Preparing for a Better End: Expert Lessons in Death and Dying for You and Your Loved Ones

www.thebetterend.com

- Dan Morhaim, MD
- Emergency Medicine Physician
  (45 years doing shifts)
- Maryland House of Delegates 1995-2019
- Author; consultant; board member
- Faculty, Johns Hopkins School of Public Health 2002-2018

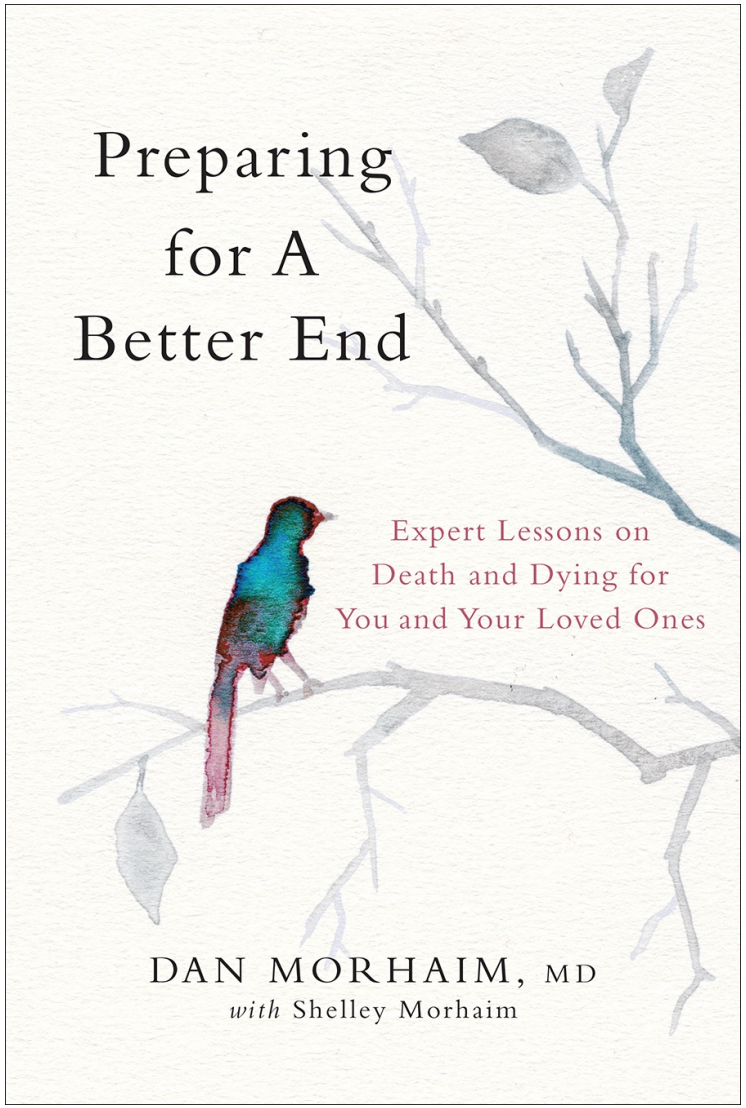
"The opinions voiced in this material are for general information only and are not intended to provide specific advice or recommendations for any individual. This information is not intended to be a substitute for individualized legal or medical advice. Please consult your legal advisor and medical professionals regarding your specific situation."

From Johns Hopkins University Press

www.thebetterend.com

Johns Hopkins Press: https://www.press.jhu.edu (go to search icon and enter ”Morhaim”)

And available via all the other usual sources…



My books endorsed by

- Maya Angelou
- US Senator Ben Cardin
- Dr. Leana Wen
- US Senator Chris Van Hollen
- Dr. Ben Carson
- Edo Banach, President National Hospice and Palliative Care Org.
- Dr. Leon McDougle, President, National Medical Association
- Tara Brach, Buddhist Teacher
- Rev. Jason Poling, Episcopal Priest
- David Fakunle, PhD, Johns Hopkins and Morgan State
- Dr. Robert Fine, Baylor Scott & White, Director Clinical Ethics; Texas
- Dr. Angelo Volandes, Harvard Medical School, Mass General
- Nathan Kottkamp, Chair, National Healthcare Decisions Day
- And others

Let’s talk about it

- Yes, this is a hard topic
- But everyone knows about it
- Our choice is to see the positive aspects of talking about end-of-life care
- A bit of my story
- Personal (family), political (state legislator), professional (physician)

AUDIENCE PARTICIPATION QUESTIONS

1) Have you been present when someone took their last breath? (in real life, not professional or military experience)

2) Have you completed your advance directive?

3) Have you asked others (that is, everybody you know) to do the same?

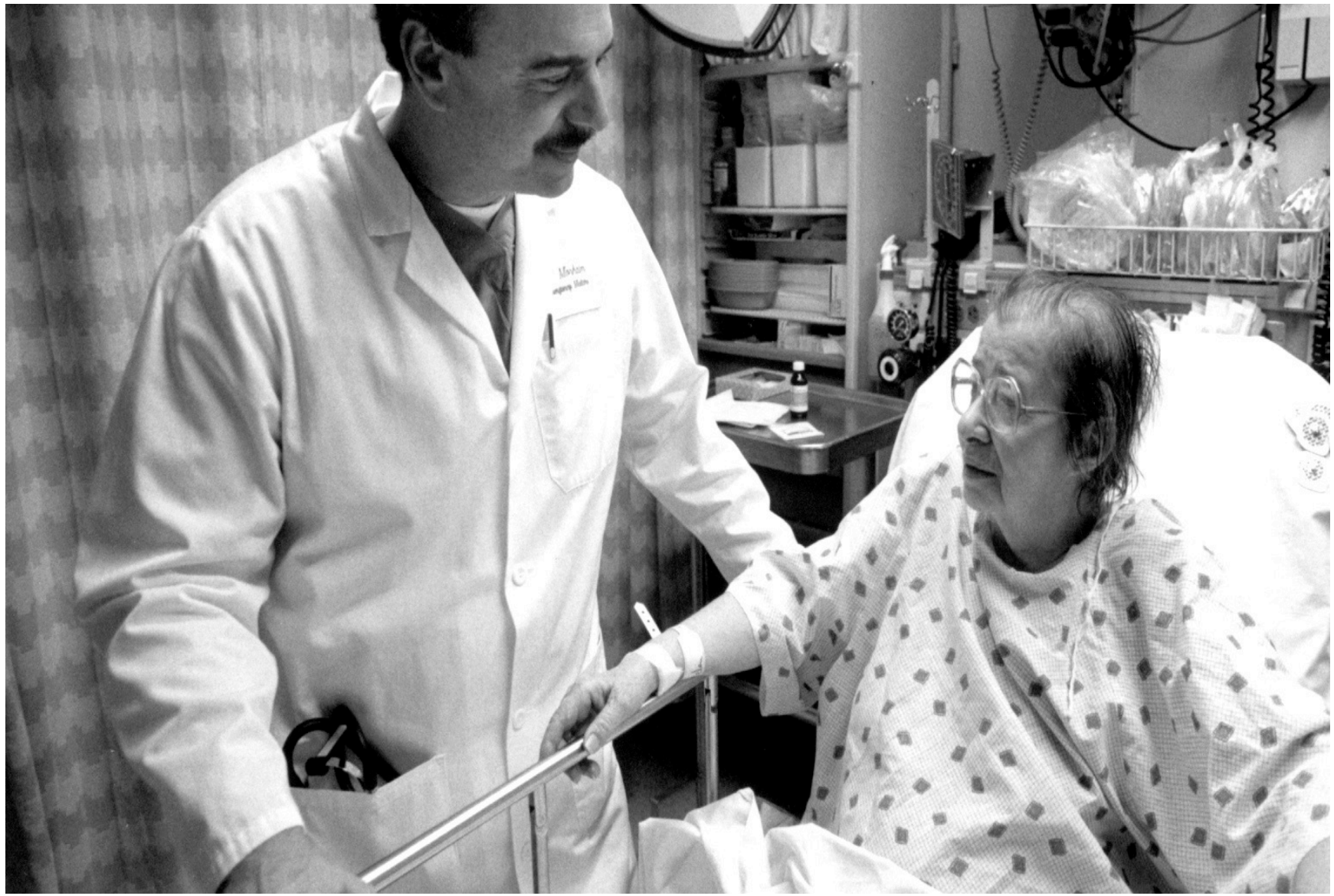
4) When the end comes, the last days, hours minutes of your life:

