

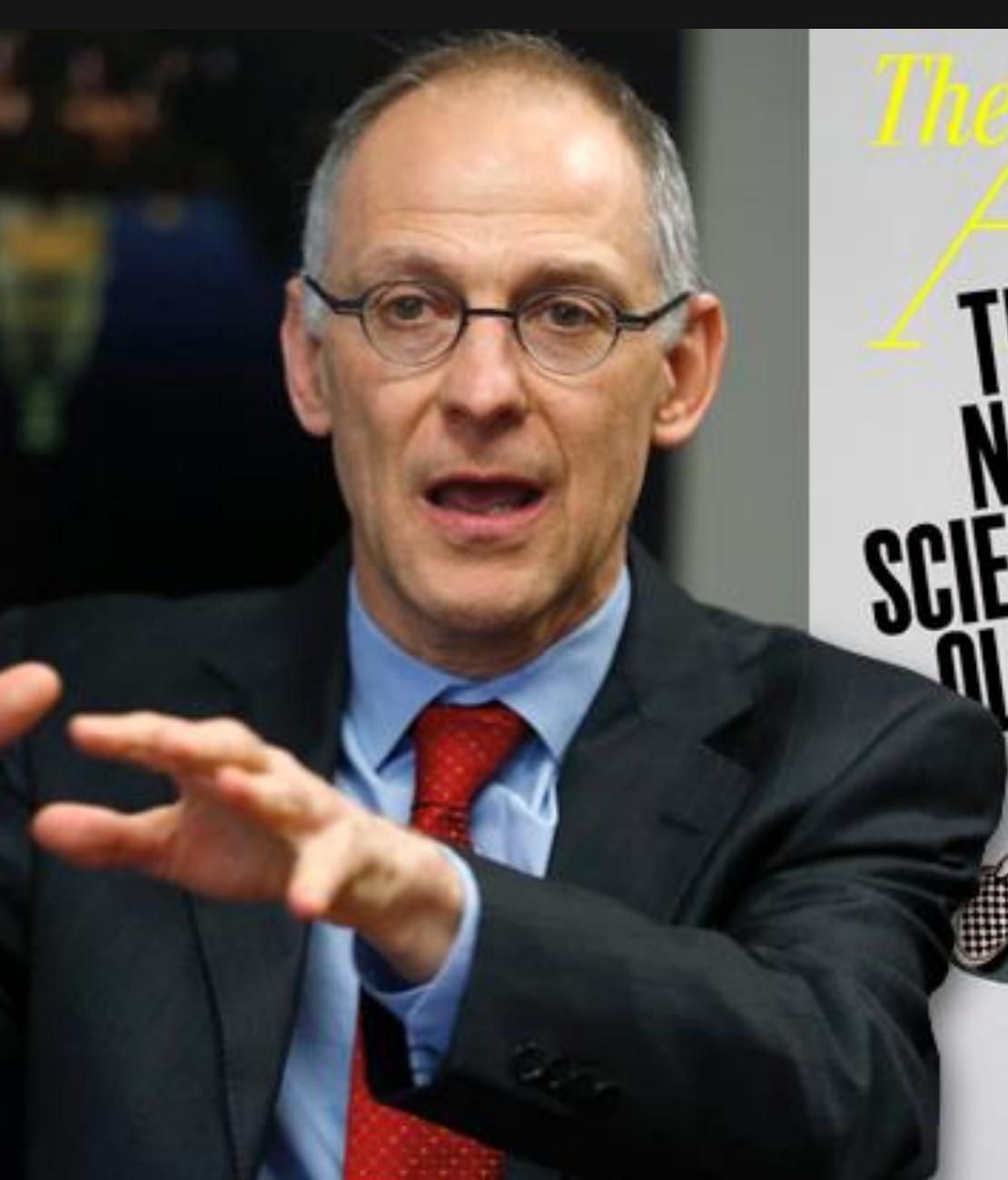
Our Lives Our Choices

Jim deMaine, MD



Everybody has got to die
but I have always believed
an exception would be made
in my case.

