



# Life and Death in America: How to be Smart Health Care Consumer

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“The truth will set you free  
but first it will piss you off”

- Gloria Steinem



# How We Live in America



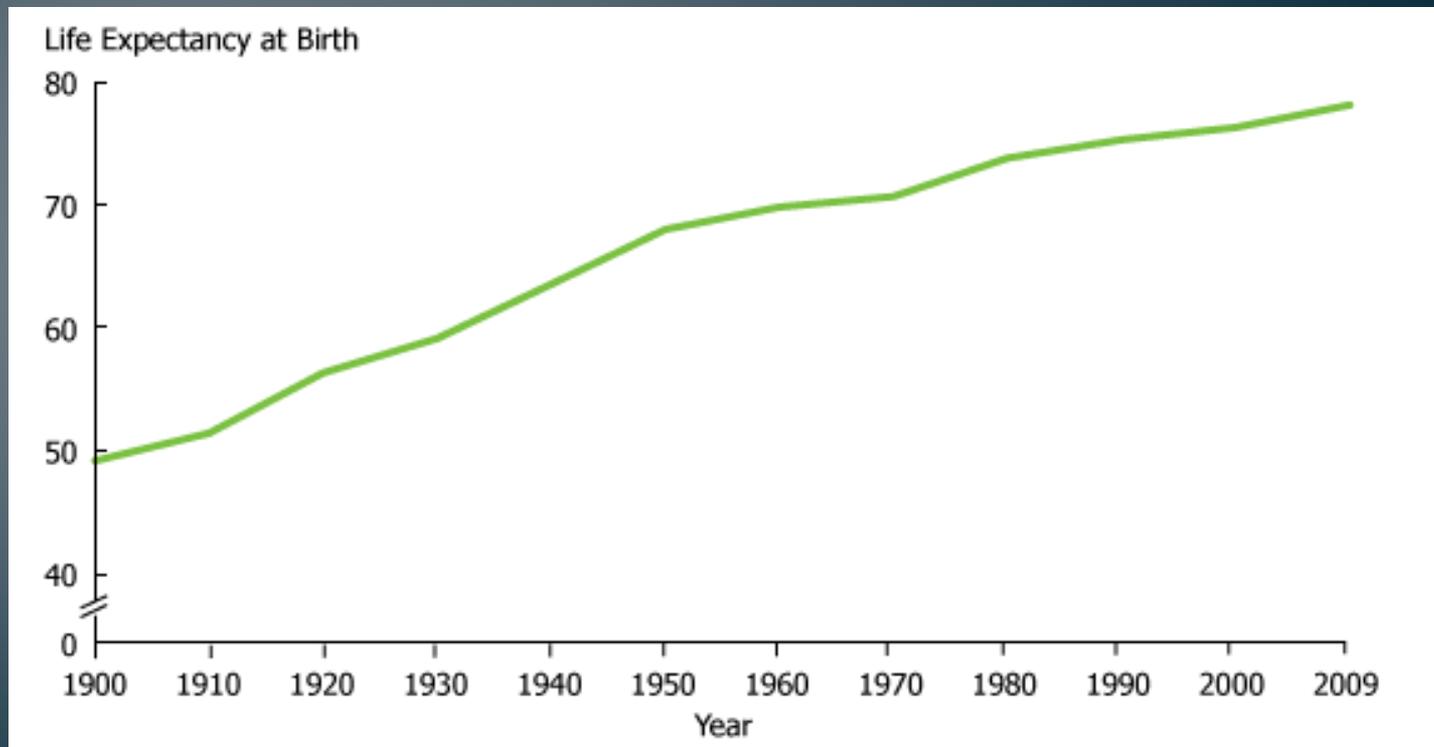
# How We Live in America





# Living in America: Living Longer

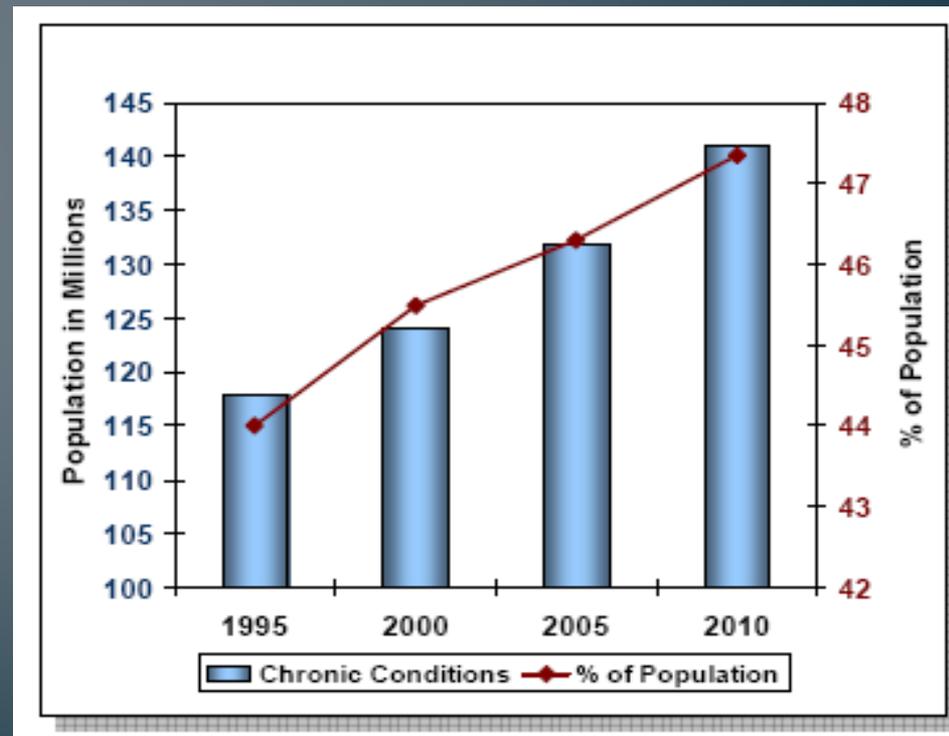
- Life expectancy is up dramatically in the past 100 years