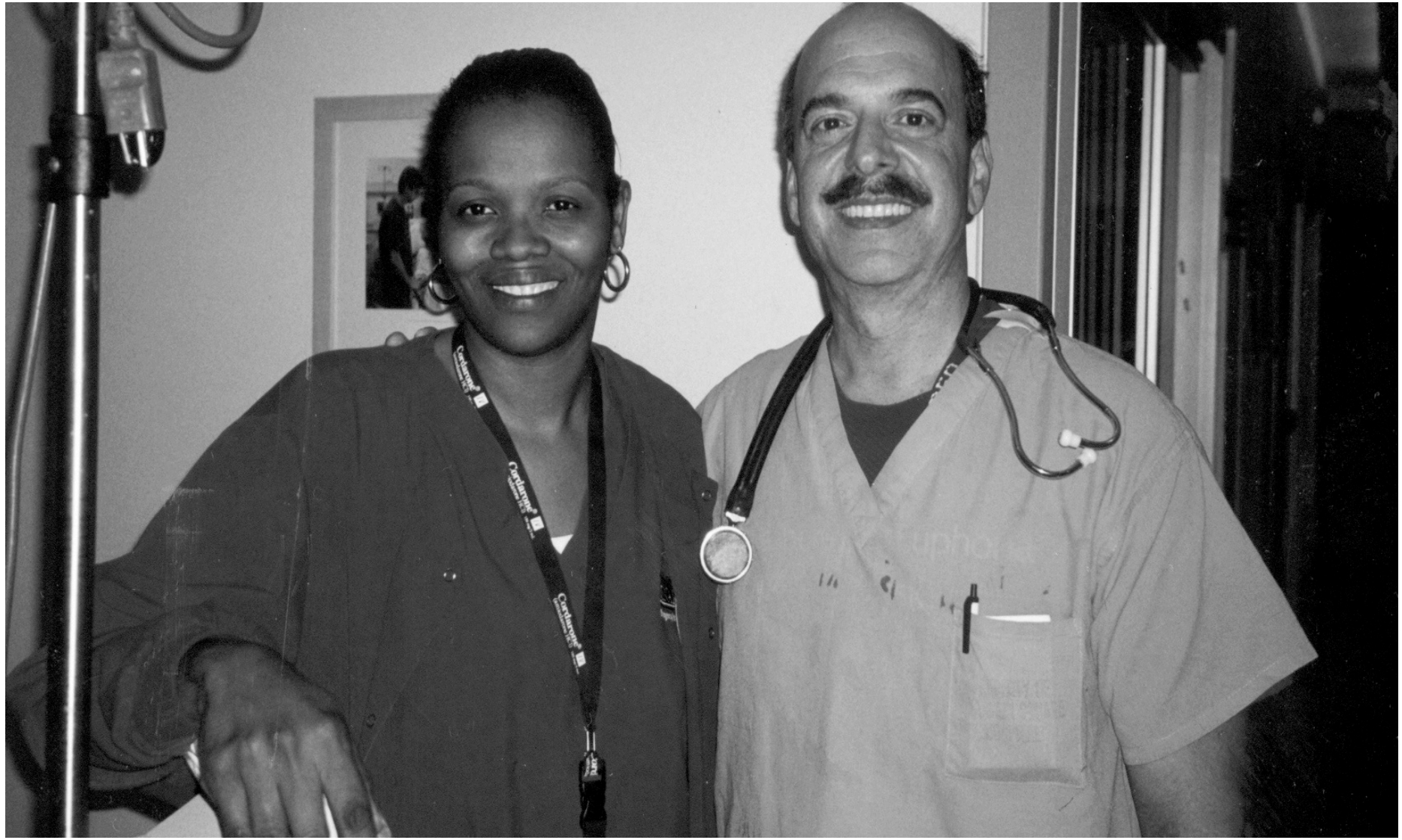
Where would like to be? Who is around you? What's going on?