William Saroyan



The Atlantic

Inside a Prison Run by Gangs

The Art of Being Lena Dunham

The Gr Scams of All T

THE NEW SCIENCE OF OLD AGE



Bill Clinton on Life After (And Maybe Before) the White House

How Can We Confront Poor Black Neighborhoods

Next: Sex and Single Parenthood

Delivering Dinosaur Creativity

What living to 100 will mean for you and for society...

By Gregg Easterbrook

End of Life Conversations

The Boomer Effect

- theconversationproject.org
- deathoverdinner.org
- deathcafe.com
- Institute of Medicine Report on Dying in America – 2014/

Philosophy of Advance Care Planning

Your health care rights include:

- Making decisions about life sustaining treatment
- Having a way to inform health care providers about your preferences for life sustaining treatments
- Treatment by health care providers skilled at providing comfort care and honoring your preferences

Making decisions, making them known

What kind of medical care do you want if you become very old, very sick, or are near the end of life?

Where do you want to be for your end of life care?

Who will speak for you when you cannot speak for yourself?

More than 50% of us
are unable to make our own healthcare
decisions during the days and weeks just
prior to death.

Advance Care Planning: a gift



Clarify values and beliefs

Choose a spokesperson

Understand life-sustaining treatments

Explain the differences in the advance directive forms

How will others know my values & wishes?

- Talk about them: www.theconversationproject.org
- Write them down in an essay, letter, or list.
- Fill out a Health Care Choices Checklist
- Fill out a Values Worksheet. Attach these to your Advance Directive forms.
- Give copies to your family, attorney, and health care team!

What is your acceptable quality of life?

Examples of questions that you should ask yourself:

- What makes life worth living for you?
- Given the nature of your illness, what are the most important things for you to achieve?
- What are your biggest hopes?
- What are your biggest fears?

What is your acceptable quality of life?

What you might talk about or write down:

“I do not want to be a burden on my family. I don’t want to ever be in such a physical state that they or someone they hire has to take care of me at my home 24/7, or in their home for a long period of time.”

“I don’t want to be kept alive in any way if I can’t recognize or interact with my family members.”

What is your acceptable quality of life?

“I love to eat, but could accept being tube-fed for a short time only.”

“It’s okay if I need a wheelchair, but I don’t want to be bed-bound.”

“I want to breathe naturally and could only accept a machine for a short time if my doctor thinks I have a good chance of breathing on my own again. If not, let me die a natural death.”

What is your acceptable quality of life?

“If at all possible I want to live and die in my own home and not in a hospital, adult family home, or nursing home. A nursing home would be okay for a short rehabilitation stay only.”

“Each day that I am here is a gift for me and my family. I want everything done for me.”

“I want to be pain-free, even if it means I’m sleepy.”

What is your acceptable quality of life?

“For life to be worth living, I must be able to at least see and hear my loved ones even if I cannot speak to them easily (or at all). It’s important to me to be alert and clear most of the time. I don’t think I could accept a constant state of confusion.”

What about the end of life?

Prior generations were born at home and died at home, cared for by family members.

Now, many of us have a “medical” birth and a “medical” death.

90% of Americans would prefer a “home” or “home-like” death.

We only die once. No time to practice!

What's a Good Death?

- Pain and symptom management
- Wishes known & honored
- Preparation for death – spiritual & natural
- Completion of goals
- Contributing to others – a legacy
- At peace surrounded by loved ones