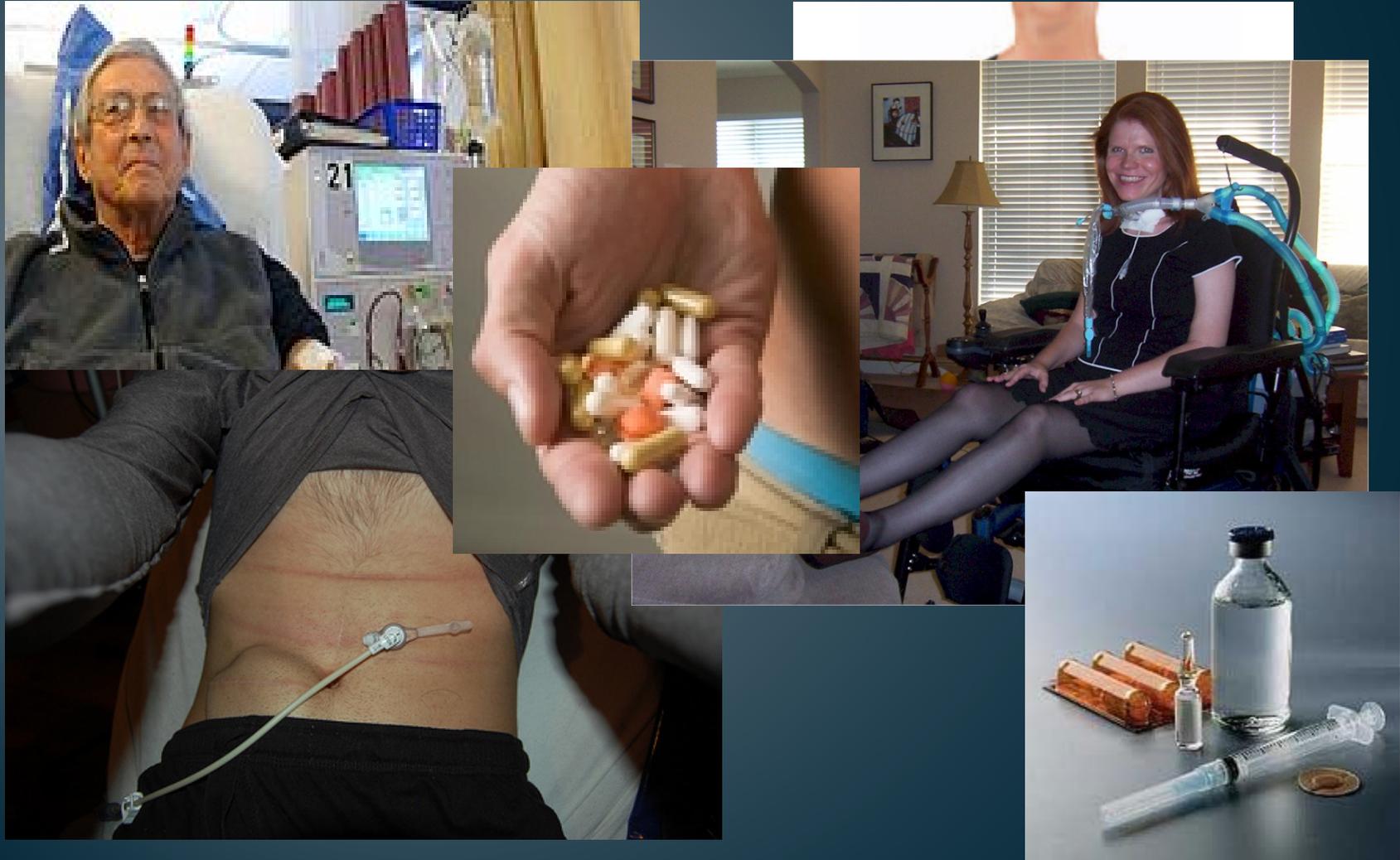
# Living in America: Living with Disease

- Not only are we living longer, the number of people living with chronic diseases are going up.





# Living in America: Living with Disease





# Living in America: Living Better?

- Baby boomer generation compared to past generations (corrected for age)
  - Higher rates of chronic disease (45% vs 37%)
  - Higher rated of disability (13% vs 9%)
  - Lower self-reported health

