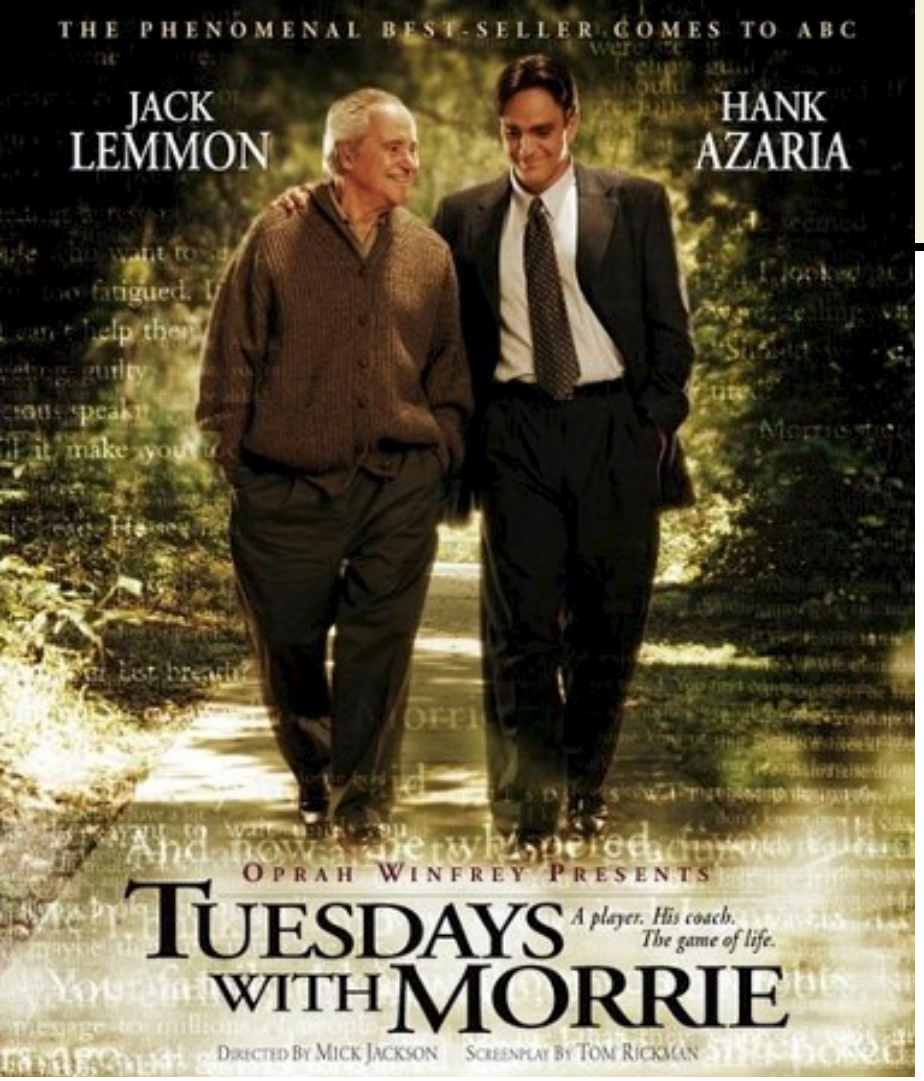
Palliative Care: Redesigning the End of Our Lives

Robert Stone MD FAAHPM

Medical Director, Outpatient Palliative Care

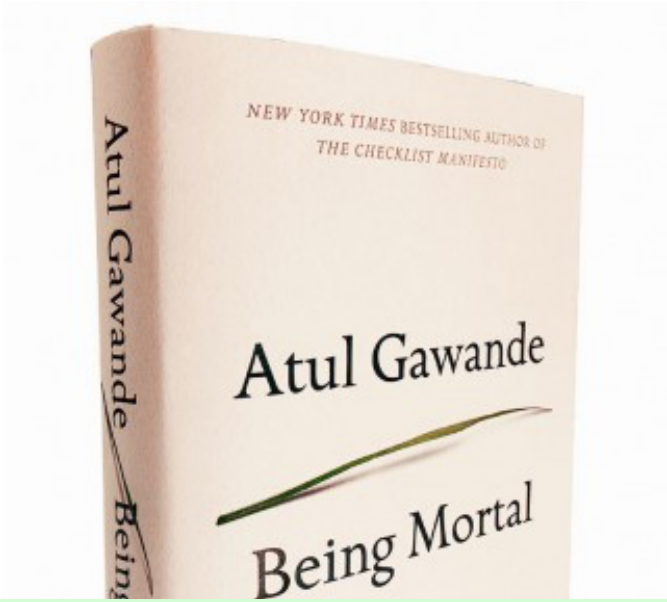
Indiana University Health Bloomington



"We all know we are going to die, but we don't believe it."