Health care in America today

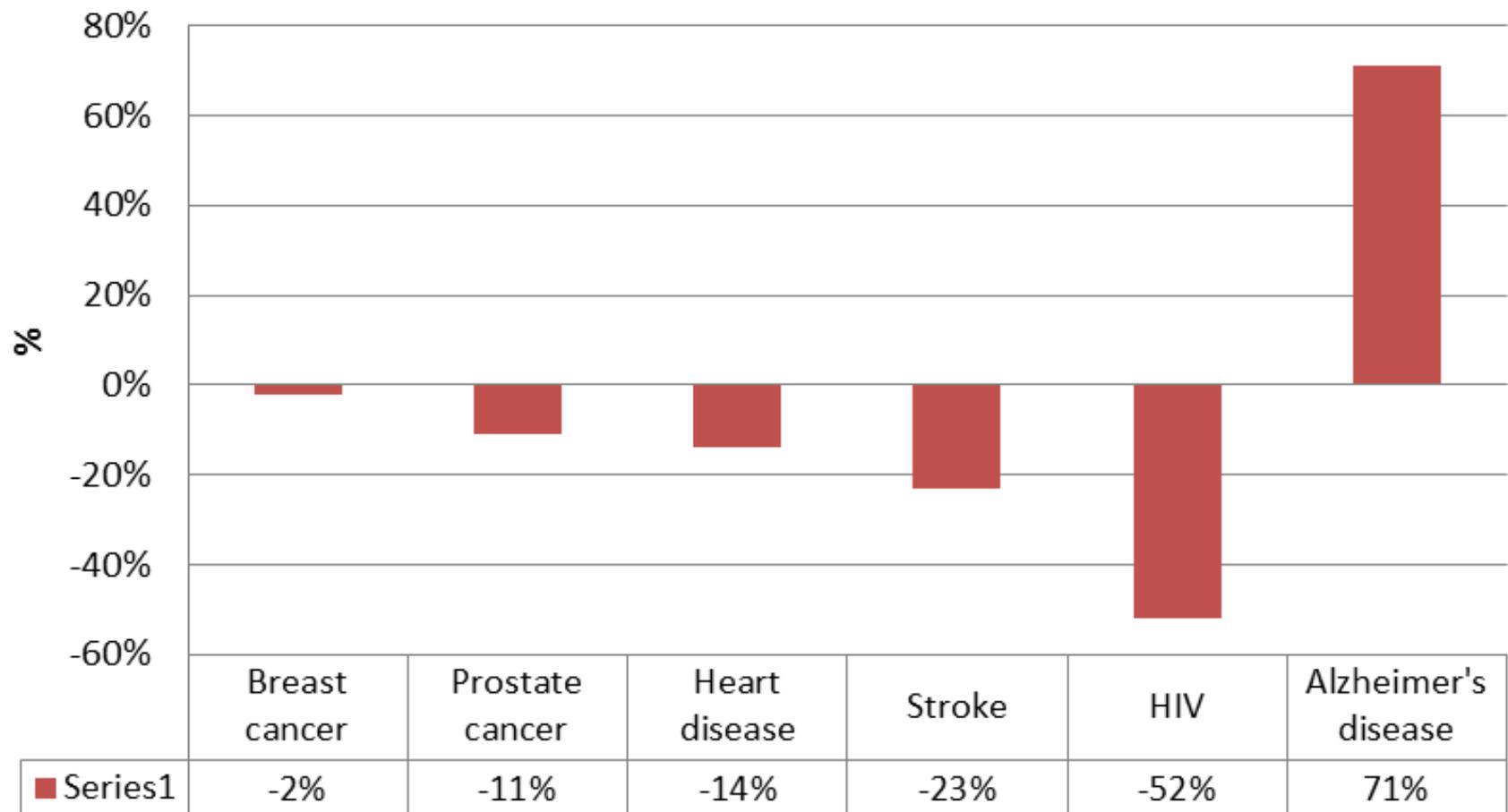
Modern health care:

- Often cures illness in young and healthy.
- Often extends life for older persons.
- Helps people live longer, but often with one or more chronic conditions.

