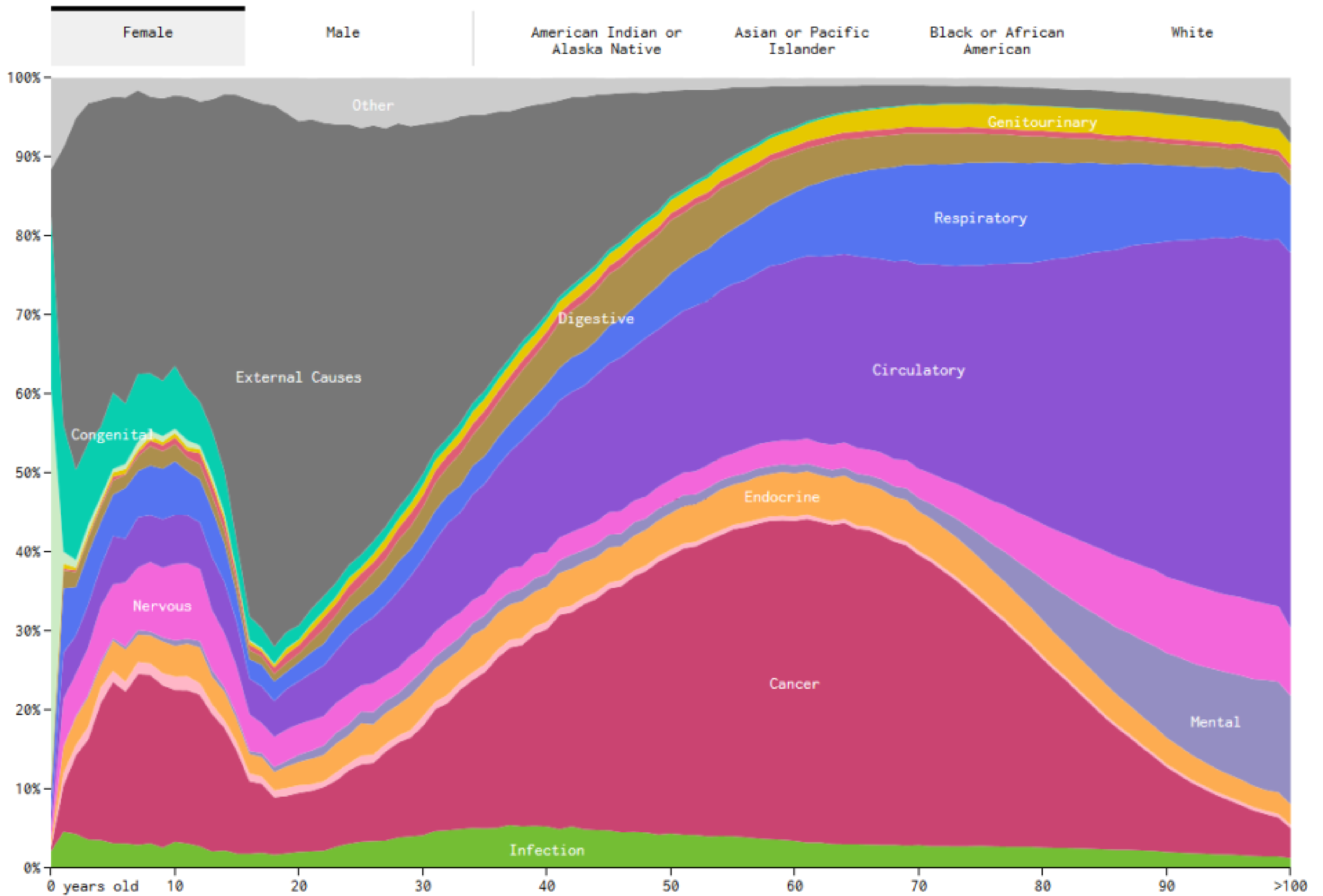
Exploring Supportive Care Options
Palliative Care & Hospice
What, When, Where & How

Martha L. Twaddle, MD, FACP, FAAHPM, HMDC
The Waud Family Medical Director of Palliative Medicine & Supportive Care
Northwestern Medicine – North Region
Clinical Professor of Medicine,
Northwestern Feinberg School of Medicine

LES TURNER ALS FOUNDATION™

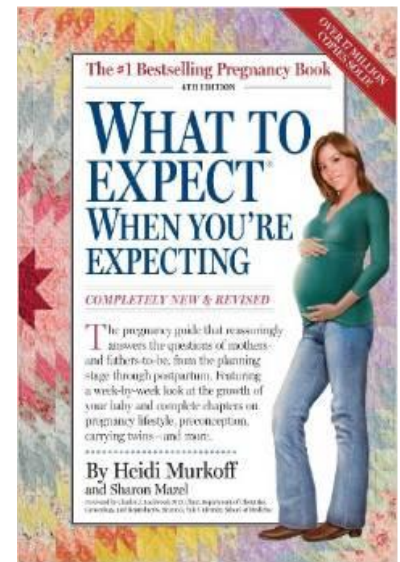
Deepest Gratitude for Life Lessons

- Dr. Randy Curtis
- Kathy



Female
Male
American Indian or Alaska Native
Asian or Pacific Islander
Black or African American
White
100%
90%
80%
70%
60%
50%
40%
30%
20%
10%
0%
Other
Genitourinary
Respiratory
Digestive
External Causes
Circulatory
Congenital
Endocrine
Nervous
Cancer
Mental
Infection
0 years old
10
20
30
40
50
60
70
80
90
>100

