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Channeling Our Inner Scout:

Hope for the Best and Prepare for the Rest

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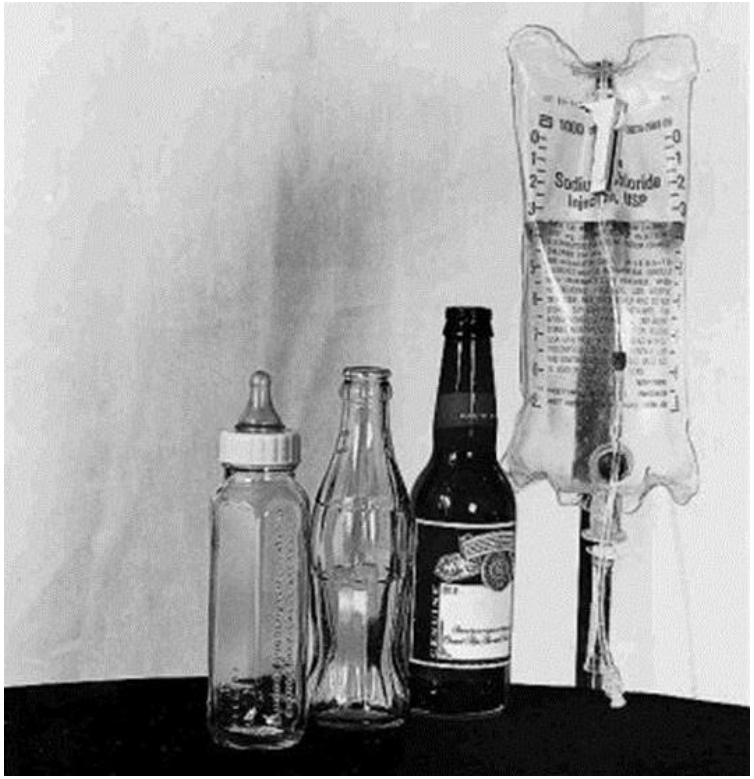
Four Stages of Life



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Let's Discuss…

- Review some definitions – What is
  - Healthcare?
  - Preventative Care?
  - Palliative Care?
  - Hospice Care?
- When do I think about What – timing and planning?
- How do I prepare for the "Act 3" phase of life?
- How do I create and nurture a network of support to live well and age well in my preferred setting?

What is Healthcare?

Healthcare is the system and services for **maintaining or improving physical and mental well-being** through **prevention**, **diagnosis, treatment, and management** of illness, injury, and other conditions, delivered by professionals such as doctors, nurses, and therapists in settings from home and clinics to hospitals, covering everything from wellness checks to emergency care. It encompasses a broad spectrum of activities, including **preventive care**, mental health support, rehabilitation, and chronic disease management, **aiming to restore health or prevent deterioration**.

What are the Core Values of Modern Medicine and Healthcare?

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

Biomedical model of care

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What is Palliative Care?

A form of Healthcare….

- Palliative care is an **interdisciplinary** care delivery system, beneficial at any stage of a **serious illness**, designed to **anticipate**, **prevent, and manage physical, psychological, social, and spiritual suffering** to optimize quality of life for patients, their families and caregivers. Palliative care can be delivered in any care setting through the **collaboration** of many types of care providers. Through early integration into the care plan of seriously ill people, palliative care improves quality of life for both the patient and the family.

Serious Illness

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, AS, Bollens-Lund, E. Identifying the population with serious illness: the "denominator" challenge. Journal of Palliative Medicine. Volume: 21 Issue S2: March 1, 2018.