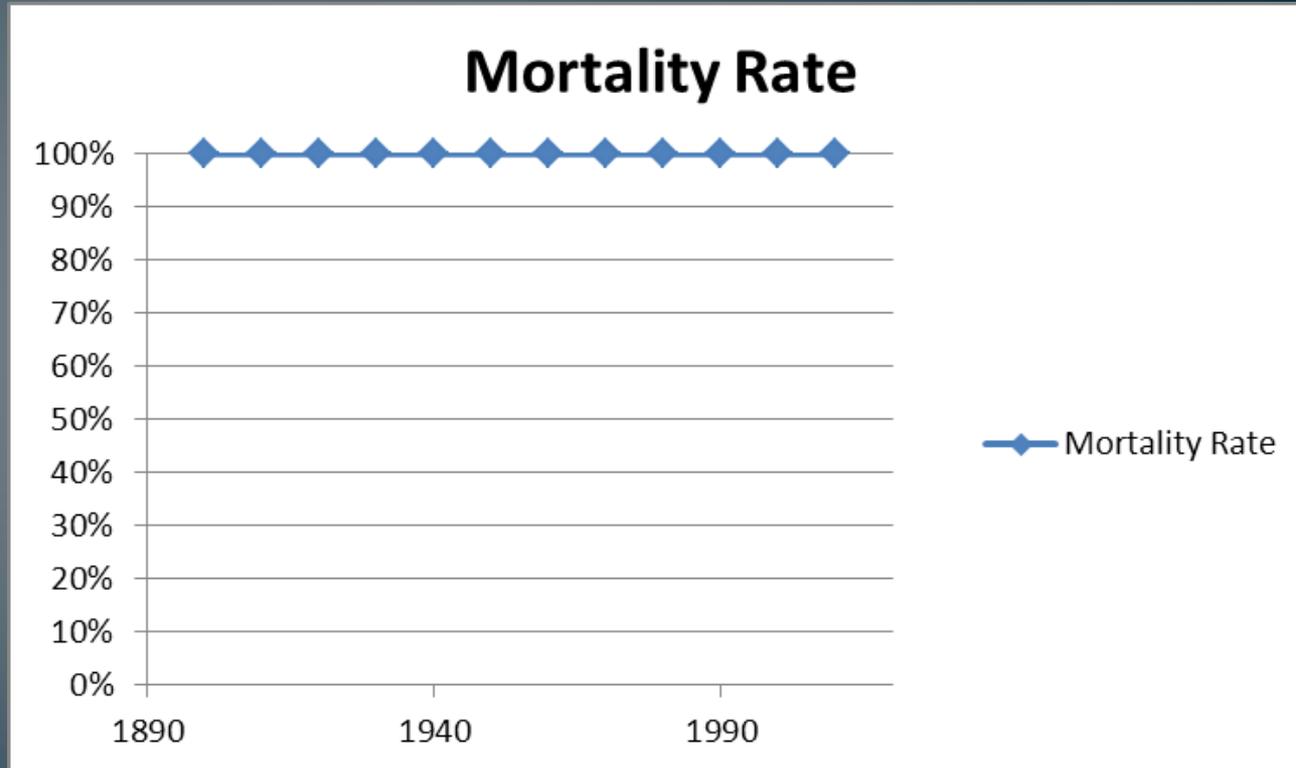


# Living In America: Conclusion

- Living Longer
- Living *with* disease rather than *free of* disease
- Living with more disability