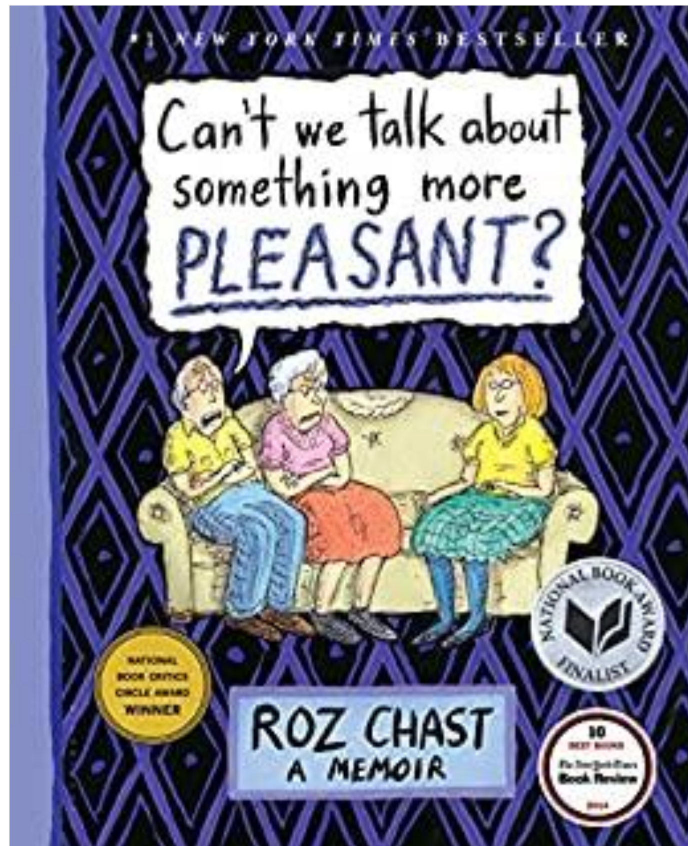
Preparing for Significant Life Events



- We routinely prepare for births, weddings, anniversaries and graduations.
- We do not routinely prepare for living with serious illness or advanced illnesses and frailty.
- Very few of us prepare for death and funerals.
- More than 80% of people believe it is important to have their end-of-life wishes in writing, yet less than a quarter of them have accomplished that planning.

Let’s Discuss…

- Review some definitions – What is Palliative Care, what is Hospice?
- When do I think of What – timing and planning
- Where do I want to be and Who do I want to have with me?
- Why? The greatest gift we can give those we love is the opportunities to discuss what’s important to us when we are ill and to PLAN for that time.



"This is a book that every family should have, the equivalent of Dr. Spock but for this other phase of life."—ABRAHAM VERGHESE, author of *Cutting for Stone*

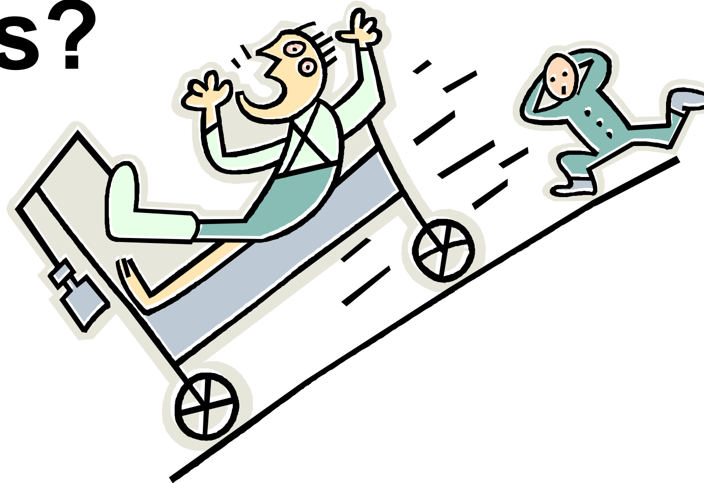
A Beginner's Guide to the End

Practical Advice for Living Life and Facing Death

BJ Miller, MD and Shoshana Berger

We’ve got us a Disease to Smite!”

- Focus on cure
- Luge ride of “care”
- Medical success = ?
  is it defined the same
  as the patient sees
  success?



What are the Core Values of Modern Medicine?