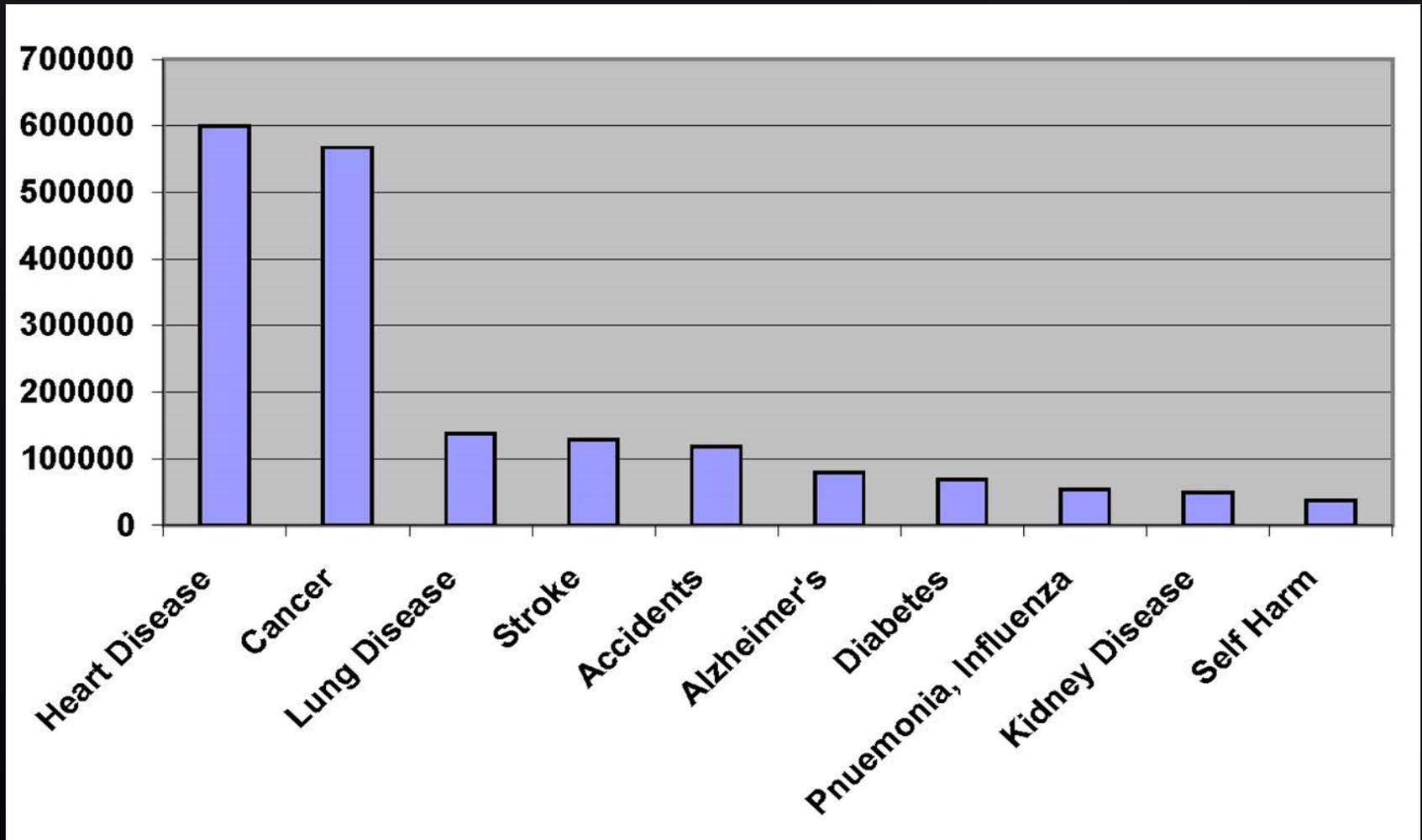
Let's look at the facts . . .