- Morrie Schwartz

Dr. Atul Gawande

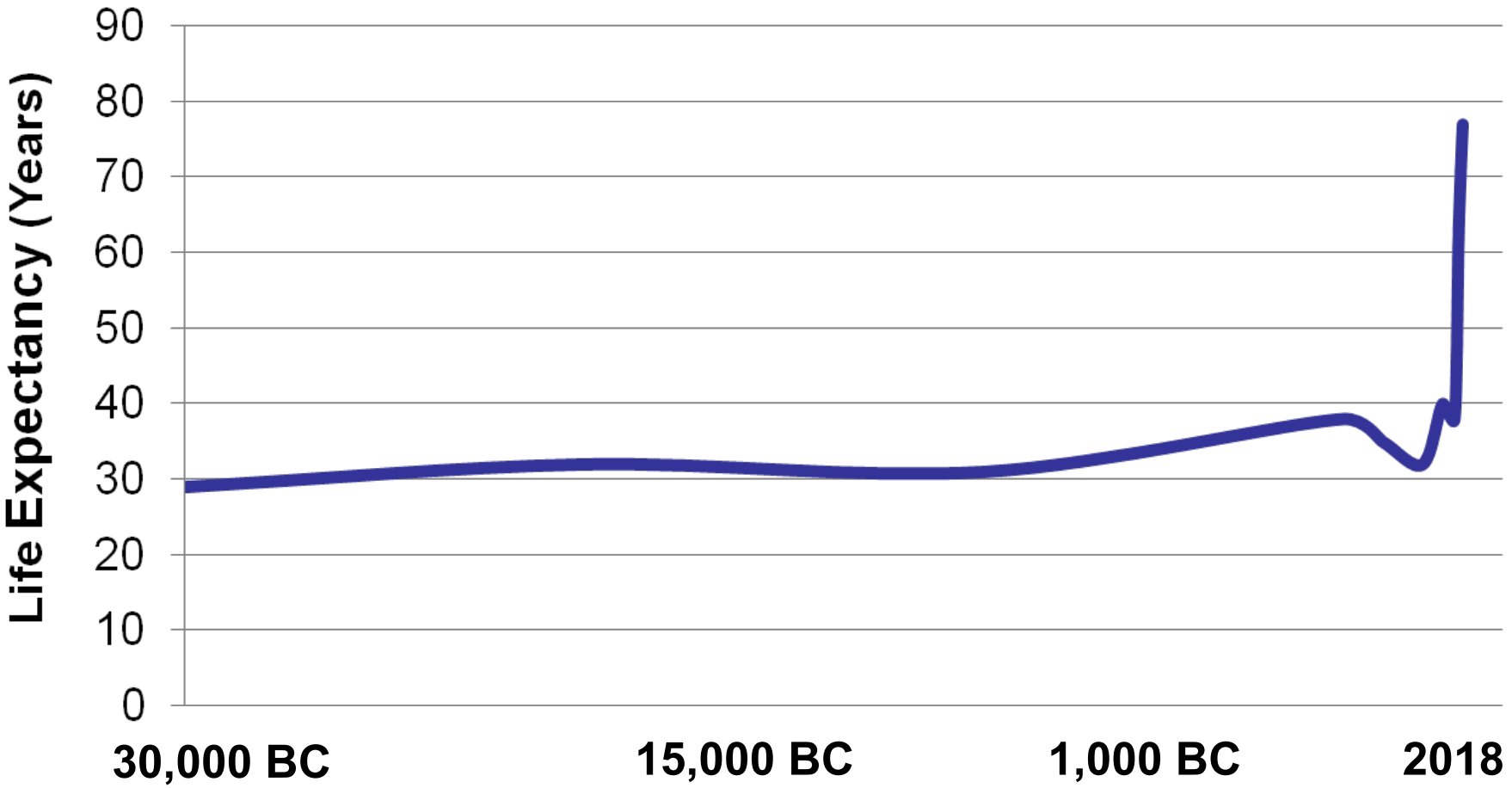


Among the many things I learned [writing this book], here are the two most fundamental:

First, in medicine and society, we have failed to recognize that people have priorities that they need us to serve besides just living longer.

Second, the best way to learn those priorities is to ask about them.

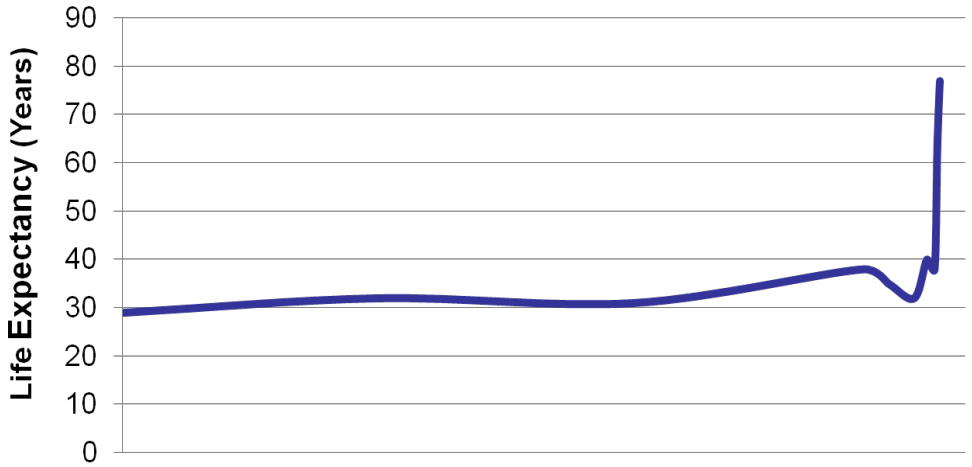
Average Human Life Expectancy



Life Expectancy

- Average age at death - 79 years.
- If you live to 65,

  average age at death – 84



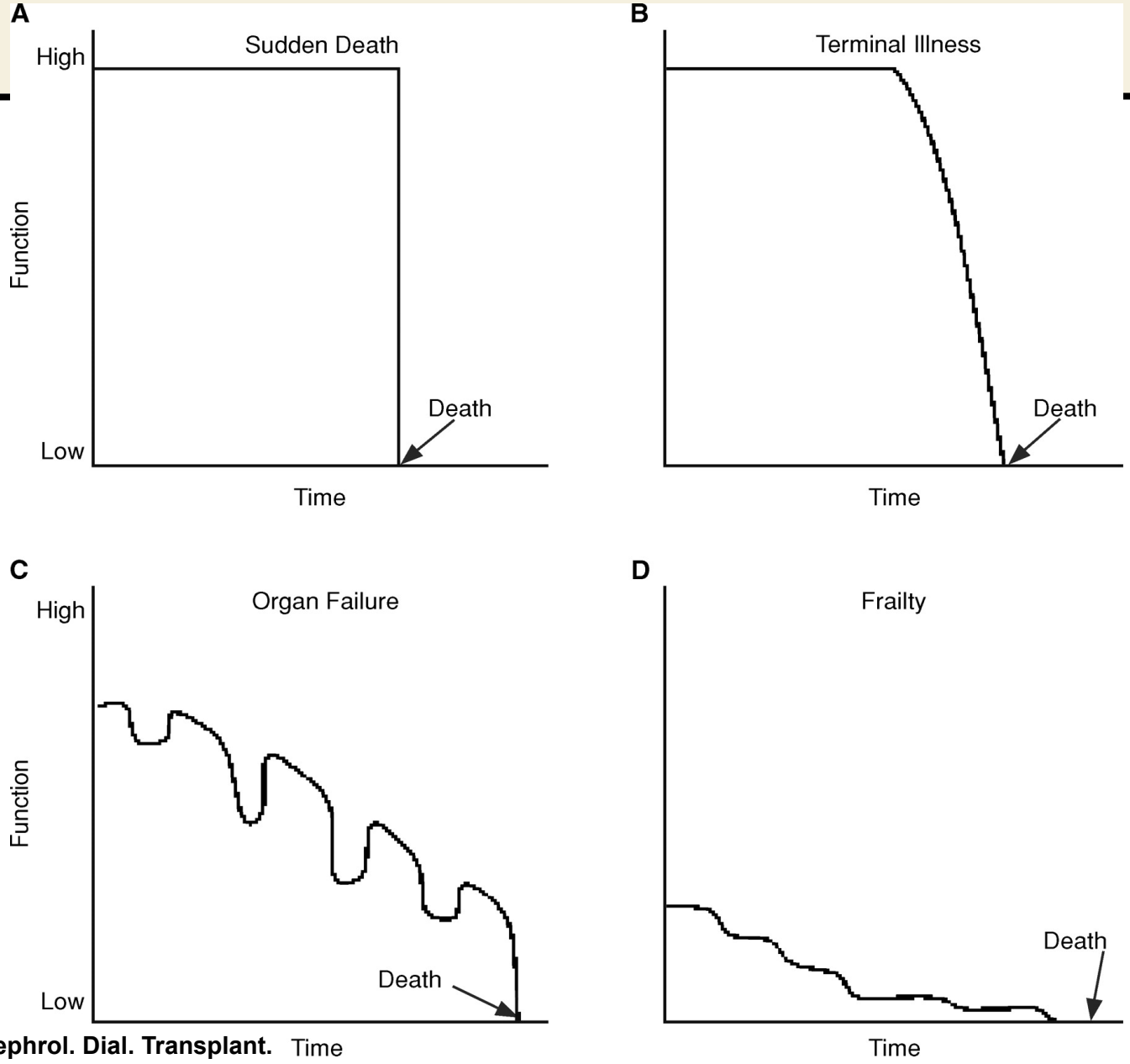
How has it changed since 1900?