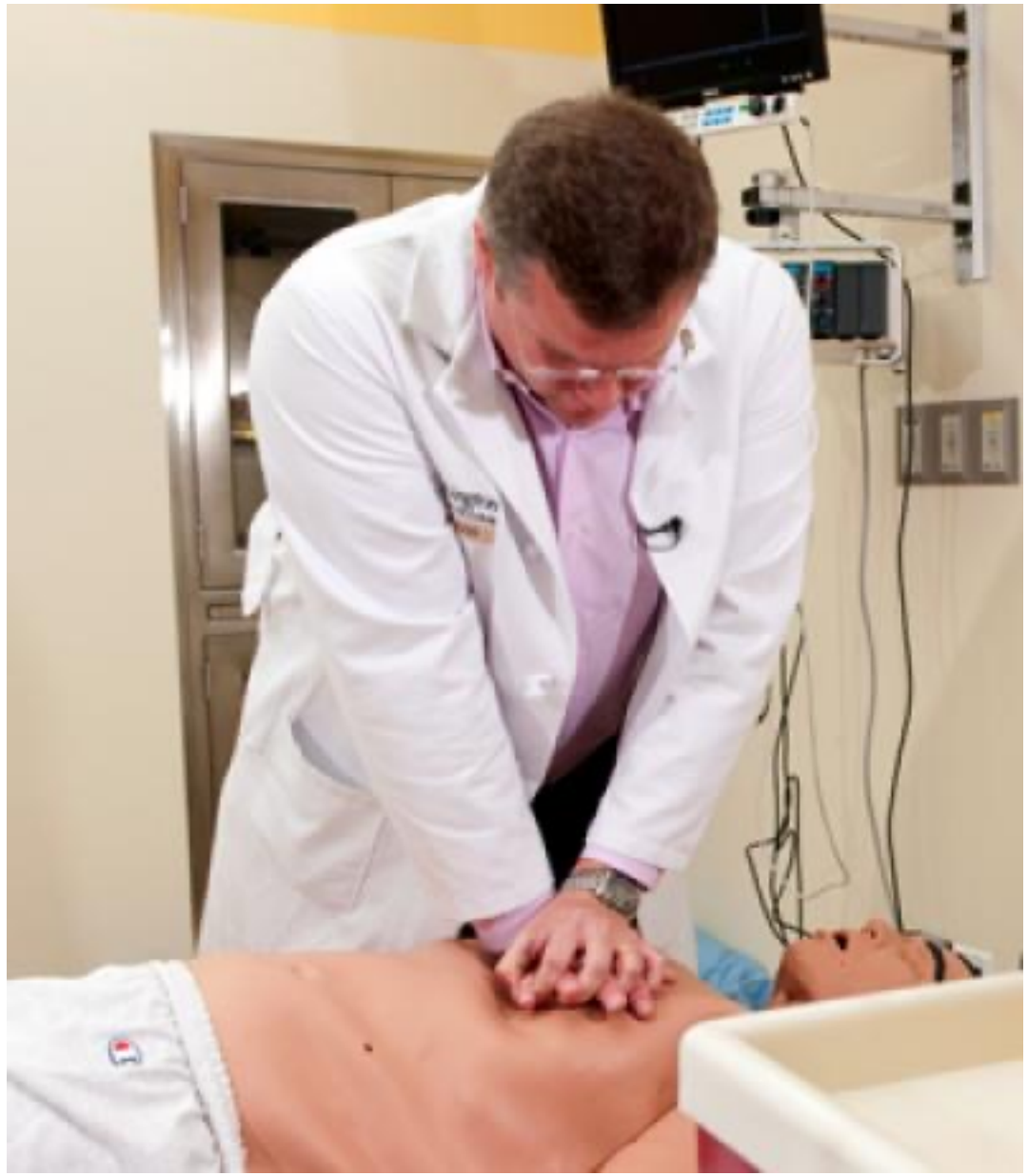
DENIAL

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

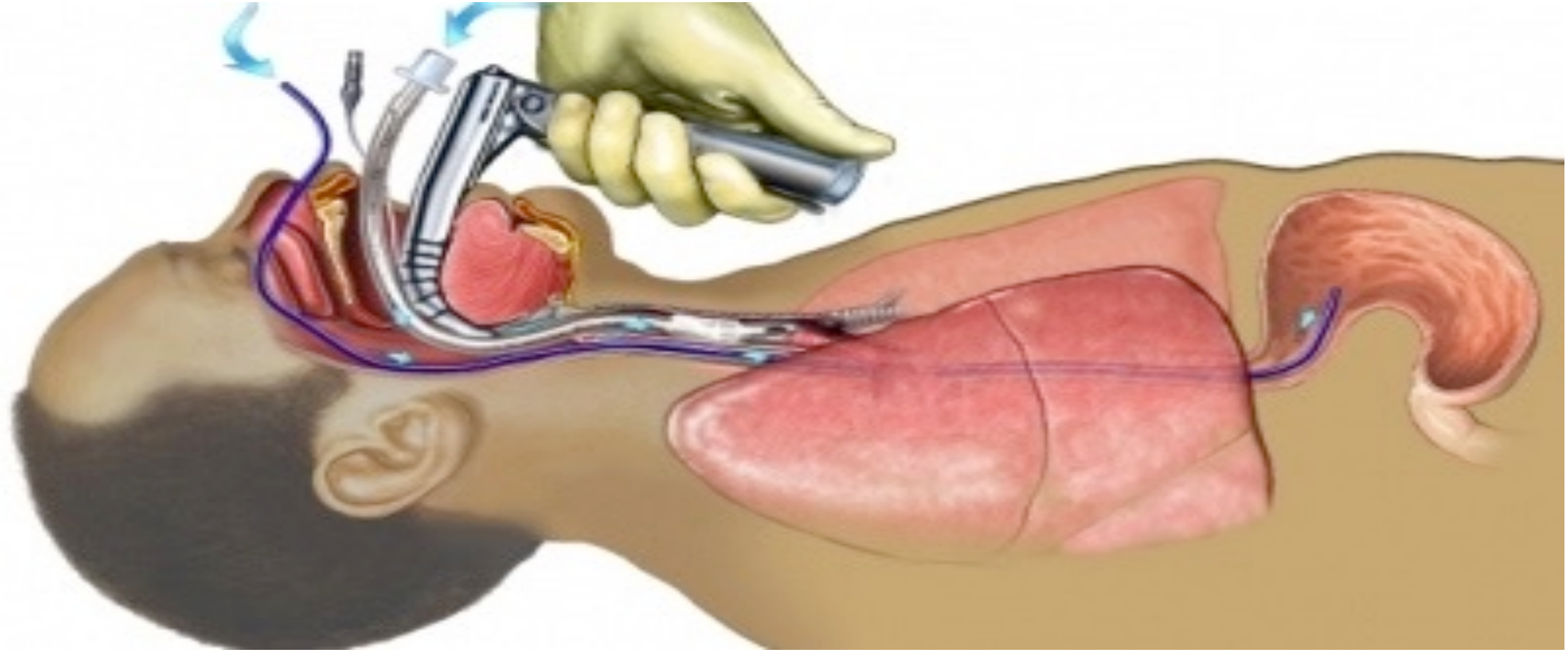
- William Saroyan

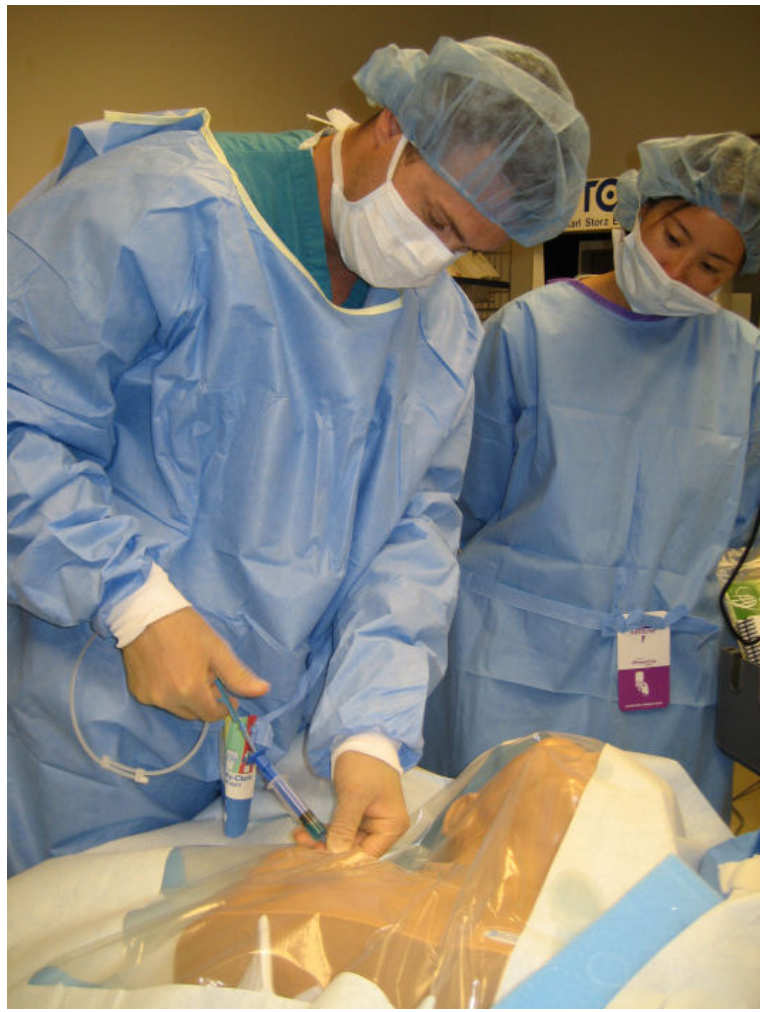






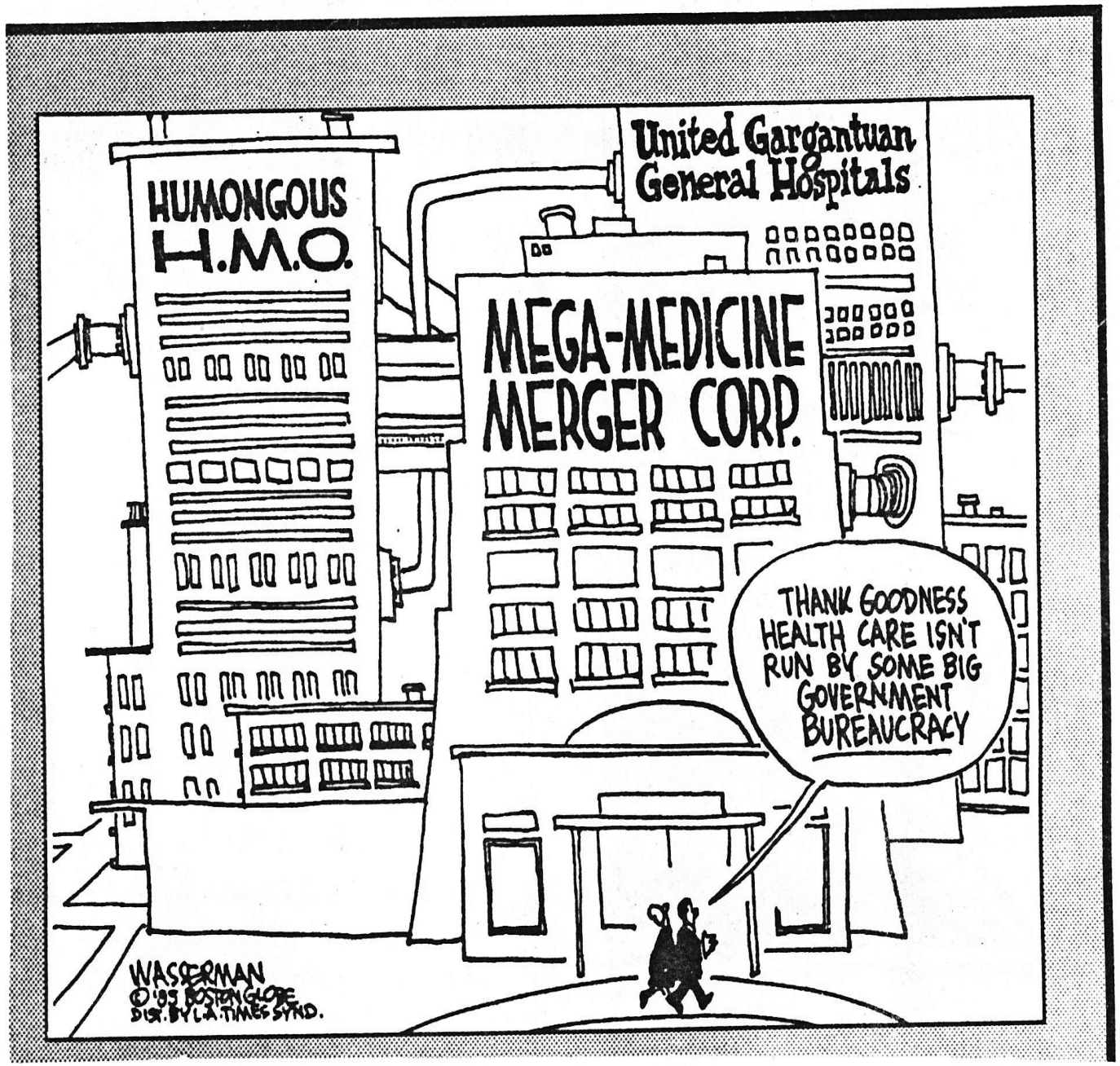
Endotracheal intubation





From Anne Tyler, “The Accidental Tourist”

You ever wonder what a Martian might think if he happened to land near an emergency room? He’d see an ambulance whizzing in and everybody running out to meet it, tearing the doors open, grabbing up a stretcher, scurrying along with it. ‘Why,’ he’d say, ‘what a helpful planet, what kind and helpful creatures’…’What a helpful race of beings,’ a Martian would say. Don’t you think so?


HUMONGOUS H.M.O.
United Gargantuan General Hospitals
MEGA-MEDICINE MERGER CORP.
THANK GOODNESS HEALTH CARE ISN'T RUN BY SOME BIG GOVERNMENT BUREAUCRACY
WASSERMAN
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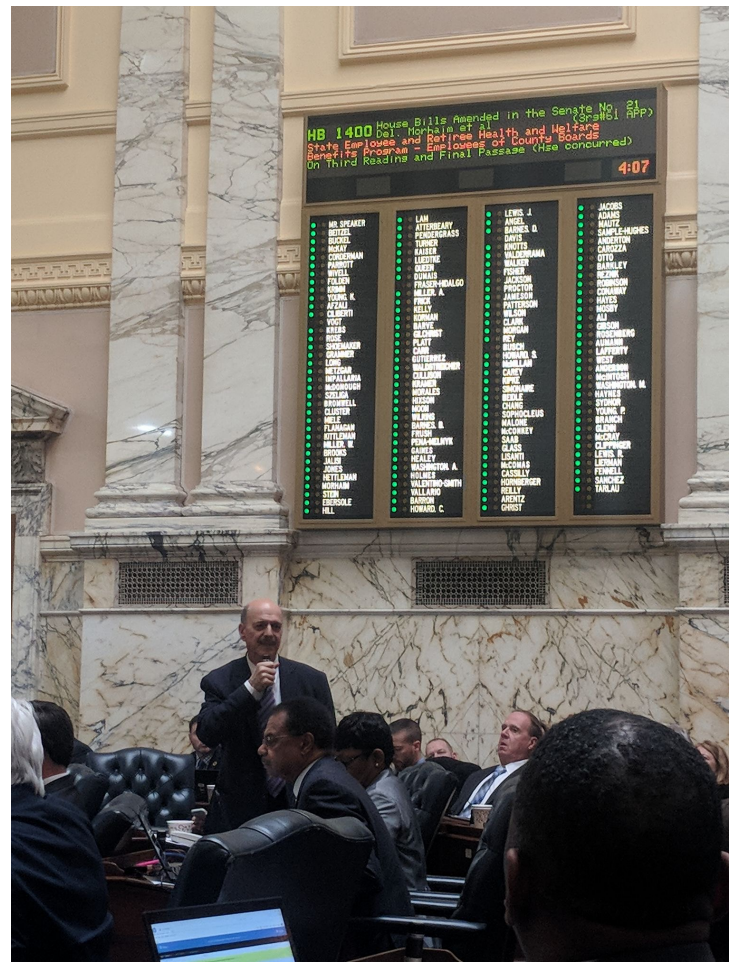
Prepare a "Medical Go-Bag" to include:

- family contact information
- physician/provider contact information
- a list of current medications
- reports of recent lab and imaging tests
- a graphic copy of your latest EKG
- an advance care plan – your advance directive
- if you were COVID vaccinated, which one and when

The medical tests above are available from your physician and/or from lab and imaging companies, usually online

Print out and bring to the hospital with you


HB 1400 House Bills Amended in the Senate No. 21
Del. Morhaim et al. (Israel, APP)
State Employee and Retiree Health and Welfare
Benefits Program - Employees of County Boards
On Third Reading and Final Passage (Hse concurred)
4:07
MR. SPEAKER
BETUEL
BUCKEL
MALEY
CONDERMAN
PARROTT
WYGAL
FOLKEN
BROWN
YOUNG, K.
AFZALI
CLEVIDI
VOGT
REHER
ROSE
SHOEMAKER
GRAMMER
LONG
METCALF
IMPALLARIA
McKNIGHT
SZELIGA
BRASWELL
CLUSTER
WELE
FLANAGAN
KITTLEMAN
MILLER, W.
BROOKS
JALEN
JONES
METTLEMAN
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EBERSOLE
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FRASER-HIDALGO
MILLER, A.
FISCH
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CAIN
GUTIERREZ
WILLIAMSON
CULLISON
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BARNES, B.
FRUSH
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HEALEY
WASHINGTON, A.
HOLMES
