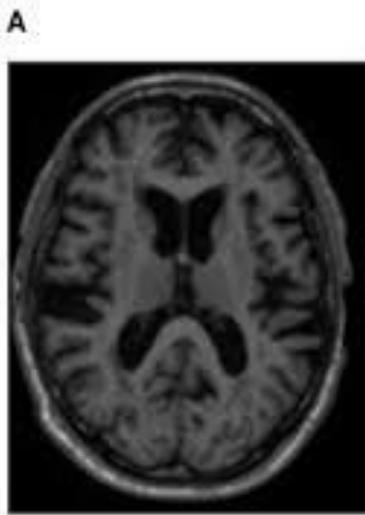
Neurology's Role in Palliative Care

- Fewer than 1% of neurologists are boarded in hospice and palliative medicine (51 in 2016) and about 1-2% of palliative care physicians are neurologists (2019)
 - In 2021, subspecialty certification was transferred from ABPN to ABIM
- Palliative care listed as a core competency by ACGME, <52% of neurology residencies had formal lectures on the topic (in 2019)
- Despite this, most neurologists already do some palliative care in day-to-day practice
 - Serious illness
 - Sharing “bad news”
 - Pain and symptom management
 - Prognostication
 - Exploration of patient's goals and wishes
 - Planning for eventual progressive disability and/or end of life