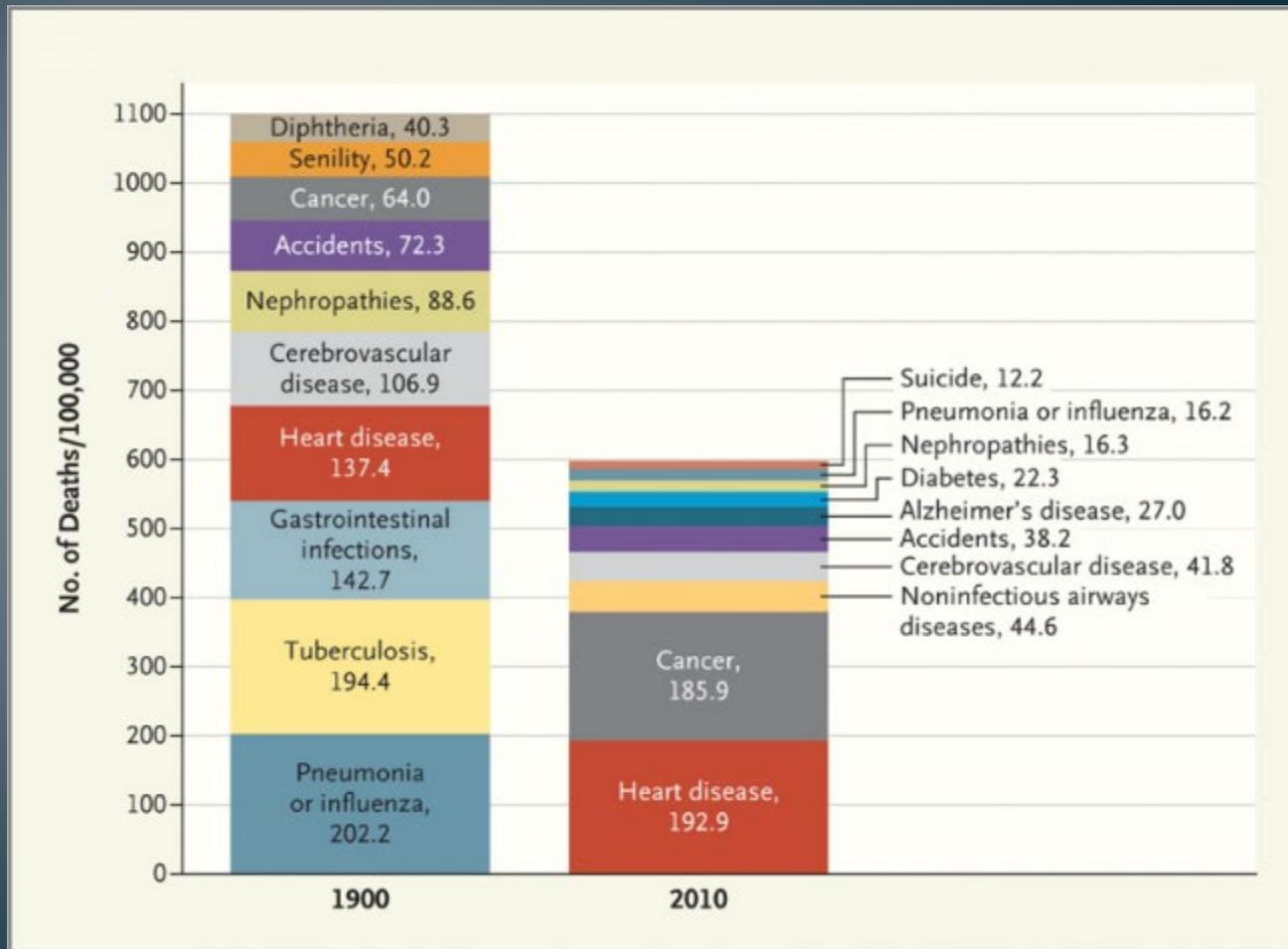


# Basic Mortality statistics

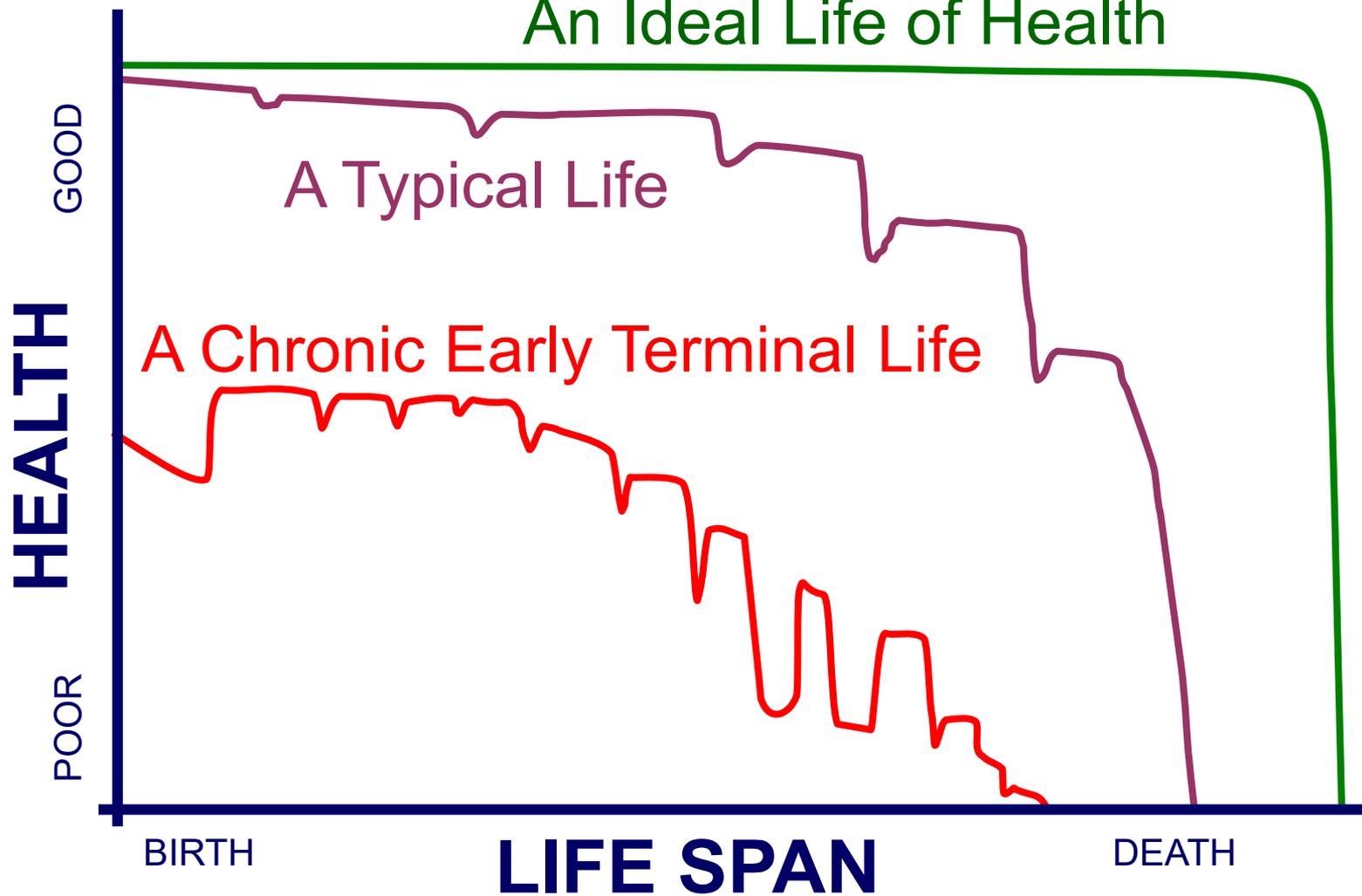




# How We Die In America: A Comparison



# An Ideal Life of Health





# What Do Patients with Serious Illness Want?

- Pain and symptom control
- Achieve a sense of control
- Relieve burdens on family
- Strengthen relationships with loved ones
- Avoid inappropriate prolongation of the dying process

Singer et al. *JAMA* 1999;281(2):163-168.