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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 illness, particularly those that are progressive and complex, associated with functional impairments
- 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

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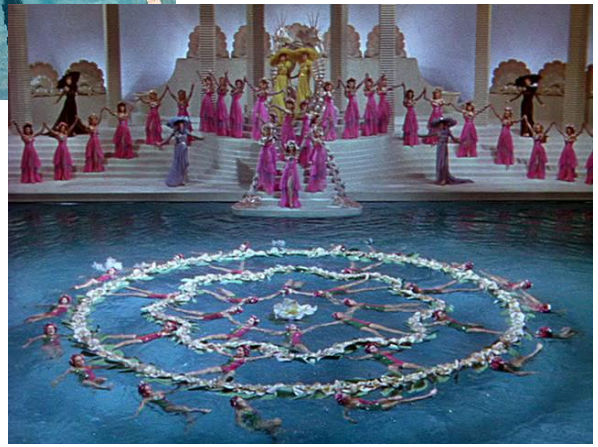

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Early Palliative Care for Patients with Metastatic Non-Small Cell Lung Cancer

The NEW ENGLAND JOURNAL of MEDICINE

The Results

- Early ambulatory palliative care, in conjunction with life-sustaining treatments, for patients with metastatic NSCLC is associated with:
  - Improved mood
  - Improved QOL
  - More documentation of code status
  - Less aggressive EOL care
  - **Improved survival**

Research shows:

- The early integration of palliative care into the care delivery of serious ill people improves
  - Symptom Burden
  - Quality of Life
  - Caregiver stress
  - Completion of ACP
  - Survival

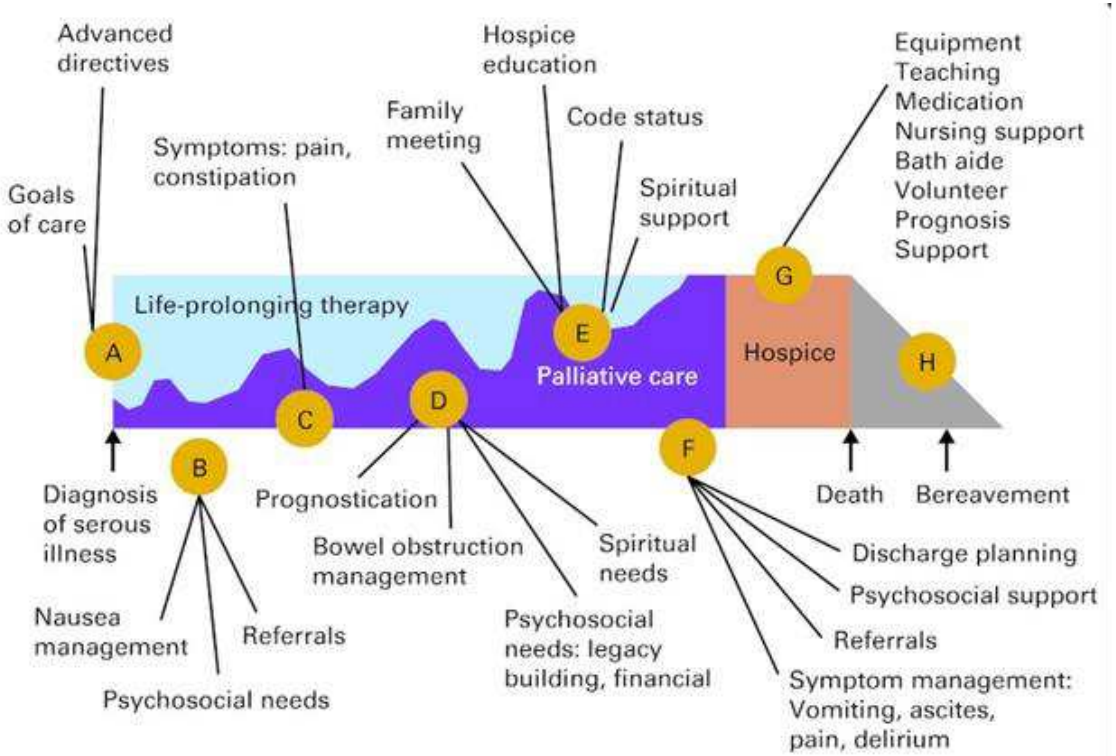
  - All while bending the cost curve…

Who Benefits?

Advanced serious illness with functional impairments…

- Cancer
- Heart Failure
- Pulmonary – Interstitial Lung Disease, COPD
- Neurologic – Parkinson's, MSA, ALS, endstage MS, Dementias and subtypes
- Kidney failure
- Frailty

Role of Palliative Care



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

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What do I need to know about you so that I can take the best possible care of you?