- Multidisciplinary Care, Specialty driven.
- Focused at
  - Diagnosis and Treatment
  - The Eradication of Disease
  - The Prolongation of Life

Biomedical model of care

© Alamy

The Nature of Suffering and the Goals of Medicine - Eric J. Cassell

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. (NEJM 1982)

Founder of the Modern Hospice Movement

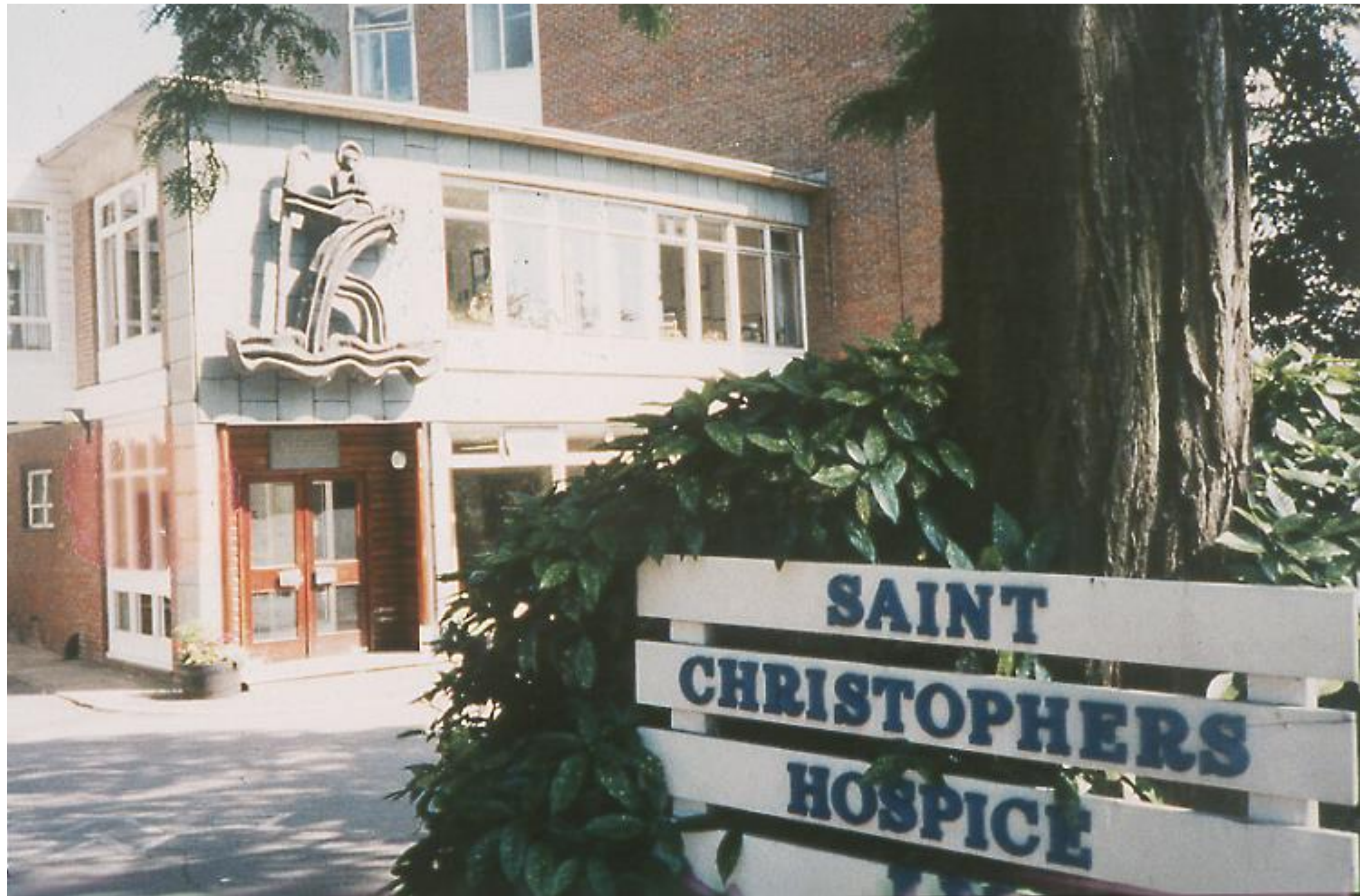
Dame Cicely Saunders

Goals of Hospice Care

- Relief of suffering
- Promotion of quality of life
- Preparation for an expected death
- Patients are no longer receiving disease– directed treatments
- Focus of care on “whole person”- directed treatments with attention to “family” as part of the experience

Hospice Care begins when goals and prognosis shift…

- When the estimated prognosis becomes defined in **months**
- When the goals of care are fully about comfort and symptom management.
- When functional status is changing along with weight loss, cognition, and eating problems (dysphagia)
- When care needs are escalating, and family fears and anxieties increase



St. Christopher's Hospice , established in 1967, was the first research and teaching hospice linked with clinical care, pioneering the field of palliative medicine.

Florence S. Wald
Founder of Hospice in the US

..a small group of thoughtful, committed citizens….