What Do Patients with Serious Illness Want?



To live as well as one can, for as  
long as one can



# What Does it Mean to Live Well?

- To remain functional and maximize independence
- To be free from distressing symptoms
- To continue meaningful relationships with our loved ones
- To stay in our place of residence and out of the hospital



# How we Want to Die in America

- At Home
- In Comfort and Dignity
- Being Mentally Aware
- Not a Burden
- With an Overall De-escalation of Medical Care
- In a state of Transcendence

# How We Really Approach our End of Life



- Majority of older adults express a preference for overall de-escalation of care at the end-of-life
  - Despite this, in Medicare patients, more than 25% of health care expenditures occur in the last year of life
    - Of that 25%, 80% occurs in the last month
  - 20% of deaths in the US occur in the ICU; of these, the majority of >65
- Having an advance directive or a documented conversation about goals of care decreases the likelihood of dying in a hospital and improves concordance between treatment preferences and the treatment received.

# Where we Die



# Is More Care Better Care?



# Does Higher Spending Improve Outcomes?

## *More is Less and Less is More*



Higher spending does not lead to better outcomes.

Medicare claims data for 4.7 million beneficiaries and 4,300 hospitals:

- Dramatic geographic differences in health care costs
- Regions of highest utilization (most specialist visits, hospital days, ICU use), have highest mortality after (partial) risk adjustment.

JAMA 2006; 296:159-160.

[www.dartmouthatlas.com/atlas/2006\\_chronic\\_care\\_atlas.pdf](http://www.dartmouthatlas.com/atlas/2006_chronic_care_atlas.pdf)

ES Fisher et al Health Affairs 2004; suppl web exclusive: VAR 19-32.

ES Fisher et al. Annals Intern Med 2003; 138:288-98.

# Less Medical Care and the Impact on Survival



## 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.



# Less is More: Impact on Survival

- 151 patients with a new diagnosis of stage IV, metastatic lung cancer
  - Has an average life-expectancy of 9-12 months
- At the time of diagnosis, the patient was either randomized to receive counseling about goal of care integrated into standard cancer care (which can include chemotherapy or radiation) or standard cancer care alone

Temel et al NEJM 2012 (13); 145-152



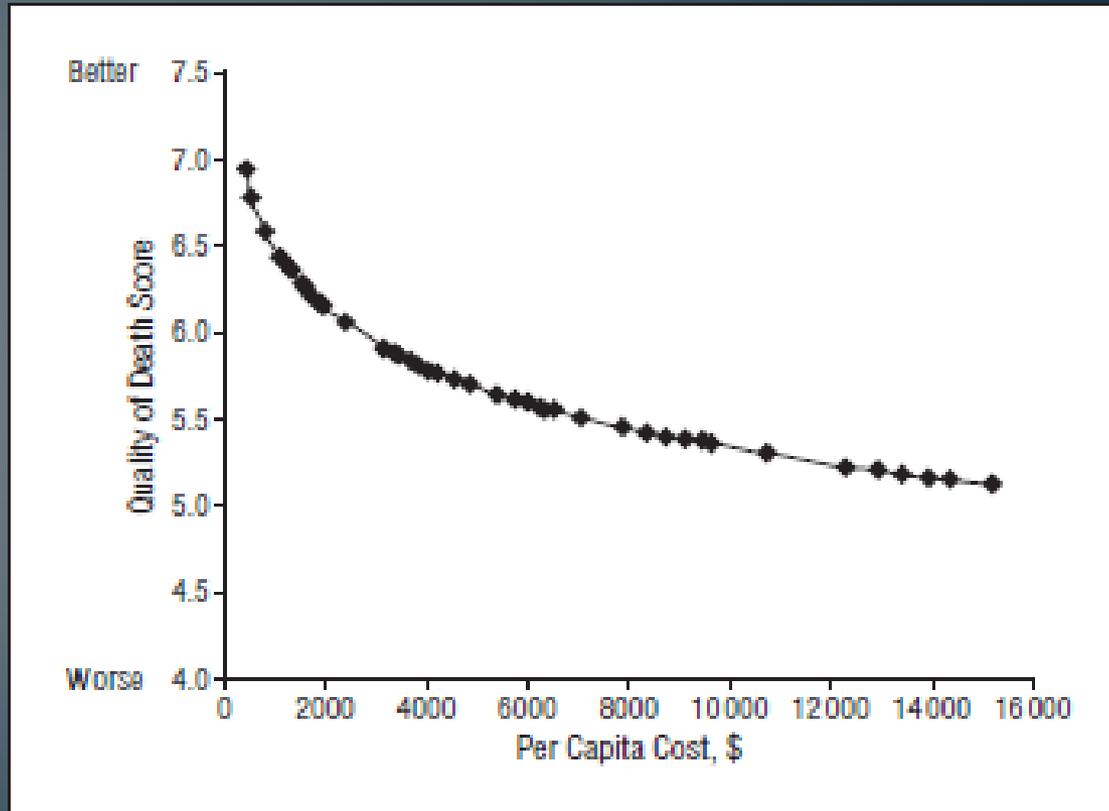
# Less is More: Impact on Survival

- The group that had goals of care discussions integrated into their standard cancer care
  - Had less symptoms
  - Reported higher quality of life
  - Were more likely to have had a discussion about their preferences for end-of-life care
  - Received less aggressive care
  - Lived almost three months longer

Temel et al NEJM 2012 (13); 145-152



# More Care is Not Better Care



Quill et al, JPM 2009

# Advance Care Planning





# So What Can I Do?

- Advance Care Planning: What Is It?
  - Designate a Durable Power of Attorney (DPOA)
  - Document preferences for life sustaining treatment and resuscitation (Living Will)

# Advance Care Planning: How it helps



- Adults who have completed an advance directive or who have documented conversations about preferences for care at the end of life:
  - Are less likely to die in the hospital
  - Are less likely to receive aggressive treatment at the end of life
  - Are more likely to receive treatment in concordance with their wishes
  - Families are more likely to report support in decision making



# Durable Power of Attorney

“If I get so sick I can’t make decisions for myself, who would make decisions for me?”