VALENTINO-SMITH
VALLARIO
BARRON
HOWARD, C.
LEWIS, J.
ANGEL
BARNES, D.
DAVIS
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CAREY
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BEKELE
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SOPHOCLEUS
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REILLY
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SAMPLE-HUGHES
ANDERTON
CAROZZA
OTTO
BARKLEY
BZIAK
ROBINSON
CROSBY
HAYES
MOSBY
ALI
GIBSON
ROSENBERG
ALBRIGHT
LAFFERTY
WEST
ANDERSON
WORTHAM
WASHINGTON, M.
HAYNES
STEWIR
YOUNG, P.
BRANCH
GLENN
McCRAY
CLIPPINGER
LEWIS, A.
LEDMAN
FENCILL
SANCHEZ
TARLAU

- 80% of Americans die from an illness over time
- 20% of Americans die suddenly

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Health Policy

journal homepage: www.elsevier.com/locate/healthpol

The public's perspectives on advance directives: Implications for state legislative and regulatory policy

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Legislative policy
End-of-life care

ABSTRACT

Objectives: Determine the prevalence of advance directives (ADs) in Maryland and identify the barriers and enablers to their adoption, in order to guide the formulation of state legislative policy.
Methods: Cross-sectional survey administered over the telephone to a representative age-stratified random sample of 1195 Maryland adults.
Results: Approximately 34% ($n = 401$) of Maryland adults reported having an AD. Older adults (65+ years) were more likely than younger adults (18–64 years) to have ADs ($p < 0.001$); the proportional difference between those with and without ADs diminished as age increased. Two times as many Whites than Blacks reported having ADs (43–23%; $p < 0.001$). Of those who had an AD, the primary motivations for creating one was a personal medical condition or a diagnosis to one's self or a family/friend (41%). Those without ADs identified lack of familiarity with them (27%), being too young or healthy to need one (14%), or uncertainty of the process for adopting one (11%) as reasons for not having one.
Conclusions: Barriers to AD adoption appear amenable to policy interventions. Policies that seek to increase access and ensure ease of enrollment, combined with a targeted public health advocacy campaign, may help increase the prevalence of ADs.