Medicare Hospice Benefit (MHB)

- **Hospice is a philosophy and model of care**
- **Medicare is an Insurance Company**
- **MHB is regulated by the Conditions of Participation (COPs)** 42CFR418.1
  - **Mandates that care is provided by an interdisciplinary team.**
  - **Mandates a percentage of care is provided by trained Hospice Volunteers – 5% of total patient care hours**
- **Hospice Medical Director role in medical oversight, compliance and quality – responsible for re-certifications**
- **Two 90-day periods and now unlimited 60-day periods if the patient remains eligible.**
- **Most commercial insurance mimics the MHB.**

Hospice Eligibility

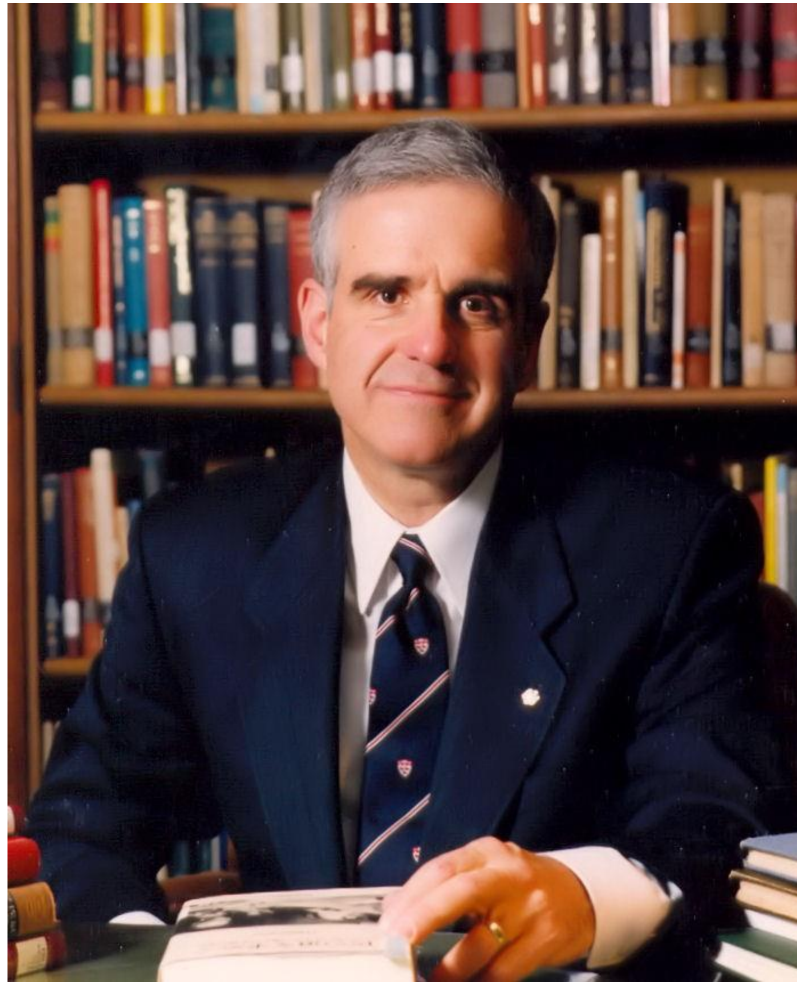
You are eligible to elect the MHB if:

- You are eligible for Medicare Part A (Hospital Insurance); and
- Your doctor and the hospice medical director certify that you are **terminally ill** and probably have less than six months to live; and (“6 months or less **if the disease follows its typical course”)**
- You sign a statement choosing hospice care instead of routine Medicare covered benefits for your terminal illness*; and
- You receive care from a Medicare-approved hospice program.

- * Medicare will still pay for covered benefits for any health problems that are not related to your terminal illness

Why do we wait?

Why is it that we wait until death is imminent or, at the very least, obvious, to talk about quality of life and the goals of care?



Dr. Balfour Mount

The application of whole-person, interdisciplinary care is needed, necessary, and vital far upstream to the end of life.

What is Palliative Care?

- Palliative Medicine = specialized holistic medical care for people with serious illness(es)
- Palliative Care = **interdisciplinary** (team-based), focused on improving quality of life for patients and their families by providing:
    - Expert symptom management
    - Emotional and spiritual support
    - Guidance in navigating the healthcare system
    - Assistance with difficult medical decisions

…What is Palliative Care?

- Any serious diagnosis, particularly those that are progressive and complex
- Any age
- Any stage of illness
- **Integrated into curative or disease-modifying treatment plans and teams**
- Provides a conceptual shift to person-centered care from a disease-focused care model.
    - Team = partnership with treating physicians & clinicians
    - Person specific – not site specific
- **Need driven – not prognosis driven**

Palliative Medicine & Supportive Care

Different from Hospice

- Hospice is a form of palliative care supported by specific insurance benefits that people are eligible to use when they are terminally ill.
- Hospice teams provide palliative care for terminally ill patients with $\leq$6mos to live.
- Hospice patients:
  - ✓Are typically no longer receiving benefit from disease-directed treatments
  - ✓Must sign on to (elect) their hospice benefit
  - ✓Must be ‘certified’ by physicians as being eligible
  - ✓Must allow the hospice team to serve as the care managers.