# Advance Directives

- **Living Will:** “If I get so sick I can’t speak for myself, what should my DPOA know about me and my preferences to make decisions for me?”
  - What aspects of my **QUALITY** of life am I willing to sacrifice so I can live longer?
  - Are there specific types of treatment that I do or do not want?
  - If get so sick it looks like I’m dying, what do I want that to look like?



# Treatment Based Decisions

- “Do you want a feeding tube or not?”
- “Do you want dialysis or not?”
- “Do you want chemotherapy, or do you want to die?”



# Value-Based Decision Making

Where the question isn't "do I want this treatment or not" but rather...

"what are my goals for the future, and will a proposed treatment get me closer to (or farther away) from those goals?"





# Value-Based Decision Making

Examples of values impacting decision making:

- Independence/Place of residence
- Cognitive State
- Physical suffering
- Terminal State

# Having the Conversation





# How to Start the Conversation

- Step 1: Plan Ahead
  - What do we need to talk about?
    - Medical Decision making
    - Finances
    - Making sure a family member is taken care of
  - Who needs to be there?
    - Spouse, children, friend, doctor, attorney?



# How to Start the Conversation

- Step 1: Plan Ahead (cont)
  - When is a good time to talk?
    - Next family gathering
    - Before the next surgery
    - After a doctor's appointment
  - Where will you feel comfortable talking?
    - Kitchen table
    - Favorite Restaurant
    - In the Car
    - Place of Worship



# How to Have the Conversation

- Step 2: Break the Ice
  - “I need to think about the future. Will you help me?”
  - “Even though I’m ok right now, I’m won’t always be, and I want to be prepared”
  - “Do you remember when (friend/family member) died? Was it a good death or a hard death? How would you want your death to be different?”
  - “If there ever comes a time when you can’t talk for yourself, there are some things I need to know. Is it ok if we talk about that now?”



# How to Have the Conversation

- Step 3: Discuss the important things
  - “When you think about your health, what worries you?”
  - “If you got so sick it looked like you were getting close to your end of life, what would you want your care to look like?”
  - “What affairs (personal, financial etc) would you want to get in order if you got sick and it didn’t look like you could get better?”
  - “Would you want to be actively involved in making medical decisions, or would you rather have your doctors do what they thought was best?”



# How to Have the Conversation

- Step 3: Discuss the important things (cont)
  - “Who do you want (or not want) to be involved in your care?”
  - “If you got so sick you couldn’t speak for yourself, who would you want to make decisions for yourself?”
  - “When would it be ok to shift the focus from aggressive, curative care to a focus on comfort care alone?”

[www.theconversationproject.org](http://www.theconversationproject.org)



## Your Conversation Starter Kit

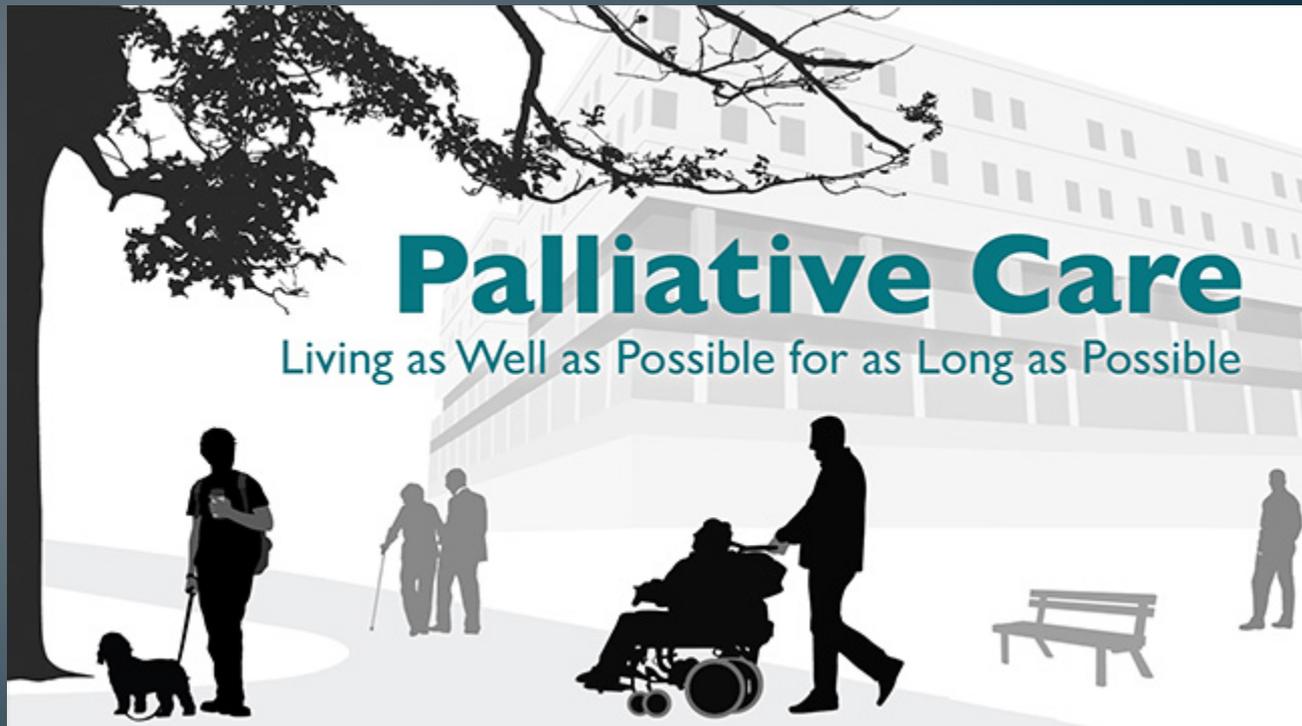
When it comes to end-of-life care, talking matters.