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Hospice is specialized palliative care

- 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 ≤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.

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Different from Hospice

- Hospice
- Hospice
- Hospice
  - ✓ Are typ
  - ✓ Must si
  - ✓ Must be
  - ✓ Must all

All that is Hospice is Palliative Care

But all that is Palliative Care is not Hospice

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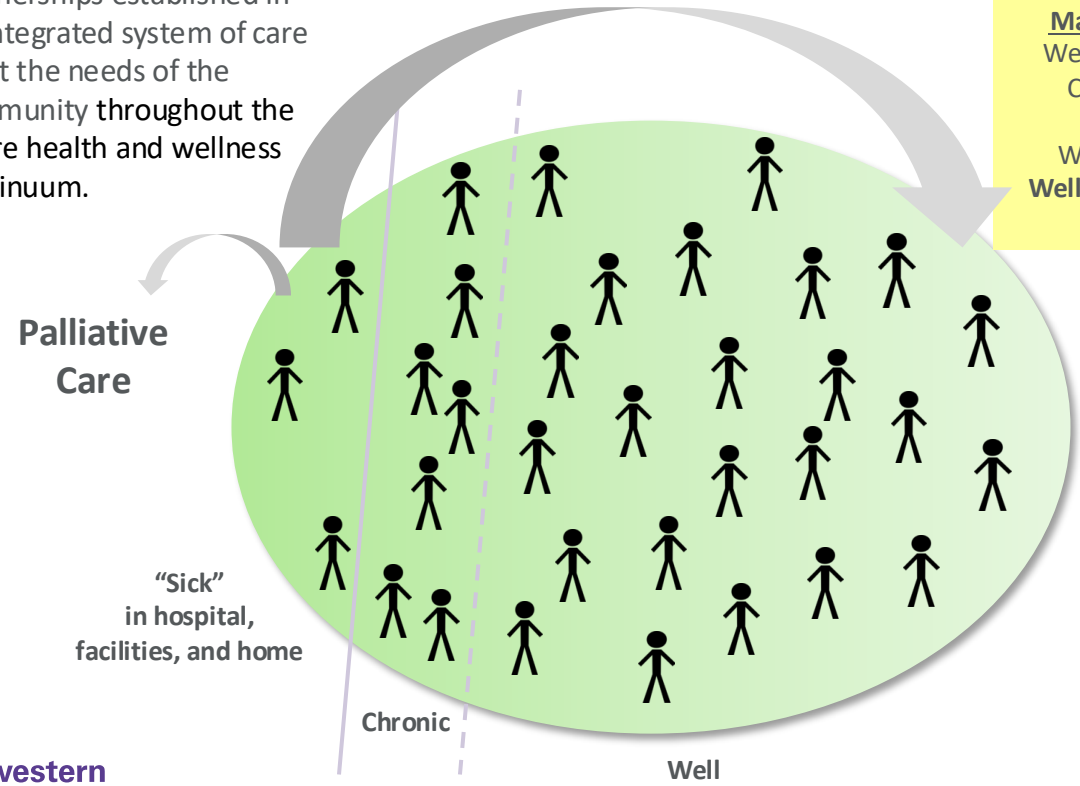
Palliative Care supports Population Based Health

The services and partnerships established in an integrated system of care meet the needs of the community throughout the entire health and wellness continuum.



Manage Populations
Well = keep them well
Chronic = manage conditions
Well → Sick → Well
Well → Sick → Palliative Care

Wellness Services:
- Wellness Center
- Diet and Nutrition Coaching
- Mammography
- Colonoscopy
- Psychiatry / Psychology
- Women's Center
- Senior Center