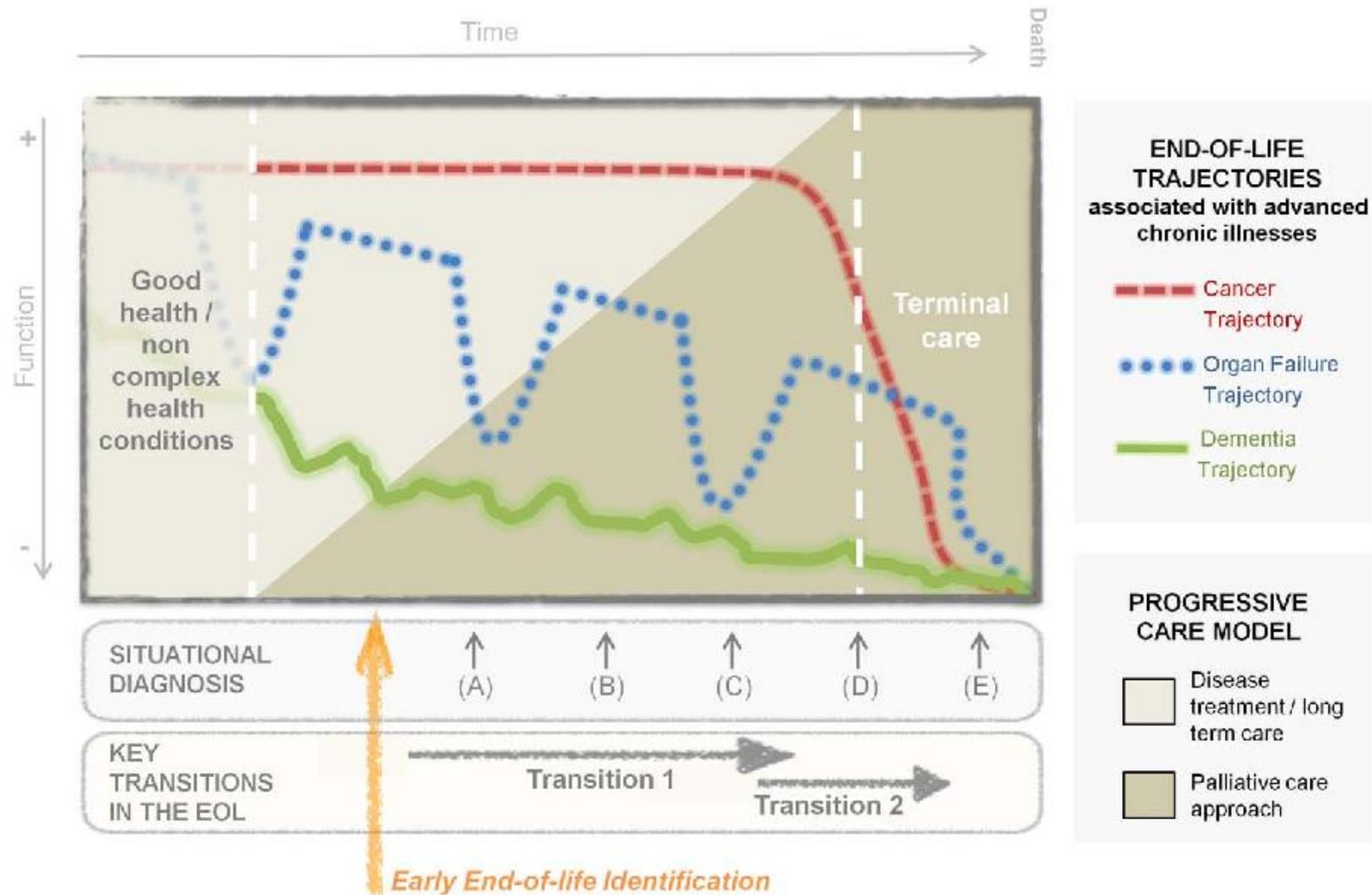
Theoretical Levels of Palliative Care

- General palliative care would be provided by all those caring for patients with life-threatening illness, ensuring good communication with patients and families, shared decision-making, goal setting and symptom management.
- Specialist palliative care would be provided by teams that would have this as their main activity and have received specialist training.
- Neuro-palliative care is a holistic approach to the care of neurological patients with significant disability, complex needs and a potentially shortened lifespan.

Case Study



Prognostication



Prognostication--Unique Aspects of Neurology



Prolonged and often fluctuating course—unexpected declines and accumulation of impairments



Significant prognostic uncertainty, with few validated predictive markers/models



Loss of mobility, communication and cognitive functioning→decreased ambulatory visits and lost opportunity for advanced planning and end of life decisions

Brizzi and Creutzfeldt “Neuropalliative Care: A Practical Guide for the Neurologist;” *Seminars in Neurology*, 2018 Oct 38(5):569-575

Prognosis of Common Neurologic Conditions

Time of diagnosis to death

- CJD 4-12 mos
- GBM 9-21 mos
- ALS 2-4 yrs
- MSA 6-9 yrs
- PSP 6-9 yrs
- AD 4-12 yrs
- PD 12-15 yrs

Discussing Prognosis

Opening Question: How much do you want to know?

For patients who want information

- Negotiate the content of the discussion
- Provide the information
- Acknowledge patient/family reaction explicitly
- Check for Understanding

For patients who don't want information

- Try to elicit and understand why
- Acknowledge the concerns
- Ask for permission to revisit the topic
- Make a private assessment about whether prognosis might change current decision making

For patients who are ambivalent

- Name the ambivalence
- Explore pros and cons of knowing/not knowing
- Acknowledge the difficulty of the situation
- Consider options for discussion and consequences

Prognostic Uncertainty

- Providers to patients and families
 - 1) **Normalize uncertainty**→reset expectations
 - 2) **Address emotions** about uncertainty→helps respond to emotional distress
 - 3) **Manage effect** of uncertainty→ability to live here and now
- Provider challenges
 - Optimistic bias, overestimate prognosis (5x)
 - Unwillingness to talk about this with patients
 - More testing to help improve prognostication

Smith AK, White DB, Arnold RM. “Uncertainty—The Other Side of Prognosis.” *N Engl J Med* 2013; 368:2448-2450.