End-of-Life Care Issues: A Personal, Economic, Public Policy, and Public Health Crisis

Advance directive documents are free, legal, and readily available, yet too few Americans have completed one. Initiating discussions about death is challenging, but progress in medical technology, which leads to increasingly complex medical care choices, makes this imperative.

Advance directives help manage decision-making during medical crises and end-of-life care. They allow personalized care according to individual values and a likely reduction in end-of-life health care costs.

We argue that advance directives should be part of the public health policy agenda and health reform. (*Am J Public Health*. Published online ahead of print April 18, 2013: e1–e3. doi:10.2105/AJPH.2013.301316)

Dan K. Morhaim, MD, and Keshia M. Pollack, PhD, MPH

IS END-OF-LIFE CARE A MATTER

of personal values, economics, public policy, or a looming public health crisis? Actually, it is all of these. But when we consider the population's demographic shift to older adults, which is associated with chronic illness and multiple comorbidities, the enormous health care costs consumed in end-of-life care, and complex ethical issues, it is time for the public health community to put this issue squarely on its agenda. Increasing the rate of completion of advance directives is a key step, and specific policy strategies can be identified to accomplish this objective.

Advance directives were created by federal and state law to ensure autonomy of patients who eventually become unable to make decisions for themselves.[1,2] Advance directives are free, legal, and straightforward forms that can be completed in a few minutes.

RATE OF AMERICANS WHO HAVE COMPLETED ADVANCE DIRECTIVES

The question of rate of completion across the general population arose as we worked on public policy questions in the Maryland legislature relating to end-of-life care (the lead author is a Maryland State Legislator).[3] Although data are collected on almost every aspect of health care, this is one area where data were scarce. Previous studies that have investigated the frequency of advance directive completion were focused on selected populations of people already confronting end-of-life care issues: nursing homes, senior centers, or oncology practices.[4–8] Information about the prevalence of advance directives across the general population was lacking, which posed a challenge to the development of evidence-informed policies.

people did not complete advance directives? About a quarter of those who did not have an advance directive said they did not know about them. Others felt they were too young or healthy to complete them or were concerned about the cost, complexity, or time that might be required to do so.

We also found that people wanted to obtain information on advance directives from their doctors or other health care providers. They preferred this to getting information from attorneys, clergy, or online sources. This means that health care providers have an important role to play. One of us (DM) has written a book, *The Better End: Surviving (and Dying) on Your Own Terms in Today's Modern Medical World,* to help encourage this discussion in families and with providers.[11]

Our study also revealed significant differences among racial and

Advance Directives: Three Parts

The first part of an advance directive:
Choosing a health care agent


To be trusted is a greater compliment than to be loved.
- George MacDonald

The second part of an advance directive: What kind of care do you want?

- Everything – the full court press
- The middle path
- Very little or nothing – let nature take its course:
- Allow natural death A.N.D. (vs. Do Not Resuscitate/no CPR)

“Under new business: Peterson, at Hammond Point Beach, reports a person in the water is flailing about and calling for help. Peterson wants to know what action, if any, he should take.”

The hardest thing to learn in life is which bridge to cross and which to burn.

- David Russell

Everything (the full court press)

- You will get full medical treatment including IVs, surgery, feeding/hygiene tubes, diagnostic tests, etc., regardless of functional state
- At times, this is appropriate; at other times, it is not
- Who decides?

Very Little

also known as:

- Allow Natural Death (AND)
- Comfort Care

- This can be a reasonable choice when all hope and expectation of any kind of physical and mental recovery is impossible
- Hospice and palliative care (early) is very useful and should be obtained

The Middle Path

- This is the choice most of us take
- It's my personal choice: I want the best modern medicine has to offer while it is still useful and beneficial
- If I'm aware of what's going on and can participate in life, if I'm not in persistent intractable pain, then keep me going
- If I'm not, please try reasonable - but not extraordinary - care should a serious life-threatening illness arise
- **Use hospice and palliative care early**

Ronald Reagan: Breaking down the barriers to discussion

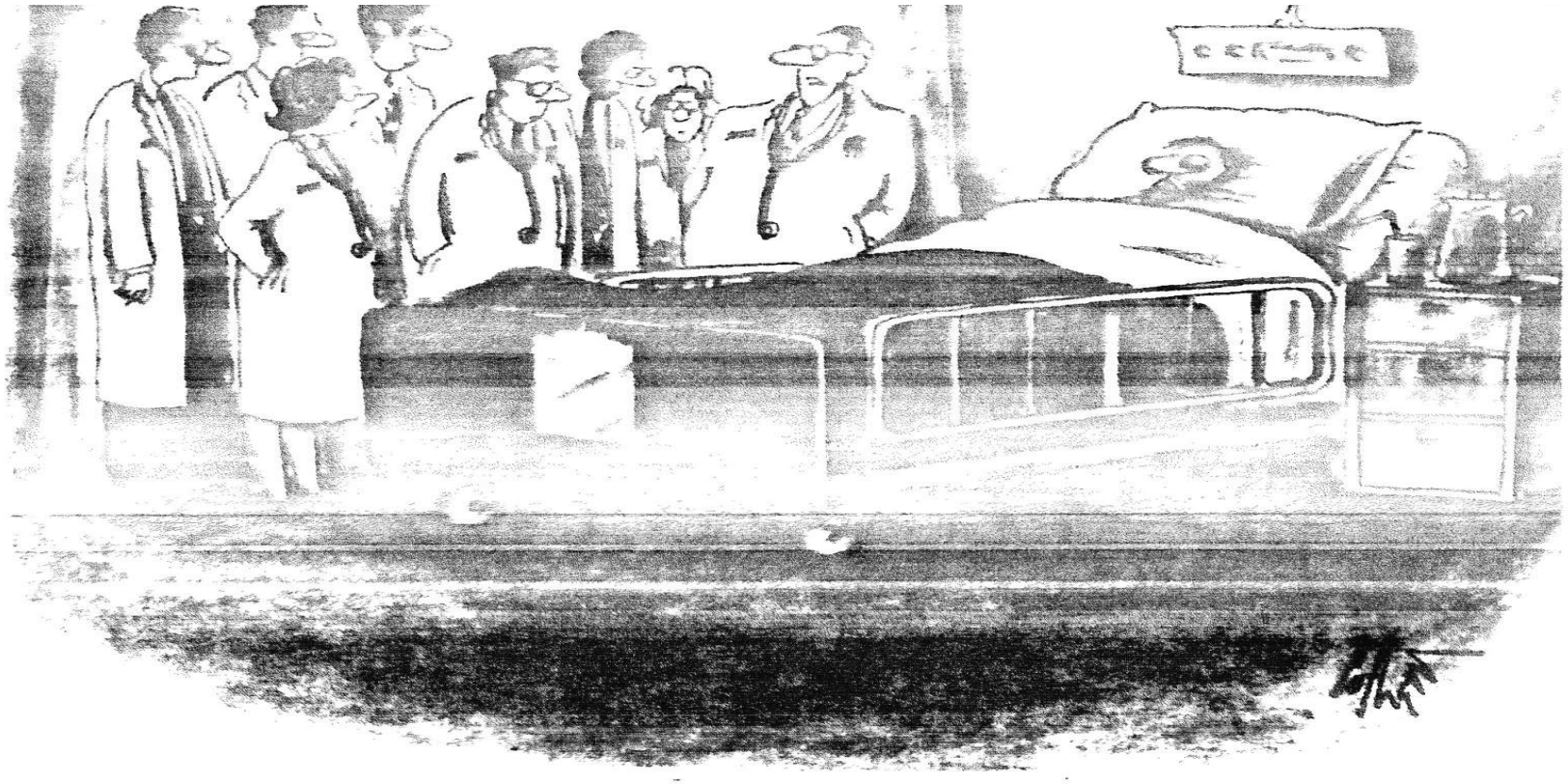
I am one of the millions of Americans afflicted with Alzheimer's disease. Nancy and I had to decide whether we could keep this a private matter or whether we would make this known in a public way. In the past, Nancy suffered from breast cancer, and I had my cancer surgeries. We found through our open disclosures we were able to raise public awareness.