Institute for  
Healthcare  
Improvement

the conversation project

# Palliative Care





# Palliative Care: A Definition

The goal of palliative care is to prevent and relieve suffering....Palliative care is accomplished through effective management of pain and other distressing symptoms, while incorporating psychosocial and spiritual care according to patient/family needs, values, beliefs, and culture(s).

Clinical Practice Guidelines for Quality Palliative Care, National Consensus Project

# Palliative Care: But what does that mean?



- Palliative Care focuses on the person rather than the disease:
  - Focus on symptom control (pain, nausea, fatigue, shortness of breath) caused by a chronic disease
  - Focus on quality of life, and recognizes that “quality of life” means different things for different people

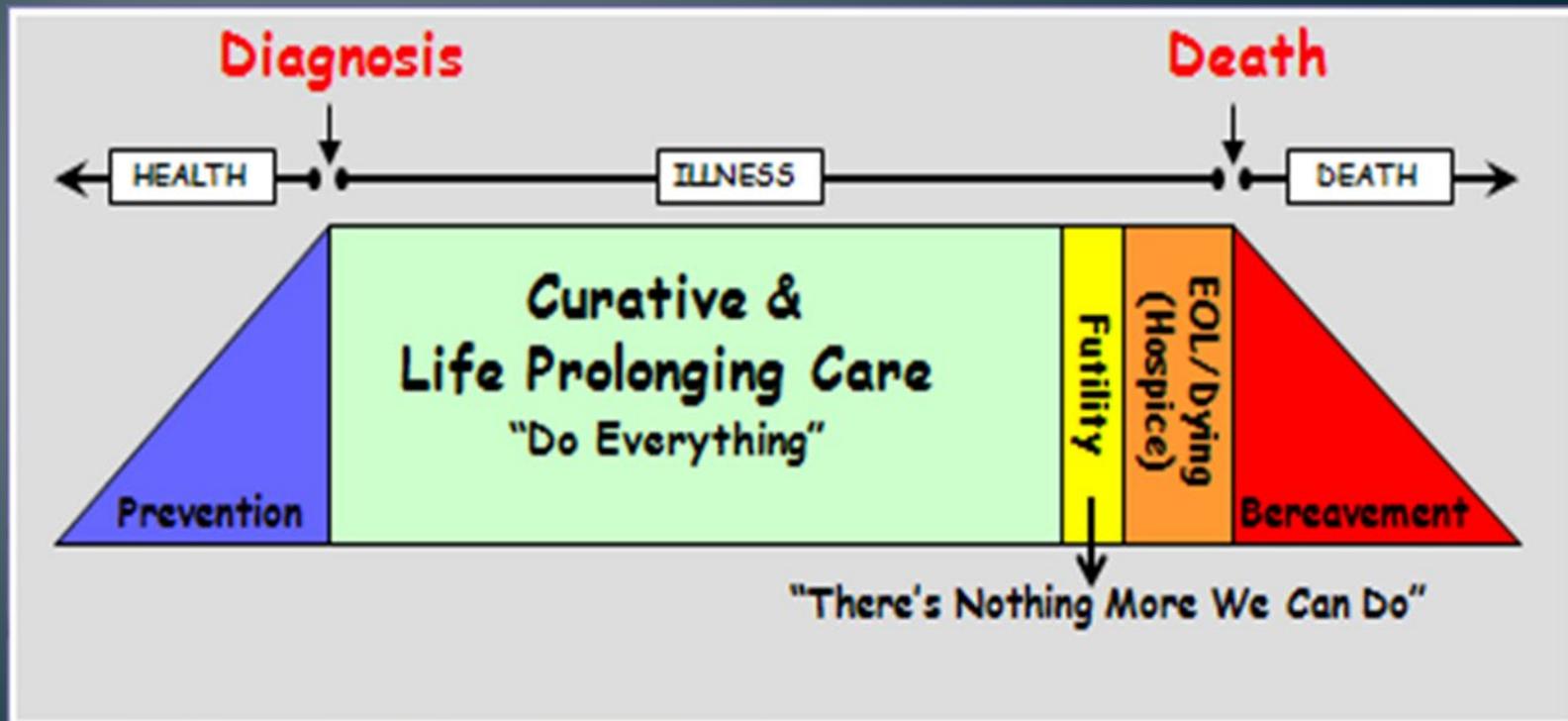
# Palliative Care: But what does that mean?