- Life expectancy was 47 (*Gain of over 30 years*)
- Infant mortality was 100 per 1000 births, now less than 7 per 1000
- If you survived to 65 you would on average live to 77 (vs 84 now = *7 years more*)

Death in the United States

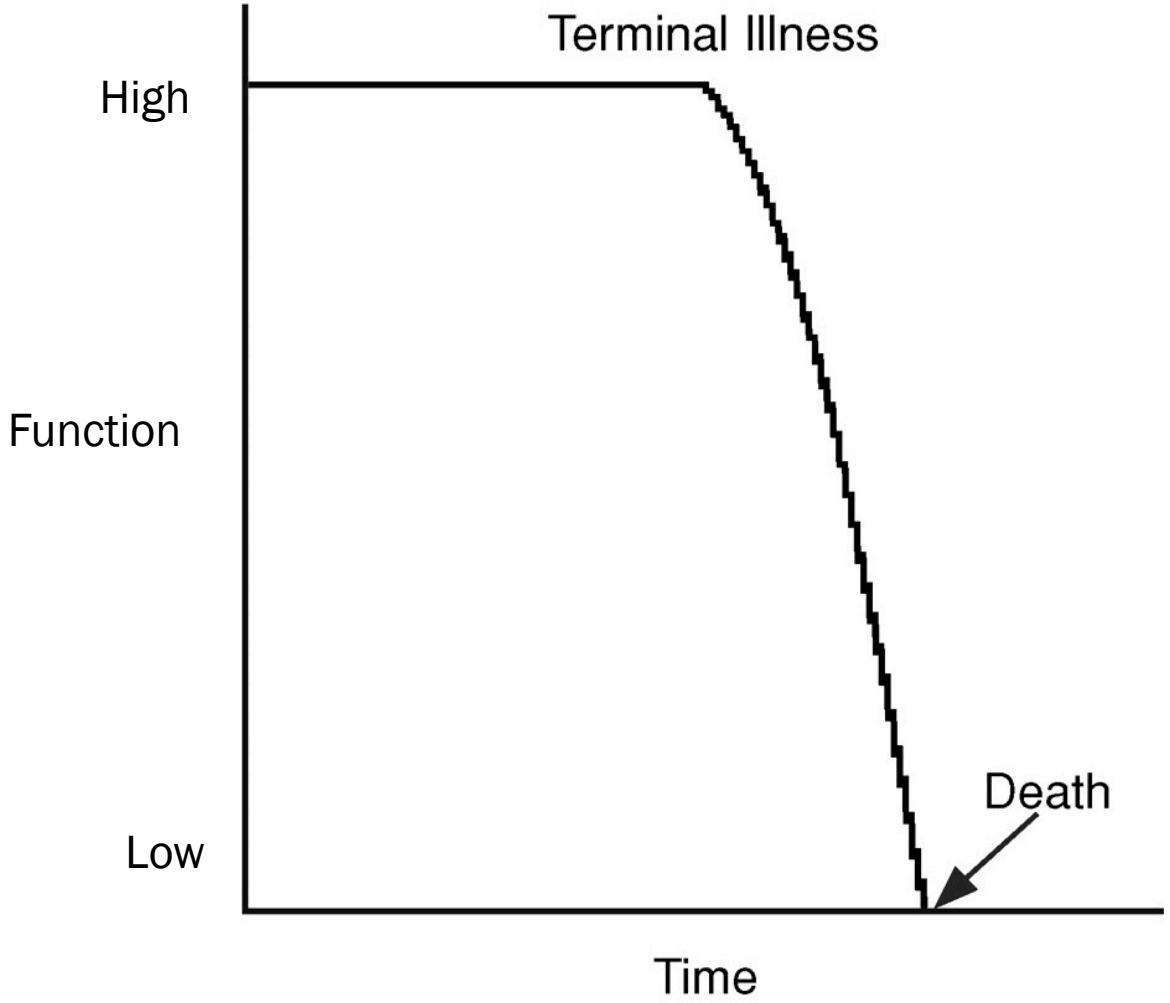
- Leading causes of death:
  1. Heart disease 23.7%
  2. Cancer 22.9%
  3. COPD 5.7%
  4. Stroke 5.1%
  5. Accidents 4.9%
  6. Dementia 3.4%
  - Other 34.3%

Typical Disease Trajectories in Patients with Different Diseases.