It’s not just for old people

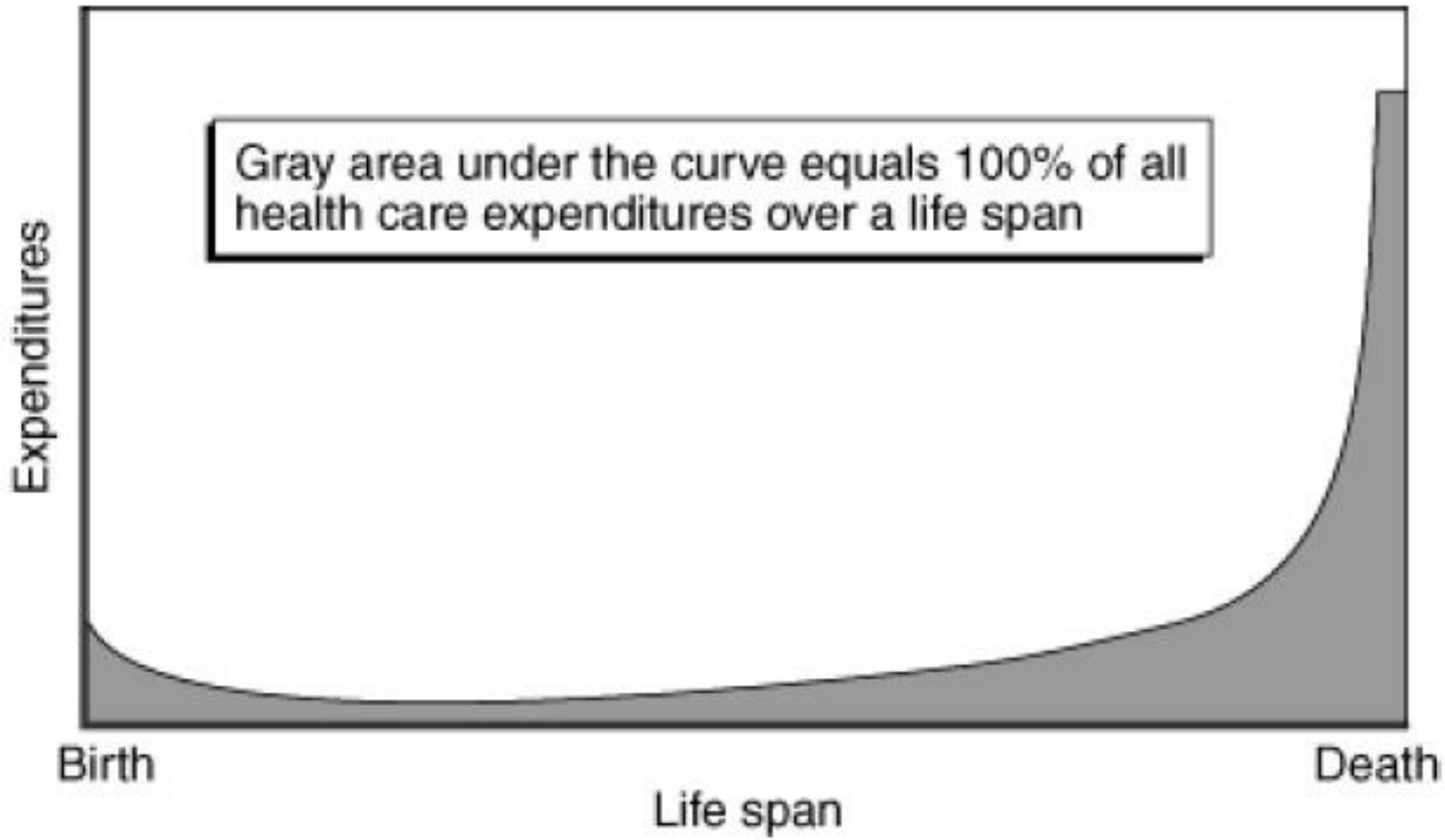
The 3 most famous cases in the legal history of end-of-life care were women under 30:

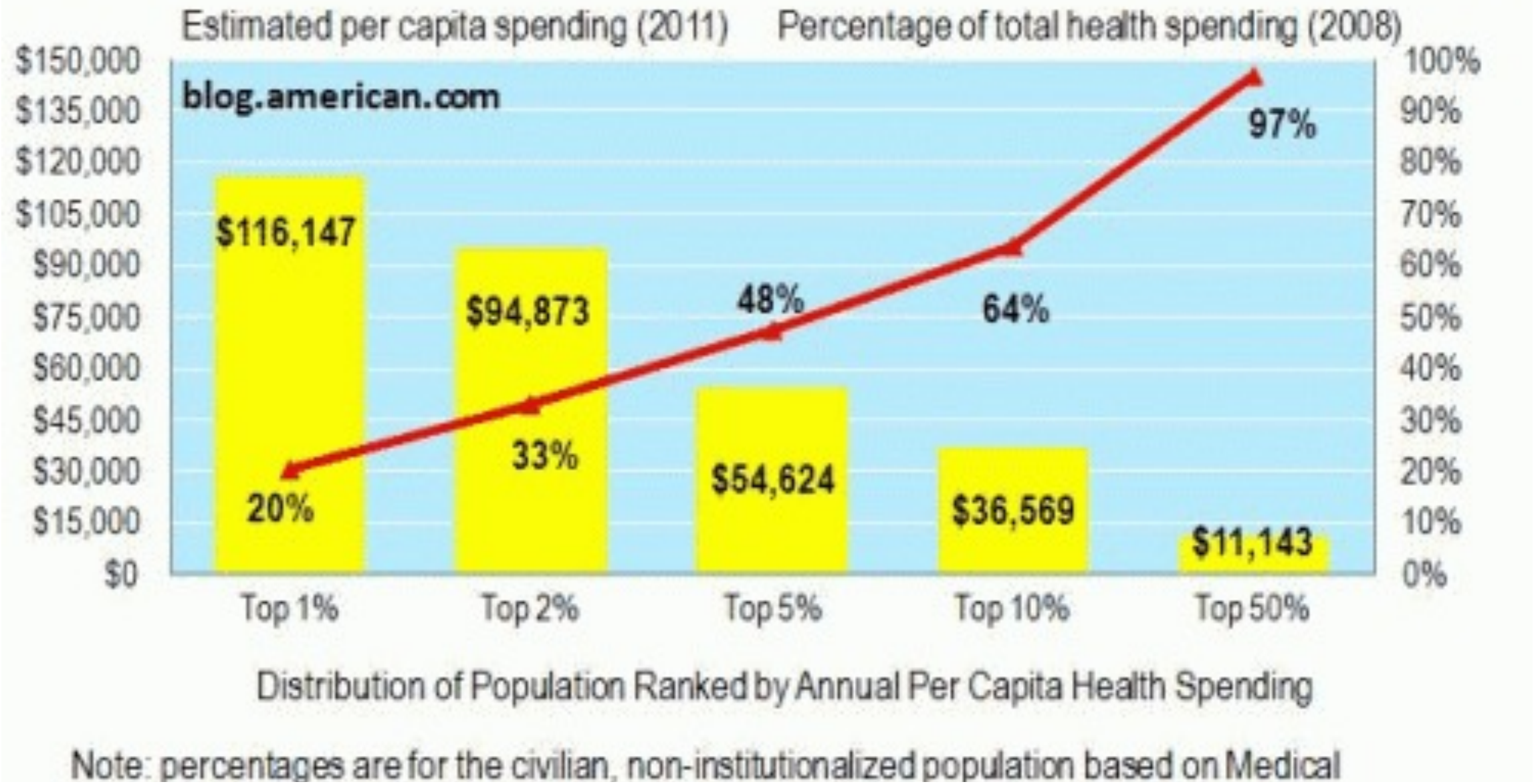
- Karen Quinlan
- Nancy Beth Cruzan
- Terry Schiavo

“This patient has a rare form of medical insurance.”