Causes of Death

% Change in Cause of Death 2000 to 2013



Top 10 leading causes of death in U.S. in 2010



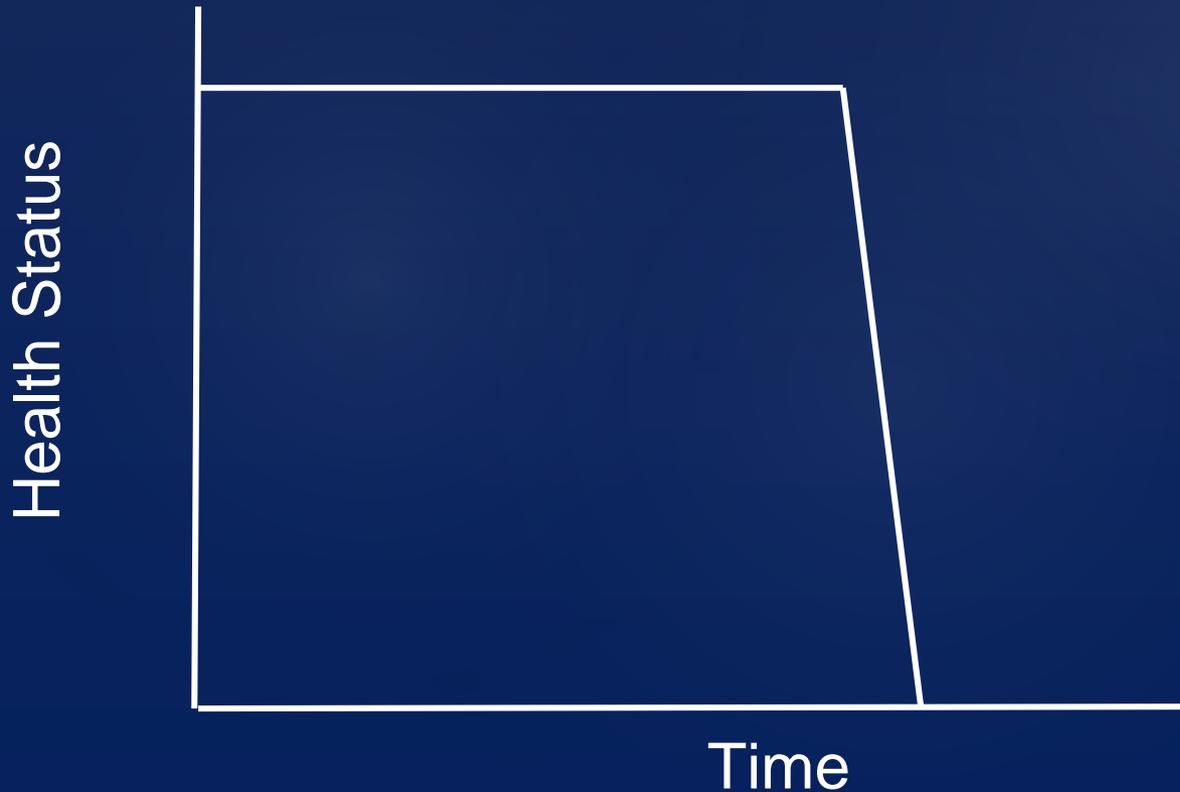
World Mortality Rate



Courtesy of The Onion®

Sudden death by an unexpected cause

Less than 5% die from massive heart attack, fatal stroke or accident.



Protracted life threatening illness

More than 90% of people have either...

- A predictable steady decline with a relatively short “terminal” phase (cancer, some cases of Alzheimer’s dementia)
- A slow decline punctuated by periodic crises (heart failure, emphysema, chronic bronchitis)

Slow decline punctuated by periodic crises



I'm not afraid to die. I just don't
want to be there when it happens

Woody Allen

Most Americans live long lives . . .

with an increasing burden of medical problems.

Eventually, they become “very sick” before they die.

Three pathways of care for the very sick

Life prolonging care

Limited medical care

Comfort care

Let's watch a short video that may help better understand these different pathways of care and the choices you may or may not want to make.



Three pathways of care for the very sick

Life-prolonging care

Limited medical care

Comfort care

Do you have any comments about the video you just watched?

Life Prolonging care

Some patients may be offered or request specific life-prolonging interventions when they are very sick.

Cardiopulmonary Resuscitation (CPR) and Breathing Machines (ventilators) were discussed in the video you just watched.

But did you know? . . .

Survival rates of CPR

The survival rate of CPR on television shows & movies is
66 out of 100 people.