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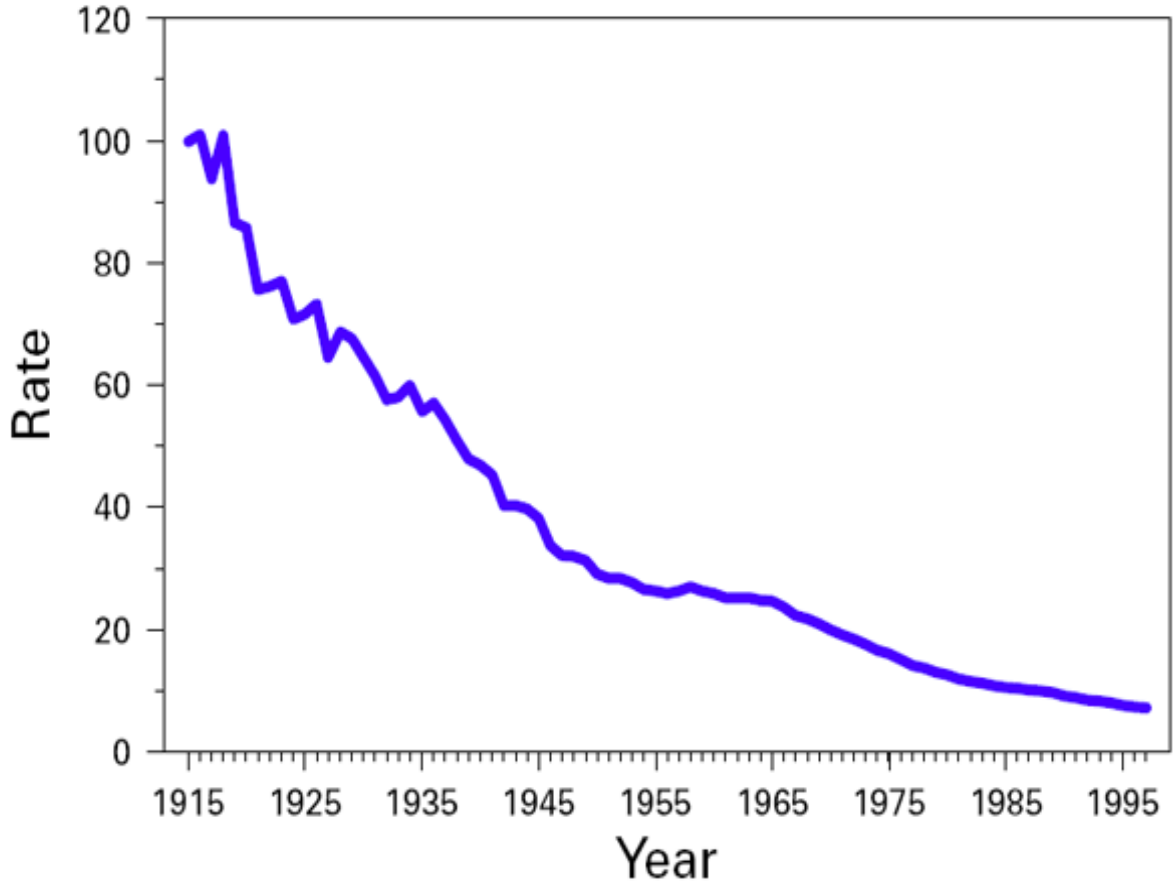