“This patient has a rare form of medical insurance.”


Gray area under the curve equals 100% of all health care expenditures over a life span
Expenditures
Birth
Death
Life span


Estimated per capita spending (2011)
Percentage of total health spending (2008)
blog.american.com
$150,000
$135,000
$120,000
$105,000
$90,000
$75,000
$60,000
$45,000
$30,000
$15,000
$0
100%
90%
80%
70%
60%
50%
40%
30%
20%
10%
0%
$116,147
$94,873
$54,624
$36,569
$11,143
20%
33%
48%
64%
97%
Top 1%
Top 2%
Top 5%
Top 10%
Top 50%
Distribution of Population Ranked by Annual Per Capita Health Spending
Note: percentages are for the civilian, non-institutionalized population based on Medical

Unfortunately, there's no cure…there's not even a race for a cure.

Filling out free forms can help save Medicare

- Published 4/1/2023 by Michael Smerconish (CNN) https://www.smerconish.com/exclusive-content/filling-out-free-forms-can-fix-medicare/

  Quotes from the article:

- The headlines warn us that Medicare is near financial distress with Part A funds (which pay for hospitals and nursing homes) being depleted by 2026. Others predict benefit reductions starting in 2028. So far, the “fixes” are focused on a series of financial manipulations, which could lead to poorer patient coverage, reduced eligibility status, and higher taxes.

- What if 95% of Medicare recipients completed advance directives and these were available to be applied by clinicians? That could lead to reductions of 20% (a conservative estimate) of that $250-$300 billion. Savings of $50-$60 billion would then be achieved not by restricting care options but by expanding them and respecting individual citizens’ personal choices.

What if?

When people complete advance directives, end-of-life care costs are reduced because of the decisions they make.

Proven in La Crosse, WI.

Smoking changes health insurance ratings. Obesity impacts life insurance ratings.

What if completion of advance directives lowered health insurance costs for individuals and employers?

Something to explore.

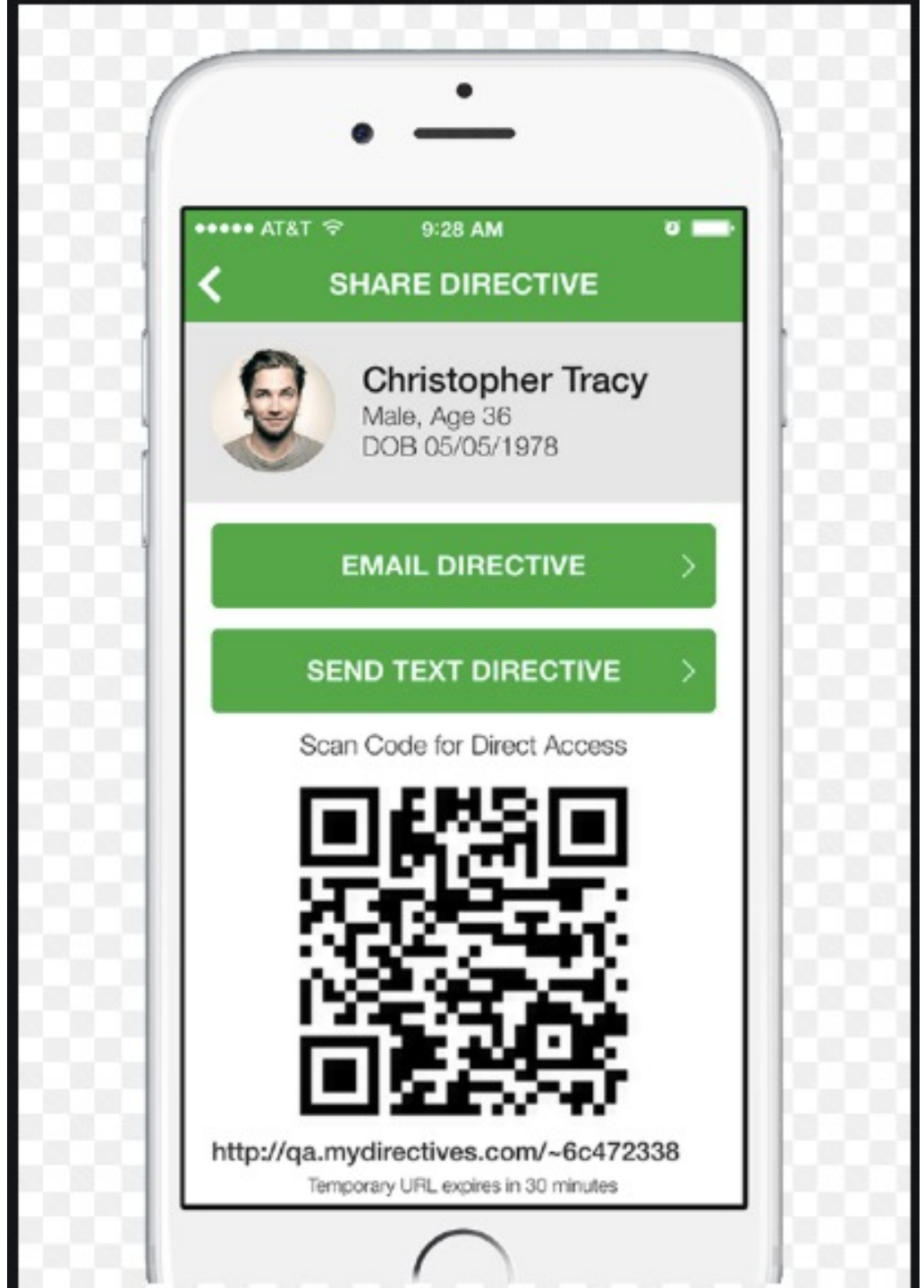
ADVANCE DIRECTIVE SOURCES

Available from many sources including:

- My Directives mydirectives.com
- State and local health departments; Attorney General
- AARP https://www.aarp.org/caregiving/financial-legal/free-printable-advance-directives/
- Faith based
- Include in personal electronic medical record

MiMirx: mimirx.org MyVax: myvax.com


myDirectives®
John Doe
My Universal Advance Digital Directive (uADD)™ can be found at: https://secure.mydirectives.com
350 × 198


AT&T
9:28 AM
SHARE DIRECTIVE
Christopher Tracy
Male, Age 36
DOB 05/05/1978
EMAIL DIRECTIVE
SEND TEXT DIRECTIVE
Scan Code for Direct Access
http://qa.mydirectives.com/~6c472338
Temporary URL expires in 30 minutes

The third part of an advance directive: After death

- Organ Donation
- Disposition of the body

(burial, cremation)

- Medical school donation must be arranged in advance

The majority of humans behave as if death were no more than an unfounded rumor.

- Aldous Huxley

“The amount of wood from coffins in a ten acre cemetery is enough to build 40 houses, and there is enough concrete to build swimming pools for all of them.”

Mark Harris, Grave Matters

Environmental Impact of Cremation

- uses fossil fuels to maintain 1900° F 2+ hours
- releases mercury and other elements into air and water
  (Britain estimates cremation accounts for 16% of emissions)
- produces 250 lbs. CO_2 per cremation
- produces byproduct emissions of nitrogen oxide, sulfur dioxide, dioxins, particulates

What is Green Burial?