However . . . real-life CPR survival rates are:

For the overall population:
15 out of 100 people

For the frail elderly:
Less than 5 out of 100 people

For those with advanced chronic disease(s):
1 out of 100 people

Artificial Fluids & Nutrition

When a person is unable to eat or drink normally, fluids and nutrition can be given by tubes:

- Fluids alone may be given through a small tube inserted into a vein (IV line).
- Short-term nutrition can be given by a feeding tube that is inserted through the nose and down the throat into the stomach. This method can be used from 1 -2 weeks.
- Long-term nutrition can also be given by a tube put through the wall of the stomach or intestine.

Artificial Fluids & Nutrition

Benefit:

Artificial nutrition can keep someone alive for a long time even if they are unable to eat normally.

Negative Effects:

- Feeding tubes can hurt the nose, throat, and stomach.
- Normal burping or “reflux” can cause the tube feeding to come back up from the stomach and then “go down the wrong way” into the lungs.
- This can lead to difficulty breathing and pneumonia.

Recent medical research has shown that patients with dementia who receive tube feedings have more uncomfortable symptoms and die more rapidly than patients who have careful feeding from a spoon. Losing the ability to swallow and digest food is an expected part of end-stage dementia.

Limited Medical Care: Antibiotics

Antibiotics are medicines to fight bacterial infections, given by mouth or by a thin tube inserted into a vein (IV). Antibiotics can stop or delay infections that may lead to death or disability.

Benefits:

Antibiotics can cure infection and save lives for many people. Treating infections that cause pain (urinary tract infection) may give comfort to the patient.

Limited Medical Care: Antibiotics

Negative effects:

Allergic reactions – or simply don't work

Development of resistant bacteria

Antibiotic treatment may only prolong the dying process. When symptoms are carefully controlled, dying of an infection is often painless.

Please remember!

“No Code” (No CPR)

“No breathing machine”

“No feeding tube”

never means

“No Care”

Care is always possible, even if cure is not.

Comfort Care

The goal is to achieve comfort, improve quality of life, and provide support for patients and caregivers.

Health care decisions are made to focus on the patient's well being and the need for symptom control and management.

Both Palliative care and Hospice care can achieve these goals.

Palliative Care

Palliative care is specialized care for people with serious illnesses to help improve their quality of life. Palliative care can be provided at any stage of a person's life, not just at the end.

The focus is on:

- Relieving symptoms & controlling pain
- Providing guidance for complex treatment choices
- Emotional support for the patient & family

Hospice

For those with advanced terminal illness, Hospice provides:

- Pain and symptom management
- Medications and medical supplies
- Specialized nursing care, social services, spiritual care, and volunteer services
- Care training for family members
- Counseling and bereavement support

Hospice is not a place—it is a program that is conducted in your own home or living situation.

Hospice is covered by Medicare and some insurance companies for those not in Medicare

Regional Variation in Care In Advanced Cancer

- In Manhattan – 50% of all deaths occur in a hospital
- In Mason City – 7% of all deaths occur in a hospital
- Many referrals to hospice are in the last few days – “too late”
- In 50 academic medical centers, less than half the dying patients received hospice

(Dartmouth Atlas 2010)

The necessity for an Advance Directive

When health professionals are uncertain,
they almost always decide to treat

If you can't speak for yourself during a medical crisis
and don't have an Advance Directive,
who will speak for you?

Your DPOA for Health Care

Be in control of who will be consulted:

Complete your Durable Power of Attorney
for Health Care form!

We love our family & friends, but we often feel we don't want to burden them with this work or don't trust that they will voice what we want.

Who is best person for the job?
Who will actually be available?

Who speaks for you in Washington state?

1. Court appointed legal guardian, if you have one
2. Durable Power of Attorney (DPOA) for Health Care, if you have appointed one

If you do not have a DPOA for Health Care:

3. Spouse or WA State Registered Domestic Partner
4. Adult children of patient (all in agreement)
5. Parents of patient
6. Adult siblings of patient (all in agreement)
7. Healthcare providers make decisions for you until a legal guardian is assigned.