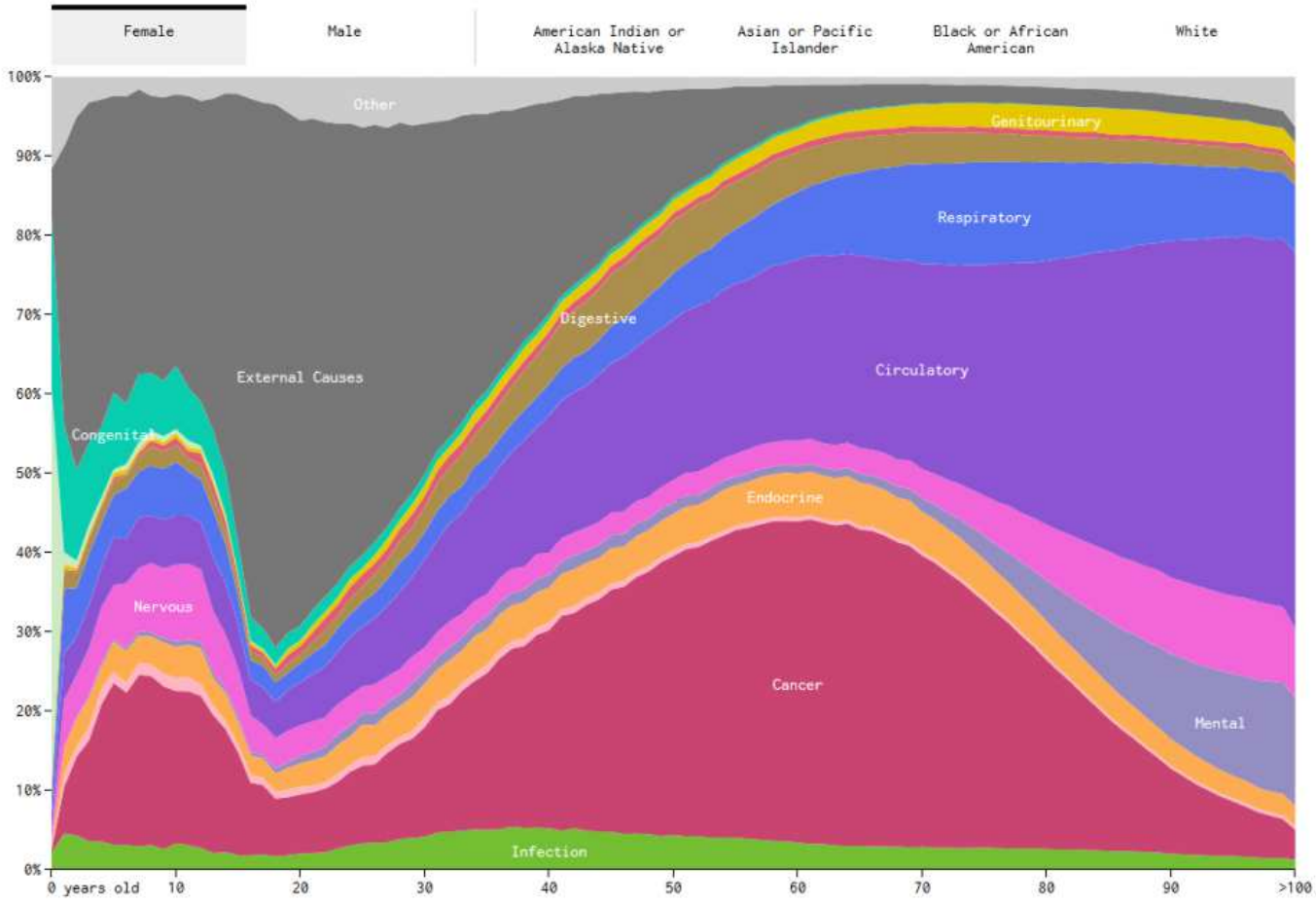
Buxton; Twaddle 2014