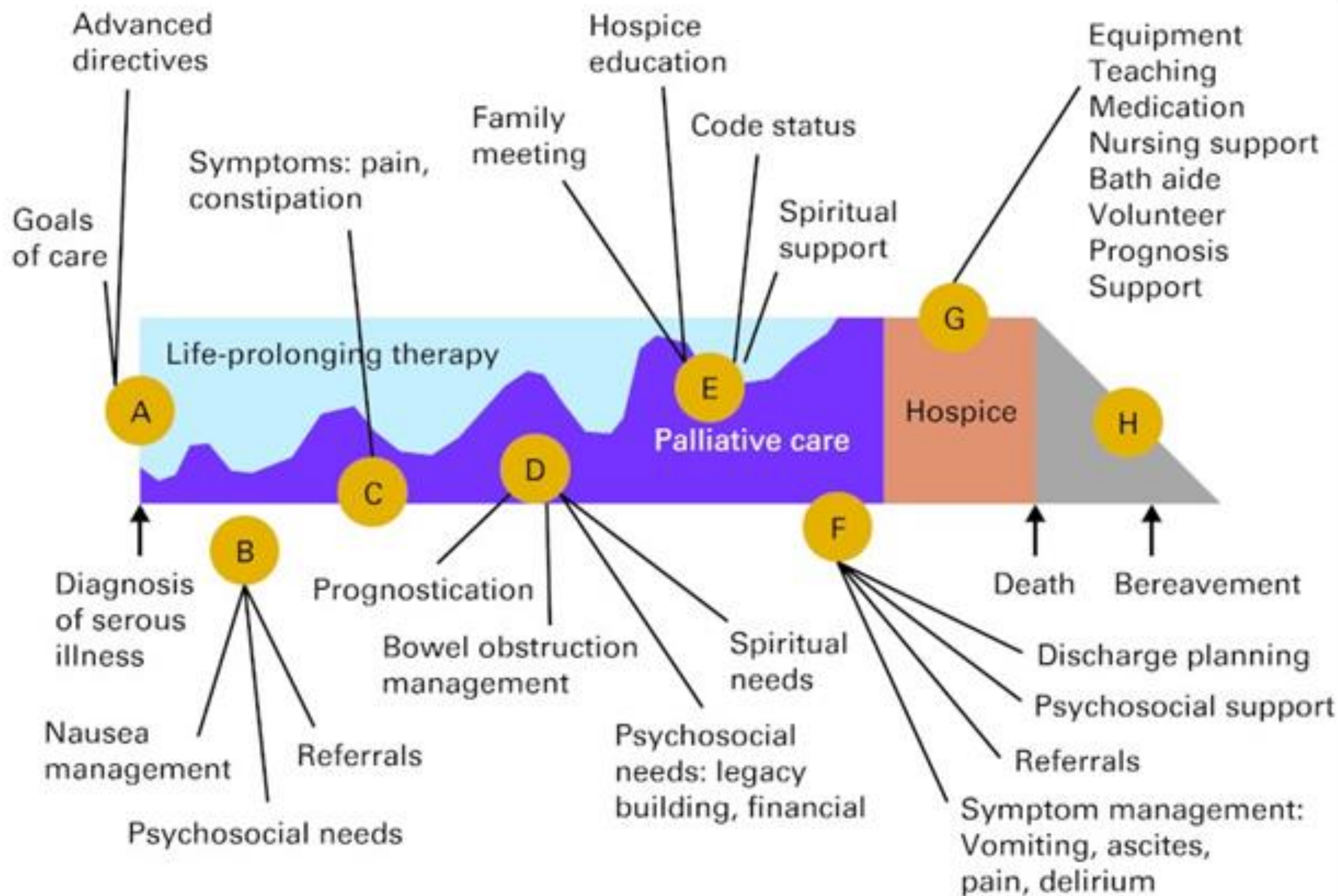
Different from Hospice

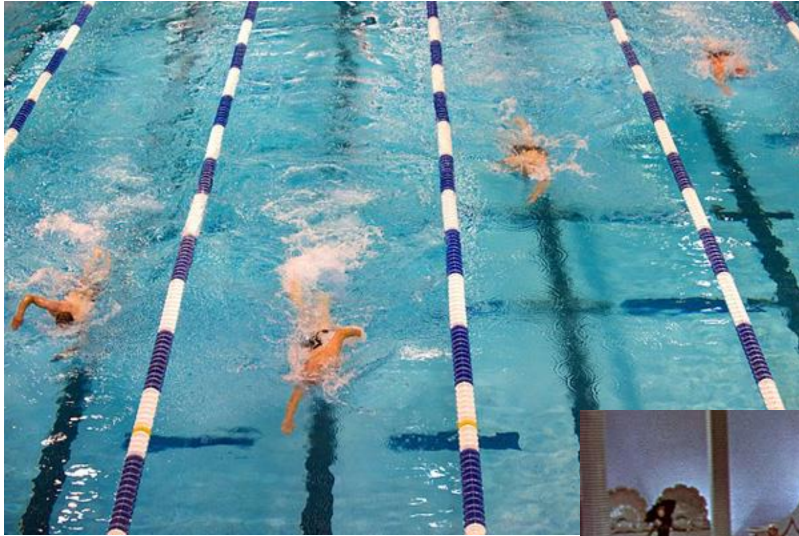
- Hospic... rted by specific... e eligible to use w...
- Hospice... terminally ill patien...
- Hospice...
  - ✓ Are typ... nts
  - ✓ Must si...
  - ✓ Must be...
  - ✓ Must all...