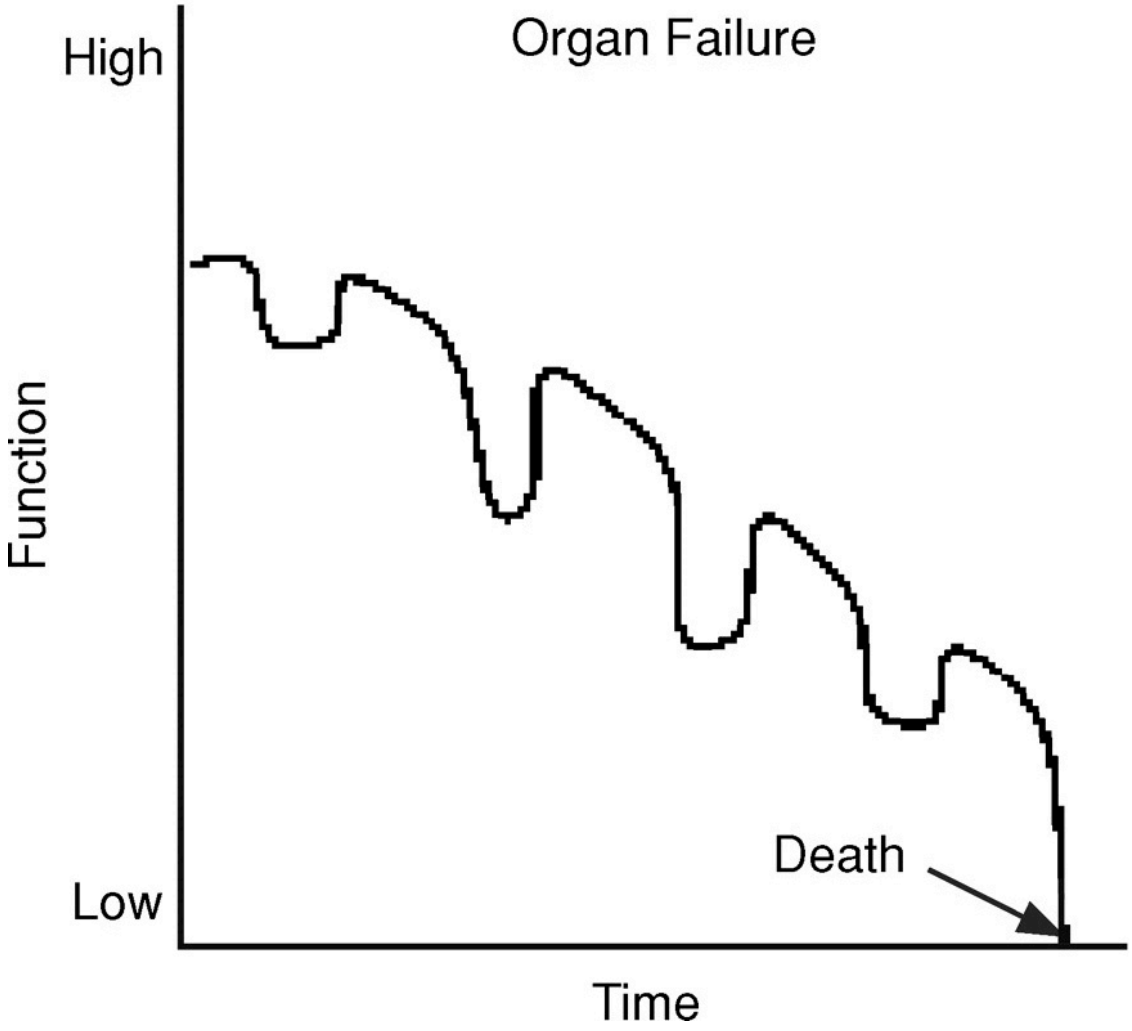
Murtagh F E M et al. Nephrol. Dial. Transplant. 2008;23:3746-3748

Typical Disease Trajectories to Death: Terminal Illness



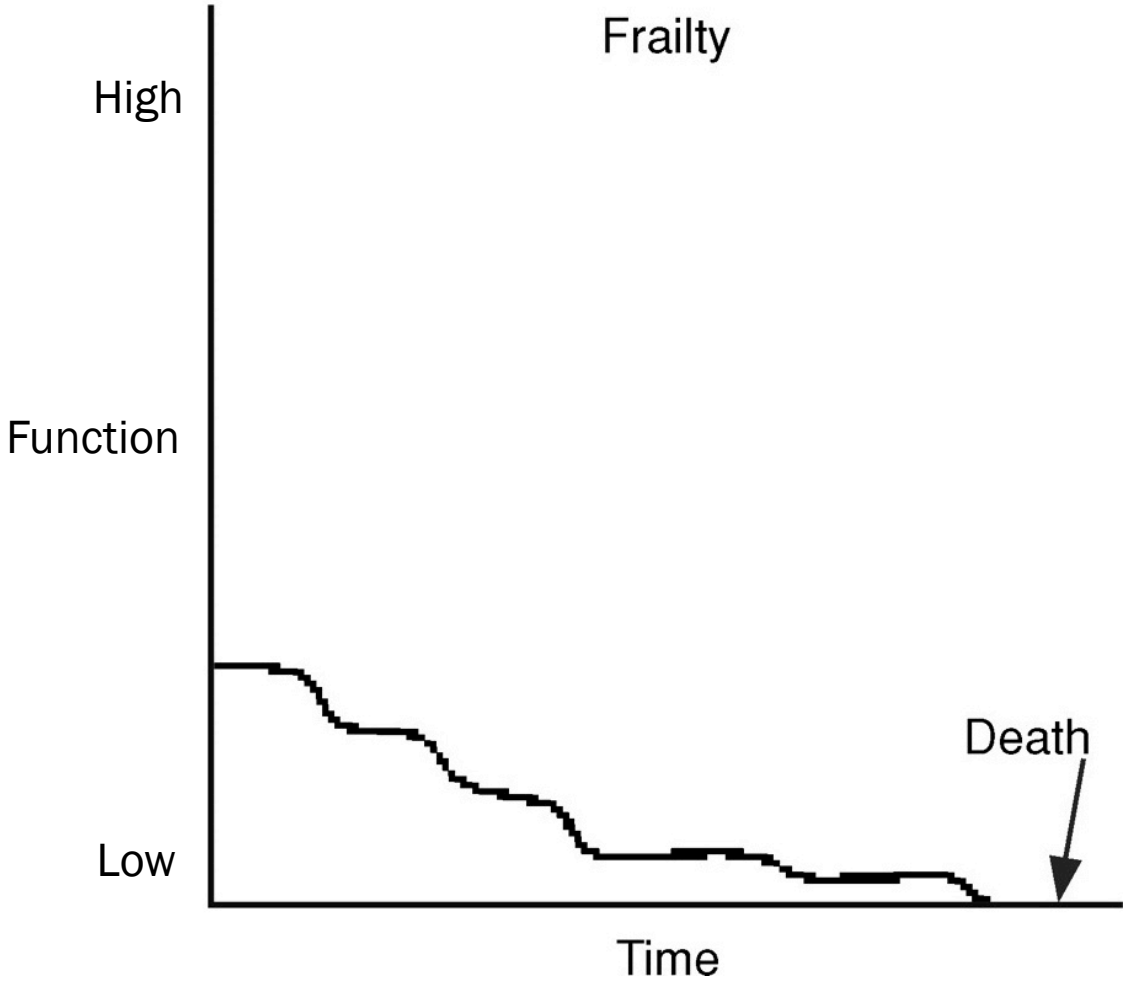
Murtagh F E M et al. Nephrol. Dial. Transplant. 2008;23:3746-3748