Washington State Death with Dignity Law

If you qualify under the Death with Dignity Law, you qualify for hospice care

All Medicare members have a hospice benefit (some insurers also offer hospice)

Many more people qualify for hospice care than meet the strict requirements of the DWD law

Washington State Death with Dignity Law

The patient must be:

- Certified by 2 physicians to be BOTH terminally ill from a known diagnosis AND expected to die within the next 6 months.
- Competent and able to make the request to the attending physician in person. Mental health consultation can be requested.
- No surrogate, Durable Power of Attorney, family, or other persons can make the request.
- No one can “give” the meds to the patient.

About 1 in 500 deaths
in Washington State are due to
implementation of the DWD law.

What forms do you need to fill out?

For All Adults

1. Durable Power of Attorney for Health Care
2. Living Will

Organ Donation (optional)

For Those Who Are Chronically Ill or Near the End of Their Lives

3. Physician Orders for Life Sustaining Treatment (**POLST**) form

Durable Power of Attorney for Health Care

Names the person you want to make health care decisions when you are no longer able to, hence the term “durable.”

It should be notarized

We recommend assigning a 2nd and/or 3rd person on this form, in case your primary spokesperson is unavailable.

Living Will (“Directive to Physicians”)

A Living Will indicates the quality vs. quantity of life

It is valid only when two MD’s certify terminal illness or PVS (Persistent Vegetative State)

Must be signed by two witnesses who are not related to you, do not benefit from your will, & are not part of your healthcare team.

It does not name the person who will speak for you if you can’t speak for yourself! You still need a DPOA for Health Care form for that role.

The POLST form

...for those who are the frail elderly,

have severe chronic illnesses,

or

are near the end of their lives.

HIPAA PERMITS DISCLOSURE OF POLST TO OTHER HEALTH CARE PROVIDERS AS NECESSARY

Physician Orders for Life-Sustaining Treatment

Last Name - First Name - Middle Initial _____

Date of Birth _____ Last-4 #SSN _____ Gender M F

FIRST follow these orders, **THEN** contact physician, nurse practitioner or PA-C. The POLST is a set of medical orders intended to guide emergency medical treatment for persons with advanced life limiting illness based on their current medical condition and goals. Any section not completed implies full treatment for that section. Everyone shall be treated with dignity and respect.

Medical Conditions/Patient Goals: _____ Agency Info/Sticker _____

A CARDIOPULMONARY RESUSCITATION (CPR): *Person has no pulse and is not breathing.*

Check One CPR/Attempt Resuscitation DNAR/Do Not Attempt Resuscitation (Allow Natural Death)
Choosing DNAR will include appropriate comfort measures and may still include the range of treatments below. When not in cardiopulmonary arrest, go to part B.

B MEDICAL INTERVENTIONS: *Person has pulse and/or is breathing.*

Check One **COMFORT MEASURES ONLY** Use medication by any route, positioning, wound care and other measures to relieve pain and suffering. Use oxygen, oral suction and manual treatment of airway obstruction as needed for comfort. **Patient prefers no hospital transfer: EMS contact medical control to determine if transport indicated to provide adequate comfort.**

LIMITED ADDITIONAL INTERVENTIONS Includes care described above. Use medical treatment, IV fluids and cardiac monitor as indicated. Do not use intubation or mechanical ventilation. May use less invasive airway support (e.g. CPAP, BiPAP). **Transfer to hospital if indicated. Avoid intensive care if possible.**

FULL TREATMENT Includes care described above. Use intubation, advanced airway interventions, mechanical ventilation, and cardioversion as indicated. **Transfer to hospital if indicated. Includes intensive care.**

Additional Orders: (e.g. dialysis, etc.) _____

C SIGNATURES: *The signatures below verify that these orders are consistent with the patient's medical condition, known preferences and best known information. If signed by a surrogate, the patient must be decisionally incapacitated and the person signing is the legal surrogate.*