FIGURE 1. Infant mortality rate,* by year — United States, 1915–1997



*Per 1000 live births.



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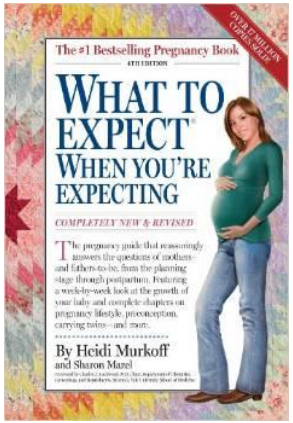
Preparing for Significant Life Events



- 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.
- **In the US, we overly rely on emergency services to meet chronic needs**

How do I prepare for the “Act 3” phase of life?

- Invest in healthy habits now
- Nutrition, sleep, exercise – the importance never changes
  - Flexibility and balance
- Nurture and sustain your spirit
- Recreation – what is fun, what does play look like for you?

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

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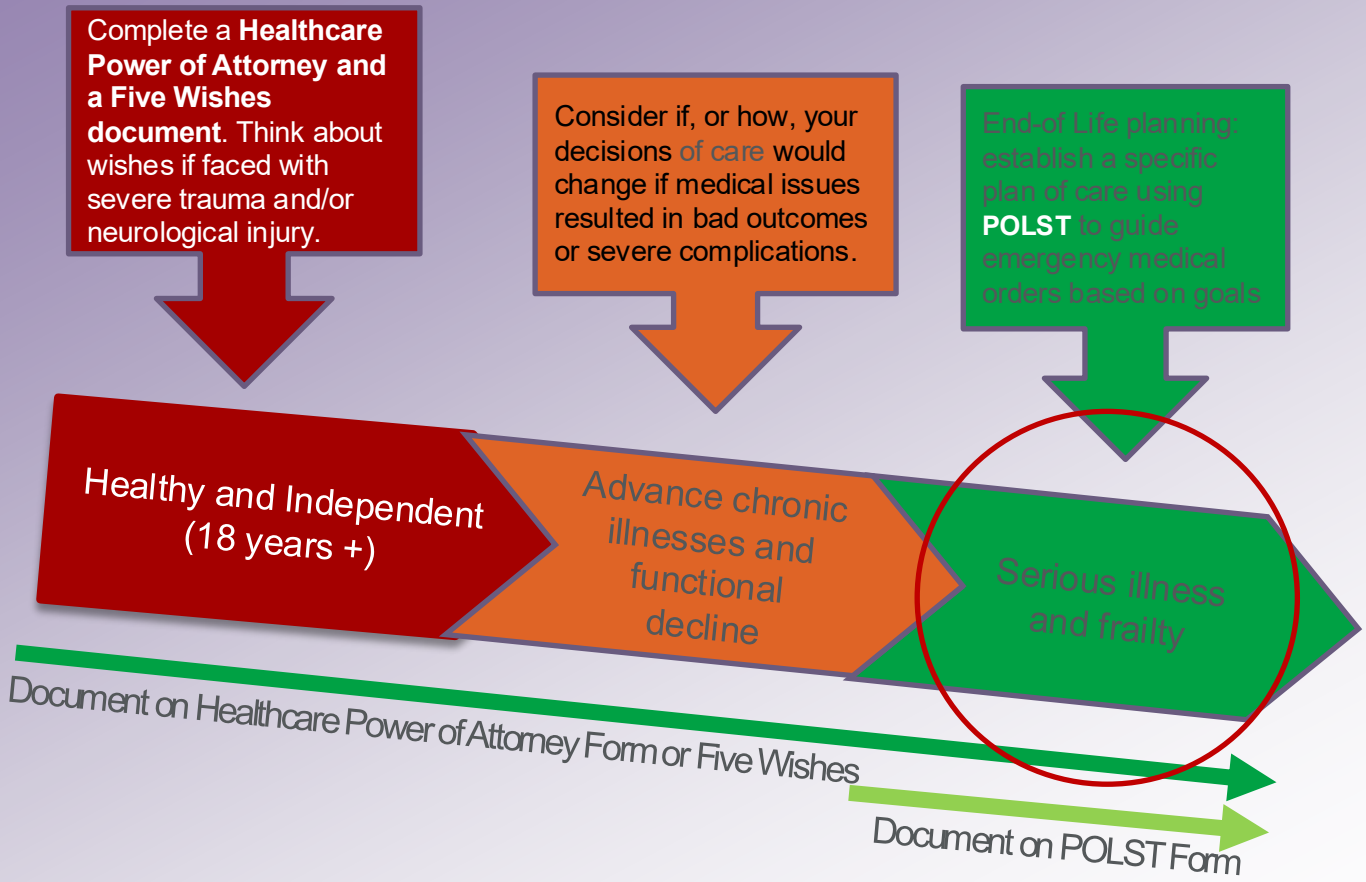
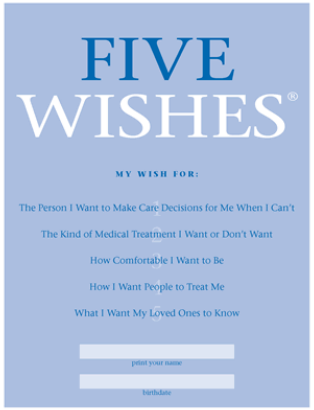
How Advance Care Planning Evolves Over Time