Typical Disease Trajectories to Death: Progressive Chronic Disease



Murtagh F E M et al. Nephrol. Dial. Transplant. 2008;23:3746-3748

Typical Disease Trajectories to Death: Frailty



Murtagh F E M et al. Nephrol. Dial. Transplant. 2008;23:3746-3748

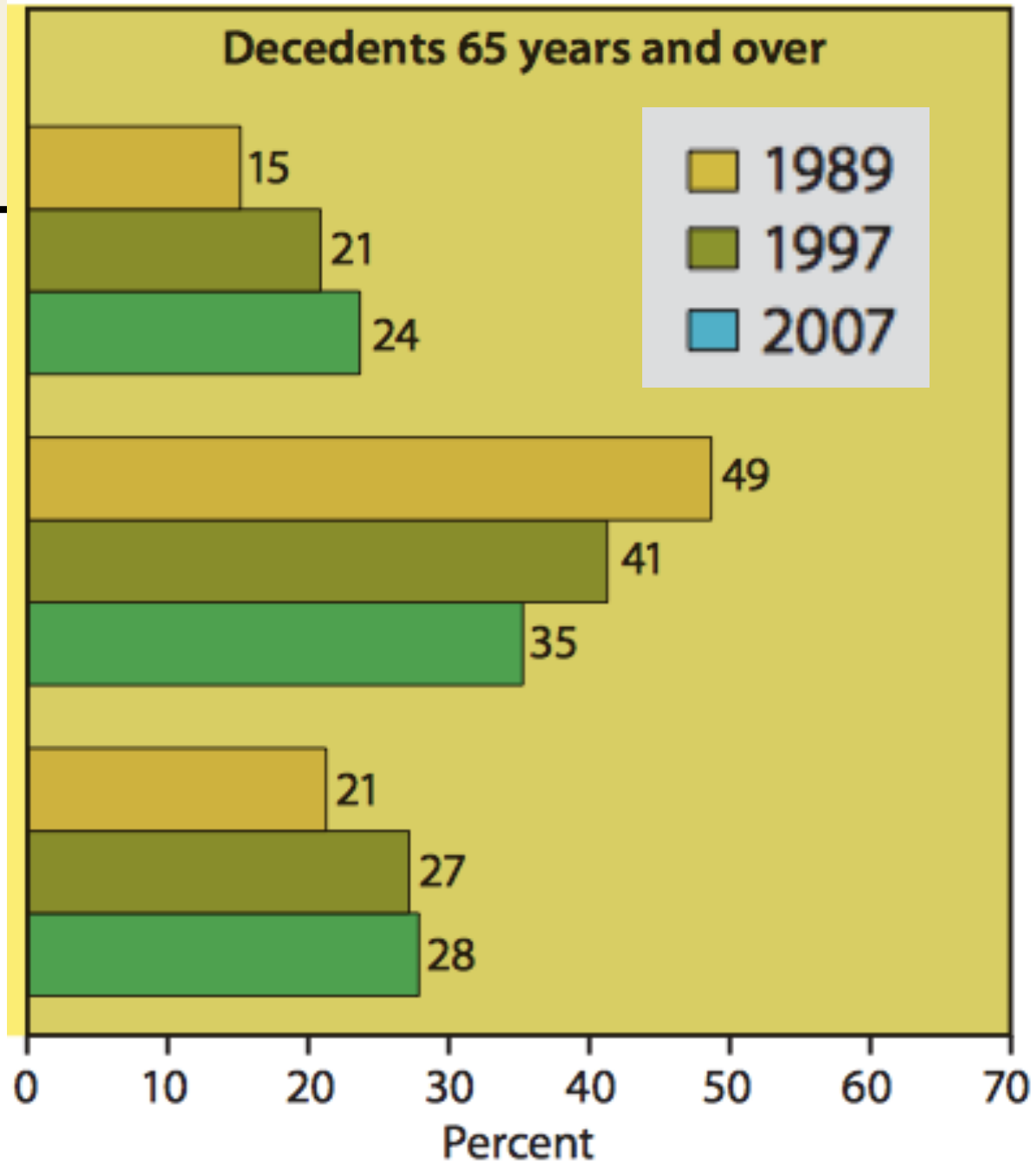
Woody Allen

“It's not that I'm afraid to die,
I just don't want to be there when it happens.”

Where do you want to die?

- More than 80% of people say they want to die at home, BUT….
- More than 60% die in an institution.

Where We Die



SOURCE: CDC/NCHS, National Vital Statistics System.

Are We Doing Better? Dr. Joan Teno

- 2000-2009 - ICU admission in last month of life increased from 24% to 26%
- Hospice use at the time of death increased from 22% to 42%
- 28% were in hospice for ≤3 days in 2009.

Change in end-of-life care for Medicare beneficiaries: site of death, place of care, and health care transitions, Teno et al, JAMA 2/6/13

Hospice

- Began in England in 1970's, Dame Cicely Saunders

- Medicare benefit 1982
  - Life expectancy < 6 months
  - Give up curative treatments
- 40% of all US deaths are with Hospice