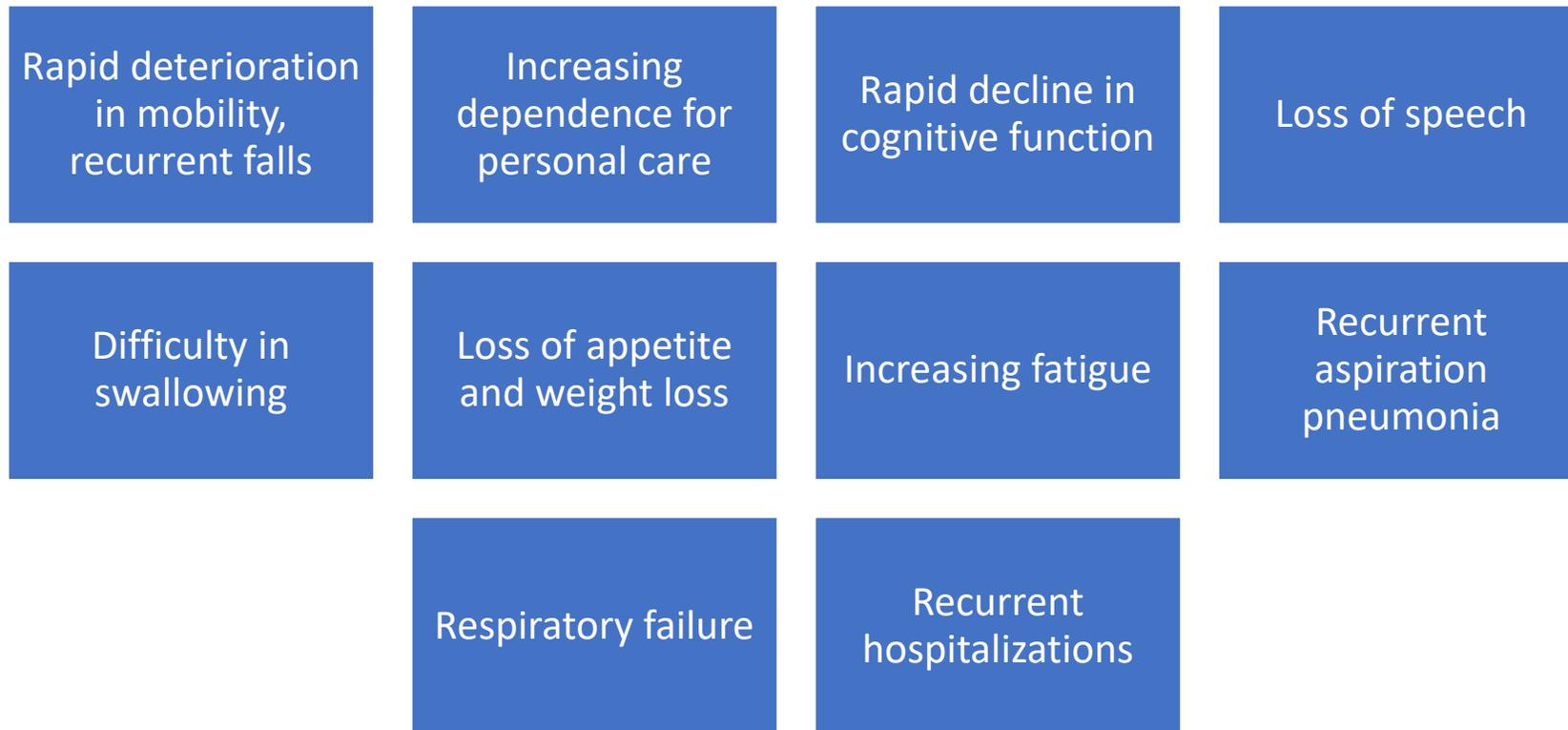
Prognostic Uncertainty

- If there is data, use it as best able
 - ICH score, survival/neurologic function after cardiac arrest
 - Time from diagnosis to disability/death in neurodegenerative disease
- If not, generalized rather than specific
 - Hours to days
 - Days to weeks
 - Weeks to months
 - Months to years

End of Life Issues in Neurology

- Typically, defined as last year
 - Discussions don't have to wait until then
 - Don't have to be held all at one time
- Widely varying course of progression
 - Timing of discussion difficult
 - Especially when cognitive decline is expected

Indicators for End of Life Phase in Neurologic Conditions



Awareness of these indicators promotes identification of end of life phase, which enables a proactive approach to discussion about priorities and planning for care and support

CMS criteria for determining prognosis in non-cancer diagnoses (hospice eligibility)

- **Amyotrophic Lateral Sclerosis**

One of these 4 (within 12 months prior to initial hospice certification)