All that is Hospice is Palliative Care

But all that is Palliative Care is not Hospice

Role of Palliative Care





Establishing Advance Directives

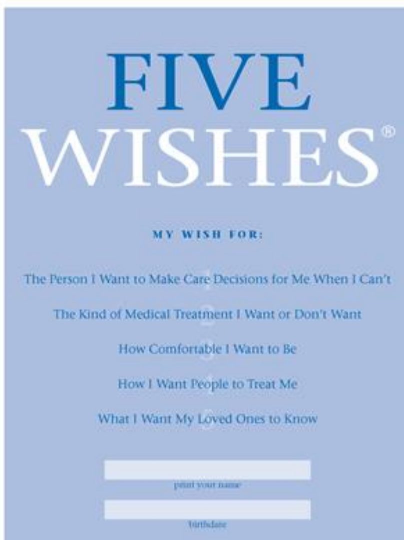
- People have the right to make decisions about their own treatments, and advance directives allow them to do this.
- **ACP allows us to speak to our values and what is most important to us – even when we are too ill to speak.**
- Advance directives can be powerful tools to assist and protect people in making healthcare decisions.

Advance Directives:

- Health Care Power of Attorney/Five Wishes
- Living Will
- POLST

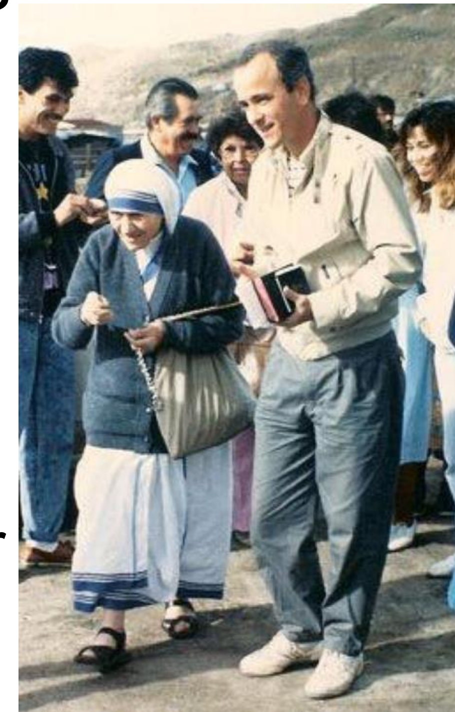
Living Will

- First advance directive developed – a “health care declaration”
  - you write out what you do and do not want in terms of medical care if you are unable to speak for yourself.
- Traditionally it applies only when the patient has terminal condition and can not speak for himself/herself/themselves.
- **Not “actionable”** – gives guidance but cannot direct care except via a professional.
- Ideally MUST be combined with a HCPOA or Surrogate



Five Wishes/IL Healthcare Power of Attorney (HCPOA)

- Essential to identifying a health agent and have them be knowledgeable of your treatment preferences



Five Wishes

- Provides more detail than the HCPOA
- Speaks to what provides you with comfort

Illinois HCPOA form

- Many organizations have developed simpler versions of the form

Our Health Care Agent (POA) Should be:

- **Someone who knows us** – and can advocate for us; would be willing to carry out our wishes, even if he or she may not agree with them.
- Would be comfortable talking with and questioning physicians and other health care providers; and
- Would not be distressed to carry out our wishes, even if we very sick.
- You can designate second and third (and more) successors if your HCPOA is not available.
- At least 18 years old

What Can a Health Care Agent (POA) do?

Our “Agent” or Champion is selected to make all health care decisions if a we are unable to do so. This includes:

- Talking to HealthCare Professionals;
- Giving permission for medical tests;
- Choosing where medical care is received;
- Deciding to accept, withdraw or decline treatments;
- Agreeing or declining to donate organs; and
- Deciding what to do with remains.

Once Form a HCPOA is Completed

- You need to sign the form in front of a witness.
  - The form **does not need to be notarized, does not require a lawyer**.
- A copy should be given to your physicians
  - scanned into the hospital medical record.
- If you go to the hospital or travel out of state, a copy should be taken with you.
- Share copies with family and friends to ensure your wishes are known – **do not put it in the security box!**