The Limitation of Hospice: Dr. Diane Meyer

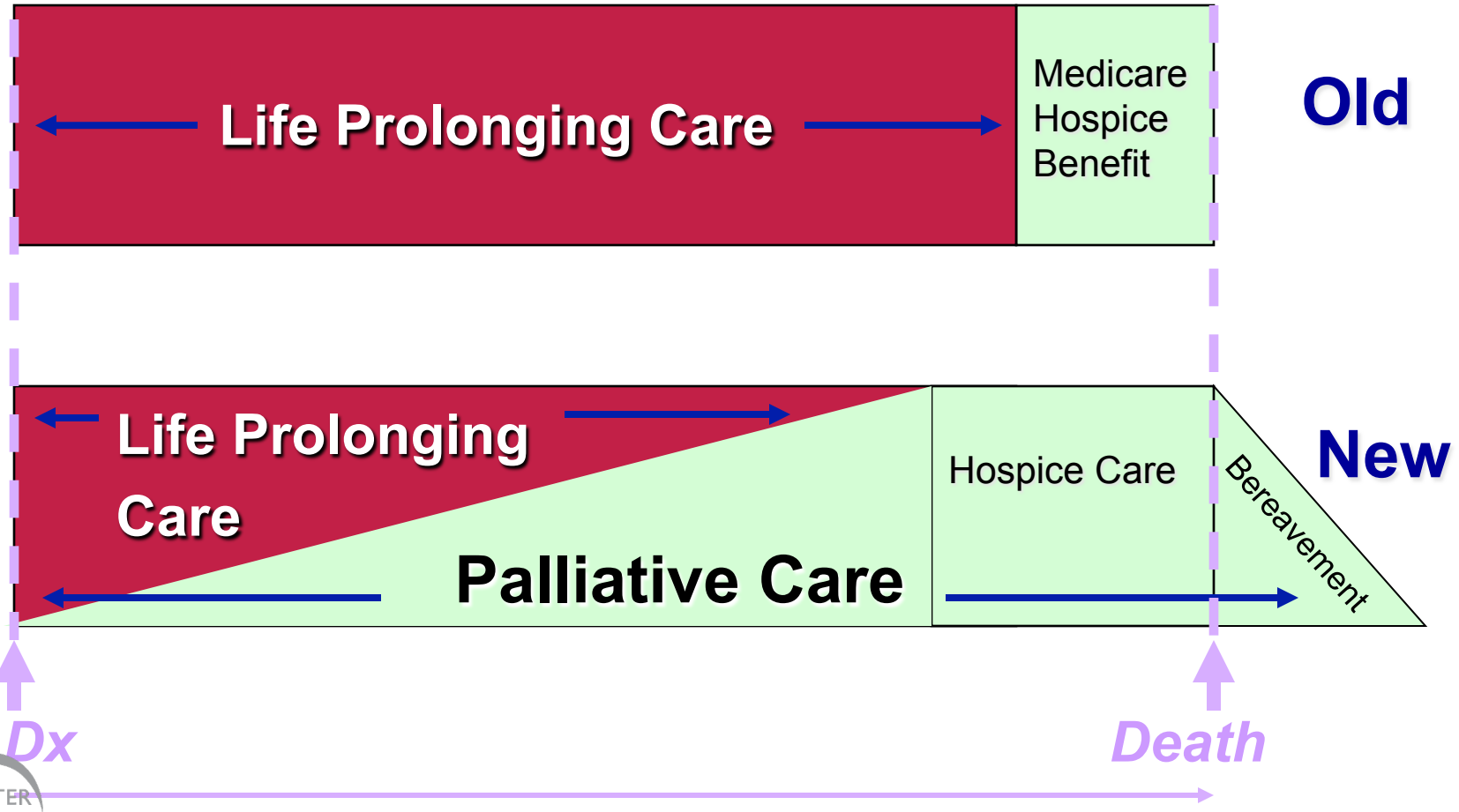
"Hospice is the gold standard of care quality for those that are predictably dying, and we are fortunate as a nation to have such a strong hospice infrastructure, but that's not where most of the problems lie."

"The problems lie in the lack of options for people who are either not hospice-eligible (prognosis uncertain or continuing to want and benefit from disease treatment) or are referred to hospice much too late in their disease course."

All Hospice is Palliative Care, but…

All Palliative Care is not Hospice.

Conceptual Shift to Palliative Care



CENTER TO ADVANCE PALLIATIVE CARE

Palliative Care Defined

Specialized medical care for people with serious illnesses, focused on providing patients with relief from the symptoms, pain, and stress of a serious illness—whatever the diagnosis.

The goal is look at the big picture and to improve quality of life for both the patient and the family.

The NEW ENGLAND JOURNAL of MEDICINE

ORIGINAL ARTICLE

Early Palliative Care for Patients with Metastatic Non–Small-Cell Lung Cancer

Jennifer S. Temel, M.D., Joseph A. Greer, Ph.D., Alona Muzikansky, M.A., Emily R. Gallagher, R.N., Sonal Admane, M.B., B.S., M.P.H., Vicki A. Jackson, M.D., M.P.H., Constance M. Dahlin, A.P.N., Craig D. Blinderman, M.D., Juliet Jacobsen, M.D., William F. Pirl, M.D., M.P.H., J. Andrew Billings, M.D., and Thomas J. Lynch, M.D.

N Engl J Med 2010; 363:733-742 | August 19, 2010

BACKGROUND

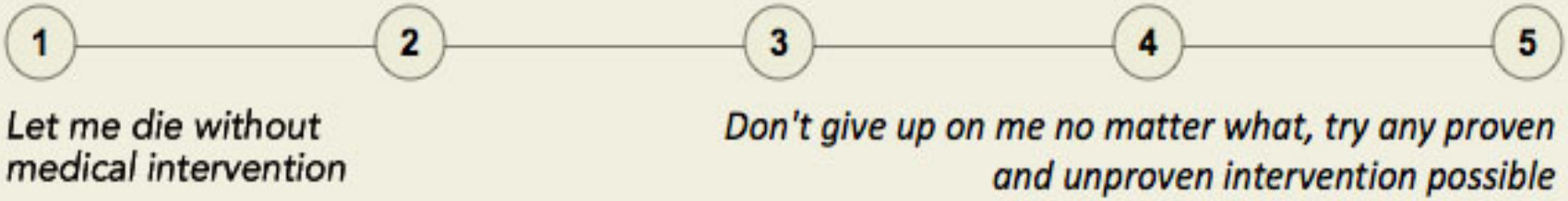
Patients with metastatic non–small-cell lung cancer have a substantial symptom burden and may receive aggressive care at the end of life. We examined the effect of introducing palliative care early after diagnosis on patient-reported outcomes and end-of-life care among ambulatory patients with newly diagnosed disease.

CONCLUSIONS

Among patients with metastatic non–small-cell lung cancer, early palliative care led to significant improvements in both quality of life and mood. As compared with patients receiving standard care, patients receiving early palliative care had less aggressive care at the end of life but longer survival. (Funded by an American Society of Clinical Oncology Career Development Award and philanthropic gifts; ClinicalTrials.gov number, NCT01038271.)