1. Progression from independent ambulation to wheelchair or bedbound
2. Progression from normal to barely intelligible speech
3. Progression of normal to pureed diet
4. Progression from independence in most ADLs to needing major assistance by caregiver

Additional criteria (signifying terminal illness)

1. Critically impaired breathing capacity
2. Critical nutritional impairment
3. Life threatening complications

CMS criteria--Dementia

Functional Assessment Tool (FAST scale)

| Stage | Characteristics | Clinical Diagnosis |
|-------|--|----------------------|
| 1 | No functional decrement | Normal Adults |
| 2 | Personal awareness of some functional decline (e.g., subjective deficit in recalling names or locations of objects). | Normal Older Adults |
| 3 | Noticeable deficits in demanding occupation and social settings (e.g., may get lost travelling by auto). | Early AD |
| 4 | Requires assistance in complicated daily life tasks (e.g., handling finances, grocery shopping, and planning meals). | Mid AD |
| 5 | Requires assistance in choosing proper attire and/or independent community functioning (e.g., the individual will wear incongruous clothing), some patients may forget to bathe regularly, and driving is compromised. | Moderate AD |
| 6 | Requires physical assistance in dressing, bathing, and toileting. Urinary and fecal incontinence in the absence of infection or other etiologies. | Moderately Severe AD |
| 7 | Speech limited to about six words in the course of an average day. Progressive losses of abilities to walk, sit up, and hold head up. Eligible for hospice. | Severe AD |

Must be FAST scale 6e or 7 and have had one of following in past 12 months

- Aspiration pneumonia
- Pyelonephritis or other upper UTI
- Septicemia
- Decubitus ulcer, multiple, stage 3-4
- Fever, recurrent after antibiotics
- Inability to maintain sufficient fluid and calorie intake with 10% wt loss in 6 mos., or serum albumin<2.5

Common Issues around End of Life

When to start discussions

Approaching Advanced Care Planning

Managing symptoms

Diagnosing the dying phase

Withdrawing life support

Providing support to family/caregivers

Judging how/when to involve a palliative care
(or hospice) team

REMAP model for End of Life Communication

Childers, et al. J Oncol Prac 2017;13:e844-50

Reframe

- ▶ Given your diagnosis, it is important we talk about things now, while you can express your priorities.
- ▶ We are in a different place because of what's happened, but we know that for all of us, thinking about the future is important.

Expect emotion and empathize

- ▶ It is hard to deal with all of this.
 - ▶ I know it will be upsetting to think about situations before they are happening.
 - ▶ I can imagine there are things that worry you about the future?

Map the future

- ▶ Given the situation, are there things that you want to do?
- ▶ When you think about the future, what concerns you?
- ▶ Are there situations that you fear? Some people worry about being kept alive when they are at a point where they can't communicate, for example.

Align with the patient's values

- ▶ As I listen to you, it sounds like the most important things for you are...

Plan next steps

- ▶ It has been really helpful to hear what matters to you. These are the things that I think we can document to make sure that we manage situations in the future to try and ensure your priorities are achieved.

Anthony Back
Robert Arnold
James Tulsky



Mastering Communication with Seriously Ill Patients

Balancing Honesty with Empathy and Hope

CAMBRIDGE
Medicine

Advanced Care Planning

Advanced Directives

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graph TD; A[Advanced Directives] --> B[Proxy]; A --> C[Instructive]
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Any decision patients make in advance concerning what they would want if unable to make decisions in the future

Proxy

DPOA for Health Care
Hospital ACP forms

Instructive

“Living Will”
DNR/DNAR/DNI (or “AND”)
POLST orders

DPOA (Proxy) for Healthcare

- All 50 states recognize some form of DPOA, as a legally binding document
 - Have to be kept current
 - Usually require at least one witness who is not related to patient or part of medical team
- Never in effect unless the patient has lost ability to make decisions
- Disadvantage of DPOA only—have to trust proxy to make decisions as the patient would want
- Consequences of not having proxy
 - State hierarchies for decision making
 - Guardianship



Living Wills

Document in which patients describe they type of treatment they would wish to receive if no longer able to make decisions

Disadvantages

- Not recognized as a legal document in all state
- Does not qualify to designate proxy decision maker
- Cannot account for all possibilities one might face in the future
- Often vague/boilerplate