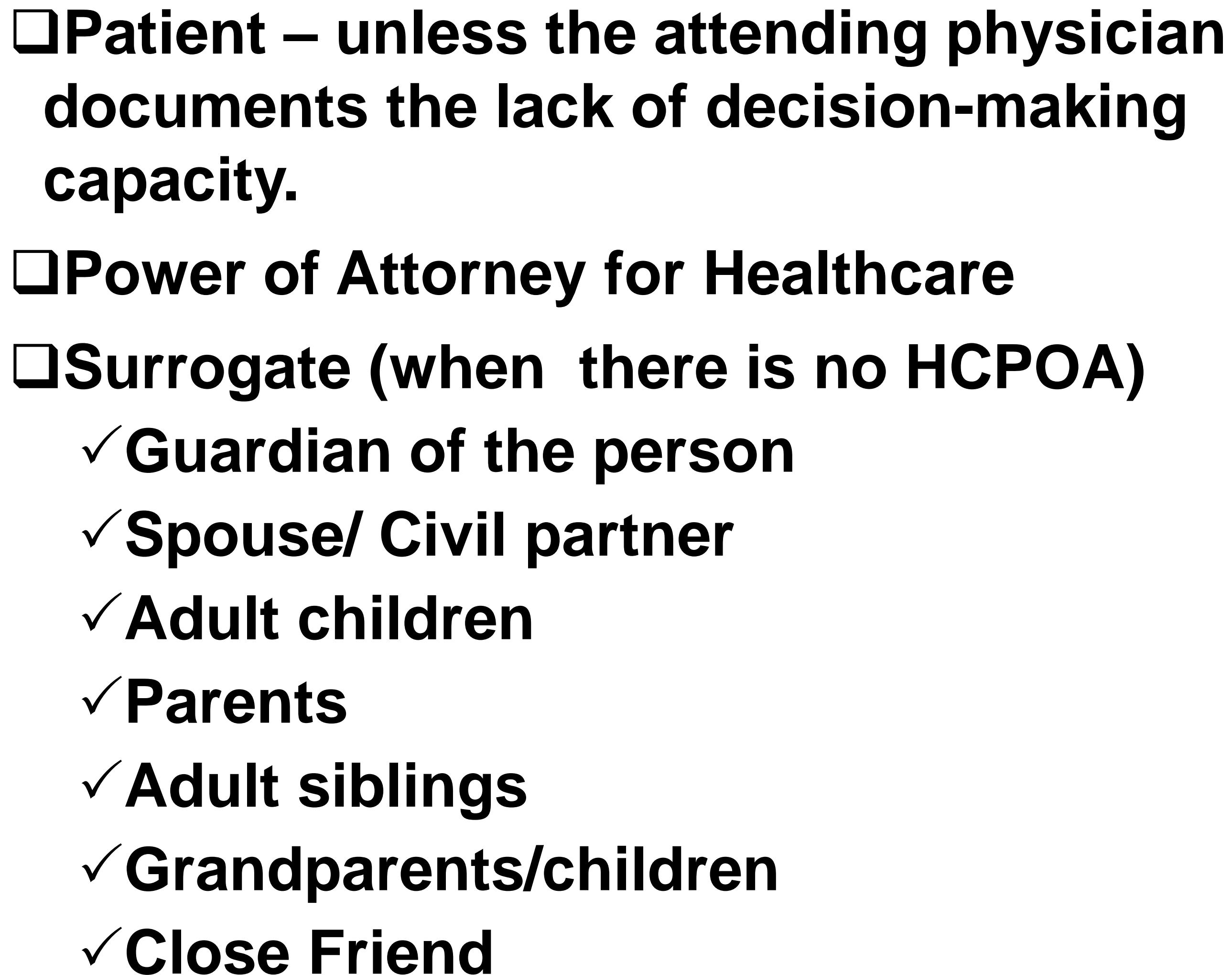
HCPOA Witness

- The witness should be at least 18 years old.
- The witness should be a "disinterested" party – someone who does not stand to gain from the outcome.
- Chaplains, social workers, nurses and other employees of health care facilities can witness the form.

In Illinois, the Witness Cannot be:

- A family member, whether the relationship is by blood, marriage or adoption.
- Physician or mental health provider – or a relative of one of these individuals
- Owner or operator (or the relative) of the health facility where you are a patient or resident

Priority Order of Decision-Maker



Priority Order of Decision-Maker

Start at the top and move down the list

- ❑ **Patient – unless the attending physician documents the lack of decision-making capacity.**
- ❑ **Power of Attorney for Healthcare**
- ❑ **Surrogate (when there is no HCPOA)**
  - ✓ **Guardian of the person**
  - ✓ **Spouse/ Civil partner**
  - ✓ **Adult children**
  - ✓ **Parents**
  - ✓ **Adult siblings**
  - ✓ **Grandparents/children**
  - ✓ **Close Friend**

POLST

- In Illinois - POLST stands for **P**ractitioner **O**rders for **L**ife-**S**ustaining **T**reatment.
- Without a POLST form, emergency medical personnel are <u>required</u> to give all possible treatments – whether a person wants them or not.
- Intended for seriously ill or frail people (expected to die within the next 12 months)
- A POLST form is voluntary!

The POLST Document

3 Medical Order Sections

- CPR for Full Arrest
  - Yes, Attempt CPR
  - No, Do Not Attempt CPR (DNR or DNAR)
- Orders for Pre-Arrest Emergency
  - Full Treatment
  - Limited Treatment
  - Comfort Only
- Artificial Nutrition
  - None
  - Trial period Acceptable

Benefits of ACP

Promoting Patient-Centered Care

- Promotes **quality care** through informed conversations and shared decision-making
  - Allows someone to document what medical treatments they want, or do not want and what provides them with comfort of not.
- **Reduces medical errors** by improving guidance during life-threatening emergencies
- The POLST gives concrete Medical Orders that must be followed by healthcare providers (particularly paramedics)
- Easily recognized standardized forms
- **Follows us across care settings**

How Advance Care Planning Evolves Over Time

Complete a **Healthcare Power of Attorney and a Five Wishes document**. Think about wishes if faced with severe trauma and/or neurological injury.