Five Critical Questions

1. On a scale of 1 to 5, where do you fall on this continuum?



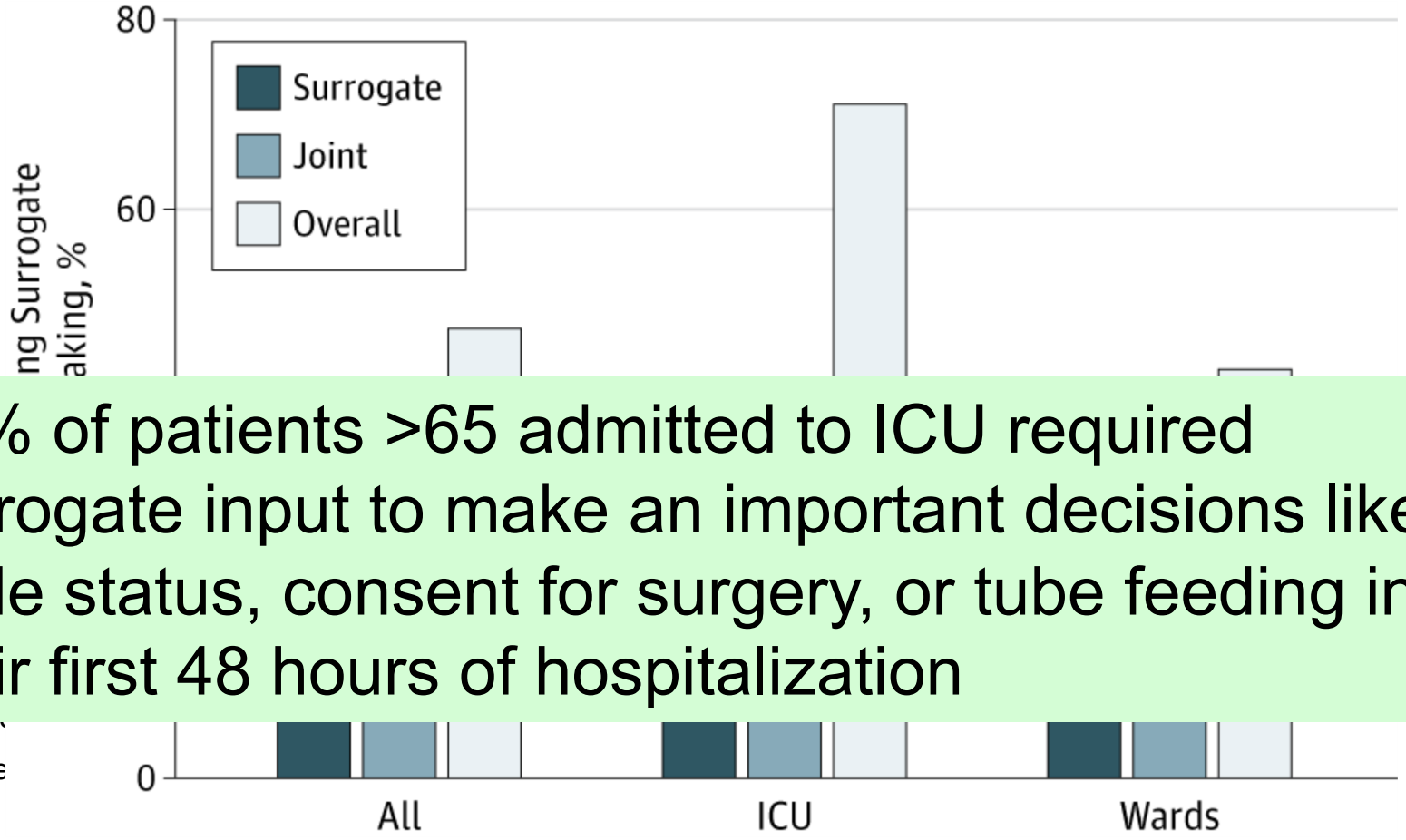
2. If there were a choice, would you prefer to die at home, or in a hospital?
3. Could a loved one correctly describe how you'd like to be treated in the case of a terminal illness?
4. Is there someone you trust whom you've appointed to advocate on your behalf when the time is near?
5. Have you completed any of the following: written a living will, appointed a healthcare power of attorney, or completed an advance directive?

Advance Care Planning

- Advance Directives
  - Appointment of Health Care Representative or POA-HC
  - Living Will
- Code status orders
  - DNR vs Full Code
  - Out of hospital DNR
  - **Indiana POST**

From: **Scope and Outcomes of Surrogate Decision Making Among Hospitalized Older Adults**

JAMA Intern Med. 2014;174(3):370-377. doi:10.1001/jamainternmed.2013.13315



75% of patients >65 admitted to ICU required surrogate input to make an important decisions like code status, consent for surgery, or tube feeding in their first 48 hours of hospitalization

Figure Legend:

Percentage

Default Surrogate Statute IC 16-36-1-5 Amended 2018 (effective July 1)

(1) A judicially appointed guardian or appointed healthcare representative

(2) A spouse*

(3) An adult child

(4) A parent

(5) An adult sibling.

(6) A grandparent

(7) An adult grandchild.

Default Surrogate Statute IC 16-36-1-5 Amended 2018

((8) The nearest other adult relative in the next degree of kinship

(9) A friend who is an adult; has maintained regular contact with the individual and is familiar with the individual's activities, health, and religious or moral beliefs

- If there are multiple individuals at the same priority level…majority rules

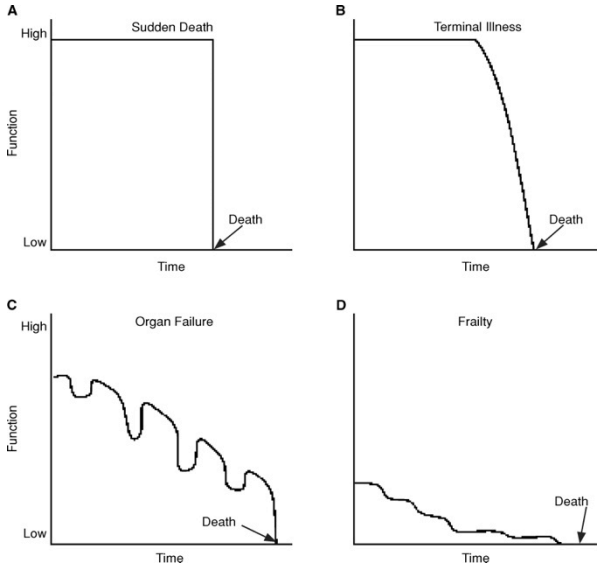
The POST Paradigm

- **POST** = **P**hysician **O**rders for **S**cope of **T**reatment
- Converts treatment preferences into medical orders
- Who: Terminal Illness, Progressive Chronic Disease, and Frailty

Who can have a POST?