Five Wishes/IL Healthcare Power of Attorney (HCPOA)

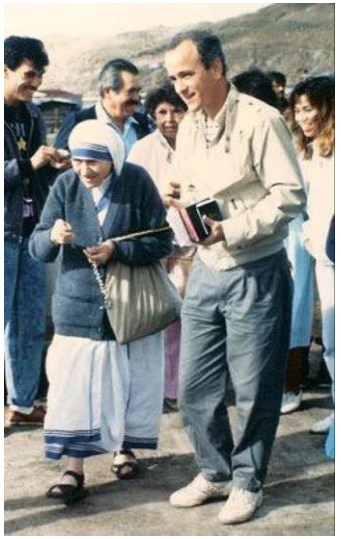
Essential to identifying a health agent and have them be knowledgeable of your treatment preferences

Five Wishes

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

Illinois HCPOA form

- Many organizations have developed simpler versions of the form



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Can You and Your Loved Ones Answer These 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?

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The One Slide Project

Living Will

- First advance directive developed – a “healthcare 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”** – meaning it gives guidance but cannot direct care except via a professional.
- Ideally MUST be combined with a HCPOA or Surrogate and further with a POLST

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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 **required** to give all possible treatments – whether a person wants them or not - even if there is a Living Will and the HCPOA is present!
- Intended for seriously ill or frail people (high risk of dying in a year or less) but also used by others with strong preferences
- 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

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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**

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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

Vital to Health: Connection and Community

- A community is a group of people who share a common characteristic, location, identity, or interest, creating a sense of belonging and connection, often involving shared values, norms, culture, and mutual support, whether in a physical place like a town or virtually online, forming social units like neighborhoods, professions, or fandoms.
- **Social networks are vital to our health** – loneliness has been shown to increase our mortality risk.
- Perceived and received support – interestingly, **perceived support** has the greatest impact – help is there when needed.

Communication provides peace of mind to everyone!

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

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"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.

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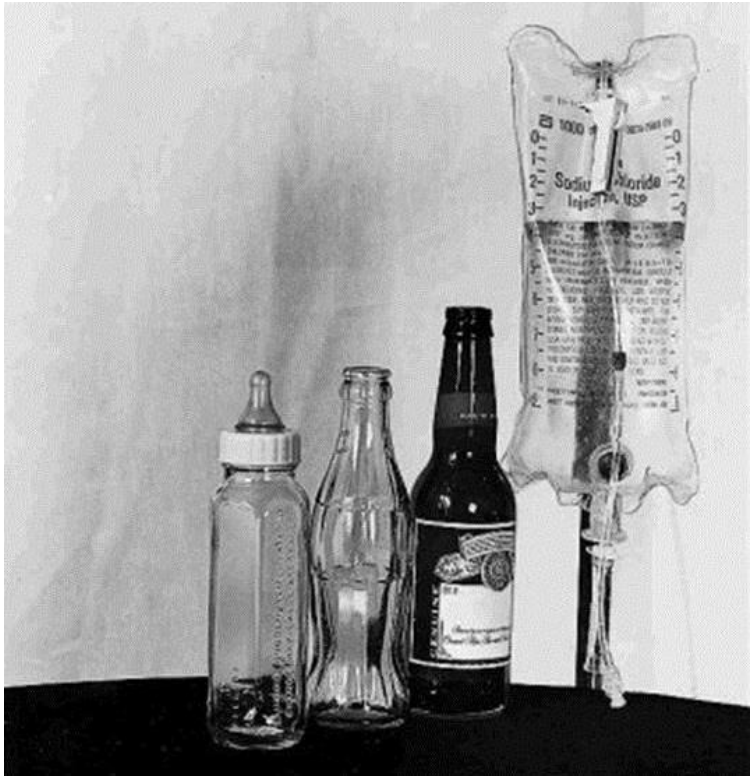
The Nature of Suffering and the Goals of Medicine - Eric J. Cassell