- Palliative Care focuses on the person rather than the disease:
  - Recognizes that chronic medical conditions not only have physical components, but also psychosocial, cultural, emotional, and spiritual aspects that effect the individual
  - Focus on effective communication about goals of care, risks/benefits of treatments proposed, and advanced care planning

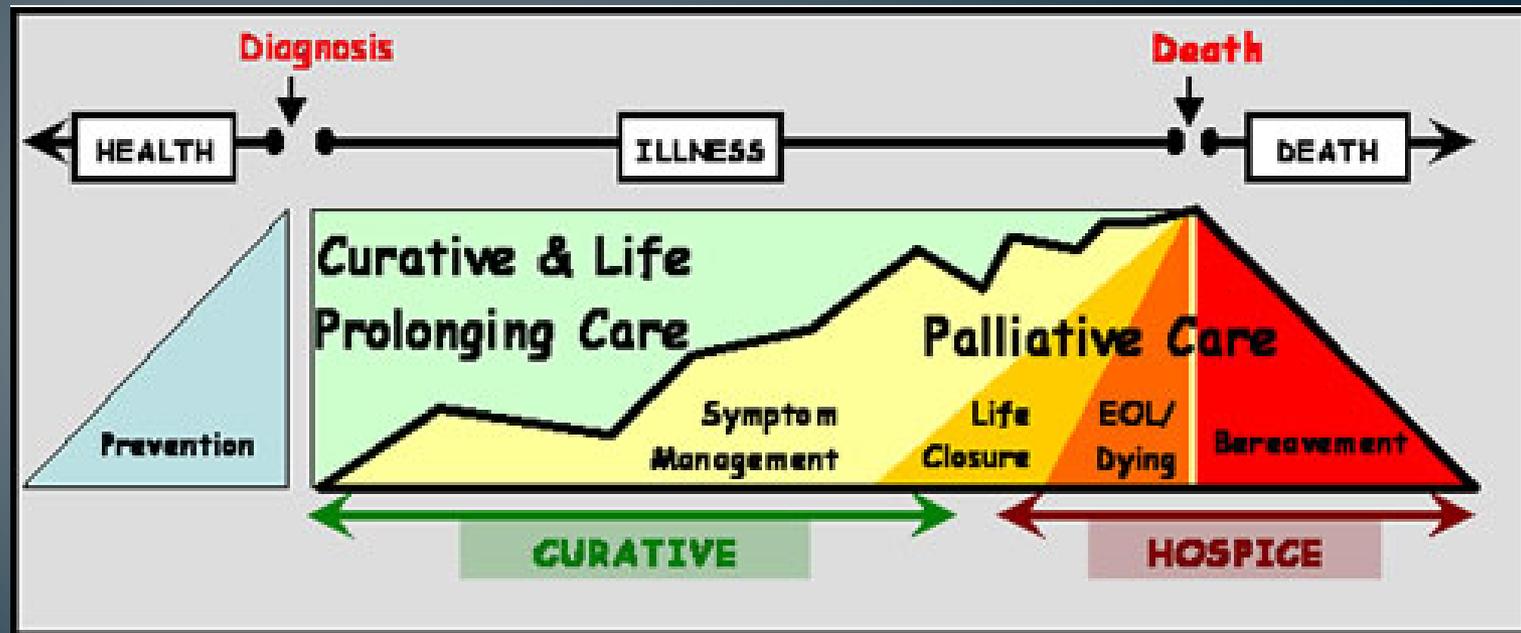


# Traditional Model of Medicine





# Proposed Integration of Palliative Care



# Palliative Care: Sounds great, but does it work?



## Attains Several Goals:

- Reduces in symptom burden for patients living this advanced disease
- Keeps patients where they want to be (at home)
- Reduces Costs



# Palliative Care Reduces Symptoms

- For those patients living with advanced disease (cancer, heart failure, kidney disease, emphysema), palliative care is superior to usual care for:
  - Emotional/Spiritual Support
  - Pain control
  - Information/Communication
  - Care at the time of death
  - Access to services in the community
  - Well-being/dignity



# When to ask for Palliative Care

- There are uncontrolled physical symptoms related to a serious illness, or its treatment
- A person or their family is experiencing emotional or spiritual distress regarding the diagnosis/prognosis
- Intra-family or family-physician conflict about goals of care or advanced care planning
- Accelerating need for medical care or hospitalizations
- A person has declined or are considering declining life-sustaining treatments, i.e. feeding tube or tracheostomy



# Palliative Care Delivery Modes

- Hospitals
  - Consultative Services
  - Inpatient Units
- Outpatient Clinics
- Home-based Palliative Care
  - Private Residential Services
  - Nursing Homes/ Long Term Care
- Hospice



# Palliative Care Services at UMHS

- UMHS Inpatient Palliative Consult Service
- Palliative and Supportive Care Clinic
  - East Ann Arbor, in the Turner Geriatric Center
  - Chelsea Family Practice
  - Livonia Family Practice
- UM Cancer Center Symptom Management and Supportive Care Clinic
- UM Cardiovascular Center Palliative and Supportive Care Clinic

# Where Can I Get Information About Palliative Care?



[GetPalliativeCare.Org](http://GetPalliativeCare.Org)



# In Conclusion

- American are living longer, with more disease than ever before
- The current health care system is providing many with care that is neither beneficial nor desired. MORE CARE IS NOT BETTER CARE
- Advance care planning is a means by which an individual can plan for the future to ensure their wishes for health care are followed

# Questions?