Discussed with:	PRINT — Physician/ARNP/PA-C Name	Phone Number
<input type="checkbox"/> Patient <input type="checkbox"/> Parent of Minor	<input checked="" type="checkbox"/> Physician/ARNP/PA-C Signature (mandatory)	Date
<input type="checkbox"/> Legal Guardian <input type="checkbox"/> Health Care Agent (DPOAHC)		Date
<input type="checkbox"/> Spouse/Other		Date
PRINT — Patient or Legal Surrogate Name		Phone Number
<input checked="" type="checkbox"/> Patient or Legal Surrogate Signature (mandatory)		Date

Person has: Health Care Directive (living will) Living Will Registry Durable Power of Attorney for Health Care

Encourage all advance care planning documents to accompany POLST

SEND ORIGINAL FORM WITH PERSON WHENEVER TRANSFERRED OR DISCHARGED

Revised 2/2011 Photocopies and FAXes of signed POLST forms are legal and valid. May make copies for records

Washington State Medical Association

OVER ►

The POLST form

Physician's Orders for Life Sustaining Treatment

A form for those with serious medical conditions or the frail elderly.

Honored by 911 responders.

Goes with patient from home to medical facilities, and then back home with patient.

Both physician and patient (or legal surrogate) fill out and sign this form together.

Completing your Advance Directives

Discuss your choices with your family, friends, and anyone you are naming as your DPOA.

Make copies

- For your DPOA(s) for Health Care
- For your family members / loved ones
- For your doctor or members of health care team
- To be scanned into your electronic medical chart
- Discuss with your attorney if you have one

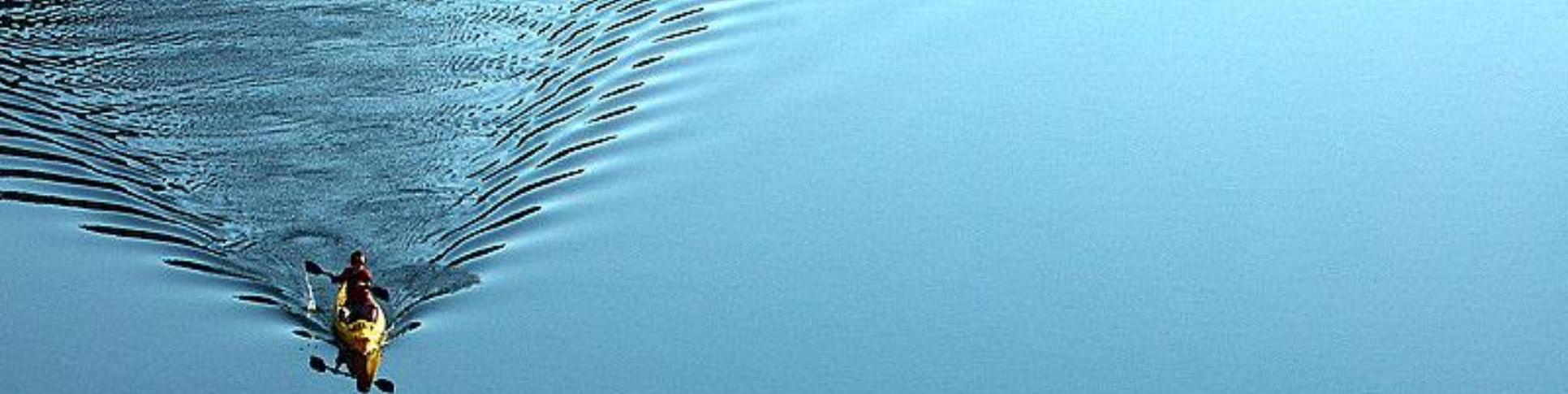
Keep a list of those who have a copy

Important truths about Advance Directives

Relying on your family without explicit discussion is not enough.

Advance Directives can't anticipate all possible circumstances.

These are reasons to name someone to speak for you who is "close to your heart."



Thank you!

Jim deMaine, MD

www.endoflifeblog.com