- A terminal condition, like cancer
- An advanced chronic progressive illness, like severe emphysema, heart, liver, or kidney failure
- Advanced frailty, usually with dementia

- Patients who are seriously ill, whose ***death within one year would NOT BE A SURPRISE*** to their physician.



The POST Paradigm

- POST = Physician Orders for Scope of Treatment
- Converts treatment preferences into medical orders
- Who: Terminal Illness, Progressive Chronic Disease, and Frailty
- Specify preference to accept or decline treatments
- Transfers across settings
- Recognizable, standardized form

INDIANA PHYSICIAN ORDERS FOR SCOPE OF TREATMENT (POST)

State Form 55317 (6-13)
Indiana State Department of Health – IC 16-36-6

INSTRUCTIONS: Follow these orders first. Contact treating physician, advanced practice nurse, or physician assistant for further orders if indicated. Emergency Medical Services (EMS) should contact Medical Control per protocol. These medical orders are based on the patient's current medical condition and preferences. Any section not completed does not invalidate the form and implies full treatment for that section. HIPAA permits disclosure to health care professionals as necessary for treatment. Original form is personal property of the patient.

Patient Last Name	Patient First Name	Middle Initial
Birth date *(mm/dd/yyyy)*	**Medical Record Number**	**Date prepared** *(mm/dd/yyyy)*

A *Check One*

CARDIOPULMONARY RESUSCITATION (CPR): *Patient has no pulse AND is not breathing.*

☐ Attempt Resuscitation/CPR ☐ Do Not Attempt Resuscitation (DNR)

When not in cardiopulmonary arrest, follow orders in **B, C** and **D**.

B *Check One*

MEDICAL INTERVENTIONS: *If patient has pulse AND is breathing OR has pulse and is NOT breathing.*

☐ *Comfort Measures (Allow Natural Death)*: Treatment Goal: Maximize comfort through symptom management. 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 to hospital only if comfort needs cannot be met in current location.

☐ *Limited Additional Interventions*: Treatment Goal: Stabilization of medical condition. In addition to care described in Comfort Measures above, use medical treatment for stabilization, IV fluids (hydration) and cardiac monitor as indicated to stabilize medical condition. May use basic airway management techniques and non-invasive positive-airway pressure. Do not intubate. Transfer to hospital if indicated to manage medical needs or comfort. Avoid intensive care if possible.

☐ *Full Intervention*: Treatment Goal: Full interventions including life support measures in the intensive care unit. In addition to care described in Comfort Measures and Limited Additional Interventions above, use intubation, advanced airway interventions, and mechanical ventilation as indicated. Transfer to hospital and/or intensive care unit if indicated to meet medical needs.

C *Check One*

ANTIBIOTICS:

☐ Use antibiotics for infection only if comfort cannot be achieved fully through other means.

☐ Use antibiotics consistent with treatment goals.

D *Check One*

ARTIFICIALLY ADMINISTERED NUTRITION: Always offer food and fluid by mouth if feasible.

☐ No artificial nutrition.

☐ Defined trial period of artificial nutrition by tube. (Length of trial: _____ Goal: _____)

☐ Long-term artificial nutrition.

E

DOCUMENTATION OF DISCUSSION: Orders discussed with *(check one)*:

☐ Patient (patient has capacity) ☐ Health Care Representative

☐ Legal Guardian / Parent of Minor ☐ Health Care Power of Attorney

SIGNATURE OF PATIENT OR LEGALLY APPOINTED REPRESENTATIVE

My signature below indicates that my physician discussed with me the above orders and the selected orders correctly represent my wishes.
If signature is other than patient's, add contact information for representative on reverse side.

Signature ***(required by statute)***	Print Name ***(required by statute)***	Date ***(required by statute)*** *(mm/dd/yyyy)*

F

SIGNATURE OF PHYSICIAN

My signature below indicates to the best of my knowledge that these orders are consistent with the patient's **current** medical condition and preferences.

Print Signing Physician Name ***(required by statute)***	Physician Office Telephone Number ***(required by statute)*** ( ) _____ – _____	License Number ***(required by statute)***
Physician Signature ***(required by statute)***	**Date** ***(required by statute)*** *(mm/dd/yyyy)*	**Office Use Only**

Section A: CPR Orders

- When does Section A apply?
  - When patient has no pulse and is not breathing

A *Check One*	**CARDIOPULMONARY RESUSCITATION (CPR):** *Patient has no pulse AND is not breathing.* ☐ Attempt Resuscitation/CPR ☐ Do Not Attempt Resuscitation (DNR) When not in cardiopulmonary arrest, follow orders in **B**, **C** and **D**.

Section B: Medical Interventions

- When does section B apply?
  - When the patient still has a PULSE and is/is not breathing

B
Check One

MEDICAL INTERVENTIONS: *If patient has pulse AND is breathing OR has pulse and is NOT breathing.*

☐ *Comfort Measures (Allow Natural Death)*: Treatment Goal: Maximize comfort through symptom management. 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 to hospital only if comfort needs cannot be met in current location.

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☐ *Full Intervention*: Treatment Goal: Full interventions including life support measures in the intensive care unit. In addition to care described in Comfort Measures and Limited Additional Interventions above, use intubation, advanced airway interventions, and mechanical ventilation as indicated. Transfer to hospital and/or intensive care unit if indicated to meet medical needs.

Section C: Antibiotics

C *Check One*	**ANTIBIOTICS:** ☐ Use antibiotics for infection only if comfort cannot be achieved fully through other means. ☐ Use antibiotics consistent with treatment goals.

- Antibiotics for Comfort
  - Examples: Urinary tract infection; wound infection
  - Literature suggests antibiotics are NOT needed to ensure comfort in a patient with pneumonia
- Consistent with treatment goals—see Section B
  - Stabilize condition
  - Cure and prolong life if possible

Section D: Artificial Nutrition

D *Check One*	ARTIFICIALLY ADMINISTERED NUTRITION: Always offer food and fluid by mouth if feasible. ☐ No artificial nutrition. ☐ Defined trial period of artificial nutrition by tube. (Length of trial: _____ Goal: _____) ☐ Long-term artificial nutrition.

- Discuss risks and benefits of feeding tubes
- For time-limited trial

For Patients & Families
GetPalliativeCare.org

- Hospital Provider Directory
- What it is & how to get it
- Patient + family resources

facebook.com/**GetPalliativeCare**

twitter.com/**GetPalliative**

GET PALLIATIVE CARE

George Burns 1896-1996

"Statistics show, if you live to be 100, you've got it made. Very few people die past that age."