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)

Four Stages of Life



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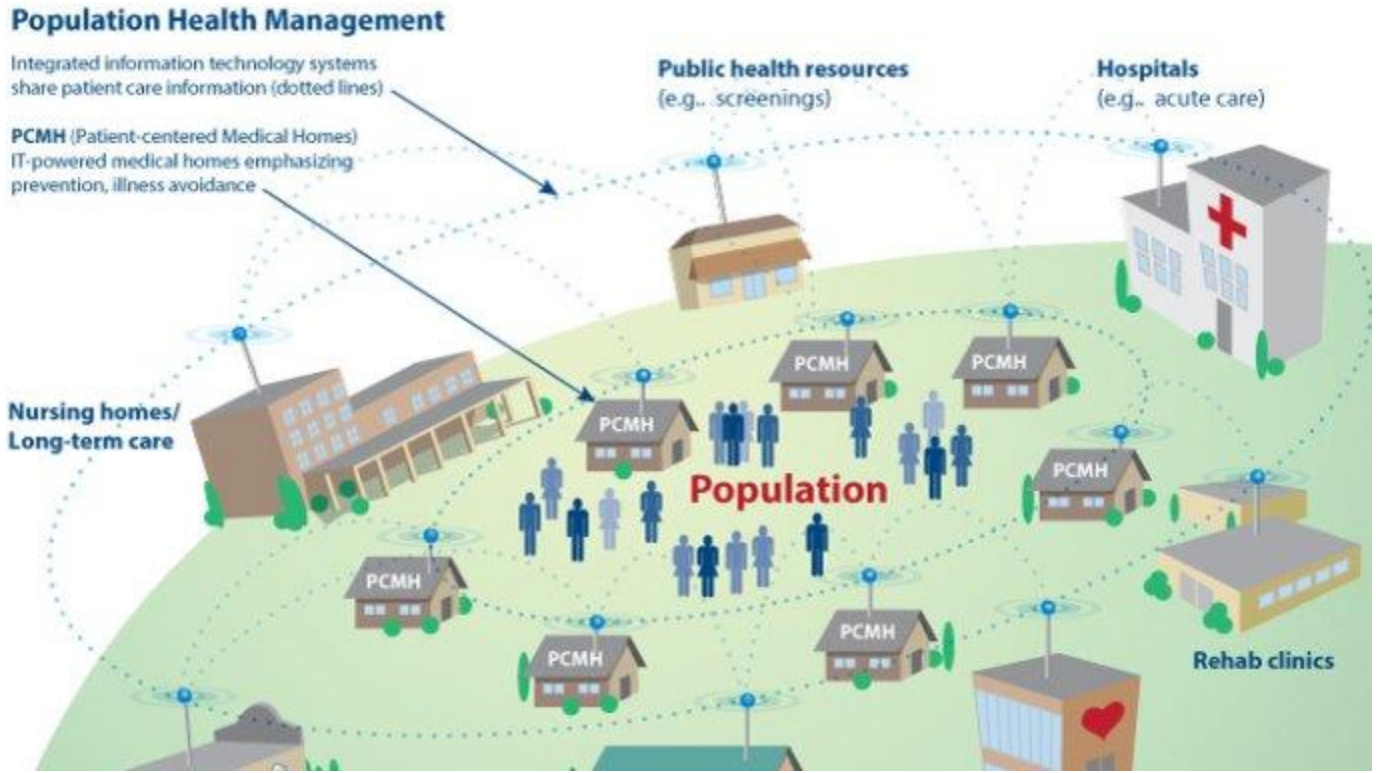

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Miguel McInnis, MPH

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
  - We need a team of people to help us – again where Palliative Care integration can make an enormous difference.
- Investing in our health is ongoing – what can I do today, what choices can I make that will help me even later
- Advance Care Planning is important
  - Each of us **must** establish a HCPOA
  - Each of us need to be able to name our fears and our needs, including to openly discuss the end of life
  - Many of us should establish a POLST
- Nurture and sustain community connections – NSSC is Vitally important to our health and wellbeing

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