Consider if, or how, your decisions **of care** would change if medical issues resulted in bad outcomes or severe complications.

End-of Life planning: establish a specific plan of care using **POLST** to guide emergency medical orders based on goals

Healthy and Independent (18 years +)

Advance chronic illnesses and functional decline

Serious illness and frailty

Document on Healthcare Power of Attorney Form or Five Wishes

Document on POLST Form

Don't ask 'what's the matter with me'…
Ask what matters to me…

Associations between end-of-life discussions, patient mental health, medical care near death, and caregiver bereavement adjustment.

Wright AA et al. JAMA. 2008;300:1665-1673.

JAMA

Results: Patients

- 123 of 332 (37%) had EOL discussions
- EOL discussions NOT associated with:
  - Worse patient emotional state
  - Meeting criteria for a mental disorder
- EOL discussions are associated with:
  - Accepting illness as terminal (53 vs 29%)
  - Preferring symptom control over life prolongation (85 vs 70%)
  - Having a DNR (63 vs 29%)

Results: Caregivers

- Caregivers of patients receiving aggressive care
  - Had higher risk of depression
  - Experienced more regret
  - Felt unprepared for the patient's death
  - Had worse QOL and self reported health

What does this mean to me?

- EOL discussions are associated with less aggressive medical care and improved perceived QOL near death
- They also improve the bereavement outcomes for caregivers
- They are NOT associated with worse psychological outcomes for patients or caregivers

I just want this to be over….

- What symptoms are so distressing as to prompt one to ask for death?
  - Can the symptom be remediated?
  - "If we could change one thing…"
  - Grief – allowing the voice to be heard
- Control of symptoms – matching the intervention to the symptom with careful titration, including sedation when necessary.
- What medical interventions literally tether people to life?

Physician Aid in Dying

- Definition: the practice of providing a competent patient with a prescription for medication for the patient to use with the primary intention of ending his or her own life.

Euthanasia vs. Physician Assisted Death

- Active Euthanasia – actively facilitating the death – not legal in the US
- Physician Assisted Suicide or PAD – the physician provides the means but does not participate in the action
  - Legal in: CA, CO, OR, VT, WA, and DC
  - Sort of, in Montana

Euthanasia

- Definition: the act or practice of killing or permitting the death of hopelessly sick or injured individuals (as persons or domestic animals) in a relatively painless way for reasons of mercy
- Means “an easy death”
- Active vs. Passive euthanasia
- Active euthanasia is legal in Belgium, Luxembourg, Netherlands
- **Passive euthanasia** is ethically acceptable most everywhere – allowing death to occur by withholding or withdrawing interventions that would prolong life

State	Date Passed	How Passed (Yes Vote)	Residency Required?	Minimum Age	# of Months Until Expected Death	# of Requests to Physician
1. California	Sep. 11, 2015	ABX2-15 *End of Life Option Act*	Yes	18	Six or less	Two oral (at least 15 days apart) and one written
2. Colorado	Nov. 8, 2016	Proposition 106, *End of Life Options Act* (65%)	Yes	18	Six or less	Two oral (at least 15 days apart) and one written
3. DC	Oct. 5, 2016	B21-0038 *Death with Dignity Act of 2016* (3-2)	Yes	18	Six or less	Two oral (at least 15 days apart) and one written
4. Montana	Dec. 31, 2009	Montana Supreme Court in *Baxter v. Montana* (5-4)	Yes	*	*	*
5. Oregon	Nov. 8, 1994	Ballot Measure 16 (51%)	Yes	18	Six or less	Two oral (at least 15 days apart) and one written
6. Vermont	May 20, 2013	Act 39 (Bill S.77 "End of Life Choices")	Yes	18	Six or less	Two oral (at least 15 days apart) and one written
7. Washington	Nov. 4, 2008	Initiative 1000 (58%)	Yes	18	Six or less	Two oral (at least 15 days apart) and one written

Communication provides peace of mind to everyone!

“Don’t ask what’s the matter with me; ask what matters to me!”

“Ultimately, good medicine is about doing right for the patient. For patients with multiple conditions, severe disability, or limited life expectancy, any accounting of how well we’re succeeding in providing care **must above all consider patients’ preferred outcomes**.”

Reuben and Tinetti NEJM 2012;366:777-9.

Objectives & Summary

Palliative Care vs Hospice – definitions. Palliative Care ideally integrates at the time of a diagnosis and Hospice is for the final months of life

Advance Care Planning –

Each of us **must** establish a HCPOA

Most of us should complete a 5Wishes or have these discussions with our POAs

Many of us should establish a POLST

All of us need to be able to name our fears and our needs, including to openly discuss the end of life – having a trusting relationship with HCP is vitally important.

And we need a team of people to help us – again where Palliative Care integration can make an enormous difference.

Live Well, Land Softly
Supportive Care

Northwestern Medicine®