DNR/DNAR/DNI or “Allow Natural Death” (AND) orders

- Try to avoid “pick from the menu” list
- Code status in the hospital is only valid in the hospital
- All states have out-of-hospital DNAR (no CPR, prehospital comfort care)
 - Any competent adult regardless of disease status
 - Always signed by physician and patient; some states require witness but less restrictive and DPOA form
 - Keep in viewable place

Physician Order for Life Sustaining Treatment (POLST)

- Many acronyms:
 - MOLST (Medical Orders for Life Sustaining Treatment)
 - POST (Physician Orders for Scope of Treatment)
 - MOST (Medical Orders for Scope of Treatment)
 - COLST (Clinician Orders for Life Sustaining Treatment)
 - Some have 1-2 letters of state name: IMOST
 - TPOPP (Transportable Physician Orders for Patient Preferences)—Kansas and Missouri

[POLST: Portable medical orders for seriously ill or frail individuals](#)

polst.org

| | POLST: Portable Medical Order | Legal documents (advance directives, living wills, etc) |
|--|---|--|
| Purpose | Provides specific medical orders when patient cannot communicate. | Identifies surrogate decision-maker and provides general treatment wishes (not orders) for individual. |
| For Whom? | Seriously ill and frail individuals (view guidance) | All competent adults |
| Can Emergency Medical Services use? | Yes | No |
| Who complete/signs? | Provider completes. Patient or surrogate signs. | Individual completes and signs. |

MI-POST

MDHHS-5836, MICHIGAN PHYSICIAN ORDERS FOR SCOPE OF TREATMENT (MI-POST)
Michigan Department of Health and Human Services (MDHHS)
(Revised 8-22)

THIS portion of the MI-POST is used when the patient is not breathing, as necessary, this MI-POST form is used if Part 1 or Section D are filled. Leaving blank any sections of the medical orders (Sections A, B, or C) does not void the form and is interpreted as "No Treatment" for that section.

PART 1 - PATIENT INFORMATION

Printed Last Name _____ Patient First Name _____ Patient Middle Initial _____

Date of Birth (mm/dd/yyyy) _____ Date Form Prepared (mm/dd/yyyy) _____

Diagnosis supporting use of MI-POST _____

This form is a Physician Order (used based on the medical conditions and decisions of the person identified on this form). Paper copies, laminates, and digital images are valid and should be followed as if an original copy. This form is for adults with an advanced illness. It is not for healthy adults.

PART 2 - MEDICAL ORDERS

Section A - Cardiopulmonary Resuscitation (CPR)
Person has no pulse and is not breathing. See MDHHS-5837 for further details.

Attempt Resuscitation/CPR (Start chested Full Treatment in Section B)

DO NOT attempt Resuscitation/CPR (No CPR, allow Natural Death)

Section B - Medical Interventions
Person has pulse and/or is breathing. See MDHHS-5837 for further details on medical interventions.

Comfort-Focused Treatment
Primary goal of minimizing comfort. May include pain relief through use of medication, positioning, wound care, food and water by mouth, and non-invasive respiratory assistance.

Selective Treatment
Primary goal of treating medical conditions, while avoiding burdensome measures. May include IV fluids, cardiac monitoring including cardiogram, and non-invasive airway support.

Full Treatment
Primary goal of prolonging life by all medically effective means. May include intubation, advanced invasive airway interventions, mechanical ventilation, other advanced interventions.

Section C - Additional Orders (optional)
Medical orders for whether or when to start, withhold, or stop a specific treatment. Treatments may include but are not limited to dialysis, medically assisted propulsion of nutrition, long-term life-support, medications, and blood products.

Send form with Patient whenever transferred or discharged.

MDHHS-5836 (Rev. 8-22) Previous version obsolete |

[MDHHS-5836, Michigan Physician Order for Scope of Treatment \(MI POST\) Form](#)

Can be revoked at any time

Must be reaffirmed annually

Question or Comments?

To cure sometimes, to relieve often, to comfort always...

Dr. Edward Livingston Trudeau, founder of the Saranac Lake tuberculosis sanitarium