- **A way of caring for the dead that furthers one or more environmental aims such as:**
  - the protection of worker health
  - conservation of natural resources
  - reduction of carbon emissions
  - preservation/restoration of habitat

- **Eliminates use of:**
  - toxic chemical embalming
  - metal or exotic wood caskets
  - concrete, fiberglass, or plastic vaults

- **Encourages:**
  - locally sourced biodegradable containers
  - family participation
  - environmentally sound management practices

Photo courtesy of Prairie Creek

Natural Green burials are here now in Maryland

- Complete natural burial center is now open in Baltimore County:

Serenity Ridge Natural Burial Center and Arboretum https://www.serenityridgemd.com/

- Reflection Park coming to Montgomery County
- Green Burial Association of Maryland (GBAM): https://greenburialmaryland.org/
- Portions of conventional cemeteries being converted

OTHER ASPECTS

- Medical cannabis
- Pain management: narcotics, sedatives
- Dementia, Alzheimer’s disease
- Organ donation
- Spiritual practices and rituals
- Palliative and Hospice Care
- What doctors want for themselves
- COVID impact
- Minority and diversity perspectives
- Compassionomics
- Helping/supporting others
- La Crosse, Wisconsin
- Assisted dying

WRONGFUL LIFE LAWSUITS

- https://www.nytimes.com/2021/01/22/health/elderly-dnr-death-lawsuit.html

- "Lawsuits charging negligence or malpractice by hospitals and doctors typically claim that they have failed to save patients' lives."
- "Some families have sued if providers failed to heed patients' documented wishes and prevented death from occurring."
- "Several plaintiffs have received hefty payments, and courts have weighed in as well."
- "**In Montana, a jury delivered what is believed to be the first verdict in a wrongful life case, awarding $209,000 in medical costs and $200,000 for "mental and physical pain and suffering**" to the estate of Rodney Knoepfle in 2019."

https://www.advisory.com/daily-briefing/2021/02/22/wrongful-life

- Why some providers get sued for 'wrongful life'
- According to a 2017 analysis of 150 studies, just under half of people over the age of 65 have an advanced directive that details their end-of-life wishes.
- But in some instances, health care providers neglect to follow those directives. In other cases, however, health care providers or organizations "overlook the documents in patients' charts or ignore conversations with health care proxies," or "[d]octors who doubt that a patient actually prefers to die may override the instructions." The occurrences have led some patients to file so-called "wrongful life" suits against their providers."
- "In the past, people have said, 'How have we harmed you if we kept you alive? Now, courts have said this is a compensable injury."
- Wrongful life lawsuits are becoming more common
- Four years ago, no one had ever received compensation for a wrongful life suit. But since that time, a number of people have won such suits against providers.

https://www.reliasmedia.com/articles/141800-lawsuits-allege-patients-end-of-life-wishes-ignored

A 91-year-old woman presented to an ED, advance directive in hand, indicating her end-of-life instructions. In addition, her granddaughter stressed to caregivers that no heroic measures were to be taken. Despite these efforts, the woman was intubated and operated on, and the family sued the hospital.

- “Our client was very much aware of advance directives, having had a family member suffer unnecessarily, and insisted on having hers in her hand whenever she went to see the doctor,” says Harry Revell, JD, an attorney at Augusta, GA-based Nicholson Revell, who represented the patient’s family.
- **The patient’s advance directive was never added to the patient’s chart.** “However, it was documented in the chart that there should be no intubation without first contacting the patient’s agent,” says Revell.
- **The hospital had appropriate policies in place for advance directives. “The problem was, they didn’t follow them,”** says Revell. “There was, we thought, a flagrant and obvious conscious choice to ignore the patient’s instructions, both written and verbal.”
- **The hospital filed a motion for summary judgment, which the trial court denied. That ruling was later affirmed by both the Georgia Court of Appeals and the Georgia Supreme Court. The case settled for $1 million shortly before trial — an amount that the family insisted would not be confidential. “We feel it’s important for the public to be informed about this issue, and for healthcare providers to be mindful of this,” says Revell. “The amount will hopefully get everybody’s attention.”**

- https://moultonlaw.com/wrongful-life/

- “Dick Magney had decided to undergo palliative treatment and his treatment providers were all complying with his wishes. That is, until someone alerted the Humboldt County’s adult protective services agency that neglect was potentially occurring. This led to Humboldt County *filing a petition* to take control of his treatment plan, which removed his wife from her role as the existing decision maker. At that point, the county decided that Mr. Magney should receive antibiotics that he’d clearly refused much earlier. The county went as far as receiving temporary conservatorship status in this case.
- “This just led to him suffering longer,” said Allison Jackson, the attorney that represented Mr. Magney’s wife. Mrs. Magney later went on to receive **over $200,000** in reimbursement payments for lawyers’ fees and followed that up with a Federal civil rights complaint, which led to an additional **$1 million settlement** with the county. **The two attorneys who filed the petition representing Humboldt County are now facing disciplinary action from the California state bar.”**

Source: https://www.washingtonpost.com/national/health-science/you-may-have-signed-a-living-will-but-scary-mistakes-can-happen-at-the-er/2018/08/03/418ec3e8-6fed-11e8-bf86-a2351b5ece99_story.html

- A new report out of Pennsylvania, which has the nation's most robust system for monitoring patient-safety events, treats mix-ups involving end-of-life documents as medical errors — a novel approach. It found that in 2016, Pennsylvania health-care facilities reported nearly 100 events relating to patients' "code status" — their wish to be resuscitated or not, should their hearts stop beating and they stop breathing. In 29 cases, patients were resuscitated against their wishes. In two cases, patients weren't resuscitated despite making it clear they wanted this to happen.

Statement to being added to directives

- If anyone threatens, overrides, or pressures my designated health care agent or me (including medical personnel or hospitals), I authorize my health care agent to seek appropriate and immediate legal action.
- Any health care provider or institution who does not follow my directives should be replaced immediately.

NEW HEDIS NCQA MEASURES COMING

NCQA=National Committee on Quality Assurance (https://www.ncqa.org/)

HEDIS= Healthcare Effectiveness and Data Information Set (https://www.ncqa.org/hedis/)

- *Every year, NCQA updates and releases the Healthcare Effectiveness Data and Information Set (HEDIS®). This process ensures that HEDIS measures remain relevant and feasible for implementation. The HEDIS process is significant: its measurements, development, and updates follow a rigorous process that includes a public comment period and input from advisory panels.*
- *New HEDIS Measures*
- *The newest additions to HEDIS address patient-centered care, as well as safety and appropriateness.*
- *Advance Care Planning. The percentage of Medicare members 65-80 years of age with advanced illness, indication of frailty or receiving palliative care, and adults 81 years of age and older who had advance care planning during the measurement year.*
- *Intent: Advance care planning is associated with improved qua lity of life, increased provider trust, and decreased hospitalizati on. This will allow plans to understand if advance care plannin g is provided to the beneficiaries who are most likely to benefit from it.*

Get paid for advance care planning

- CPT Code 99497- Advance care planning including the explanation and discussion of advance directives such as standard forms (with completion of such forms, when performed), by the physician or other qualified health care professional; first 30 minutes, face-to-face with the patient, family member(s), and/or surrogate
- CPT Code 99498- each additional 30 minutes (List separately in addition to code for primary procedure)
- Be sure to document properly

System shortfalls

(and Maryland has addressed in part)

- **Two big ones that can be addressed right now**

1) Advance Care Plans information inadequate*

Need to be available routinely: these are not in the EHR locally and nationally

In 2022, Maryland enacted legislation to help fix this: HB1073/SB824

2) Medication information inadequate*

5%-10% of hospitalizations are medication related

More new medicines: beneficial but more complicated, interactions, adverse events

Often overlooked in differential diagnosis

Clinicians can find out about Schedule 2-5 medications,

But what about the other 99.5% of medications?

In 2022, Maryland enacted legislation to help fix this: HB1127

***Read the bills and testimony at https://mgaleg.maryland.gov/**

How to respond

- **Reach out to the community: sponsor National Healthcare Decisions Day every April 16.**
- Better to plan ahead than wait until something happens. Develop a strategy now.
- It will be a gradual approach over time.
- Lead by example: encourage hospital executives, professional staff, and employees to complete advance directives.
- Create training programs about advance directives and other advance medical planning documents (e.g. POLST/MOLST) especially for ER and Intensive Care Units.
- Involve Social Workers, Chaplain staff, others.

“All humans are aware of death, so we’re all a little bit sad. All the time. That’s just the deal. But that knowledge is what gives life meaning.”

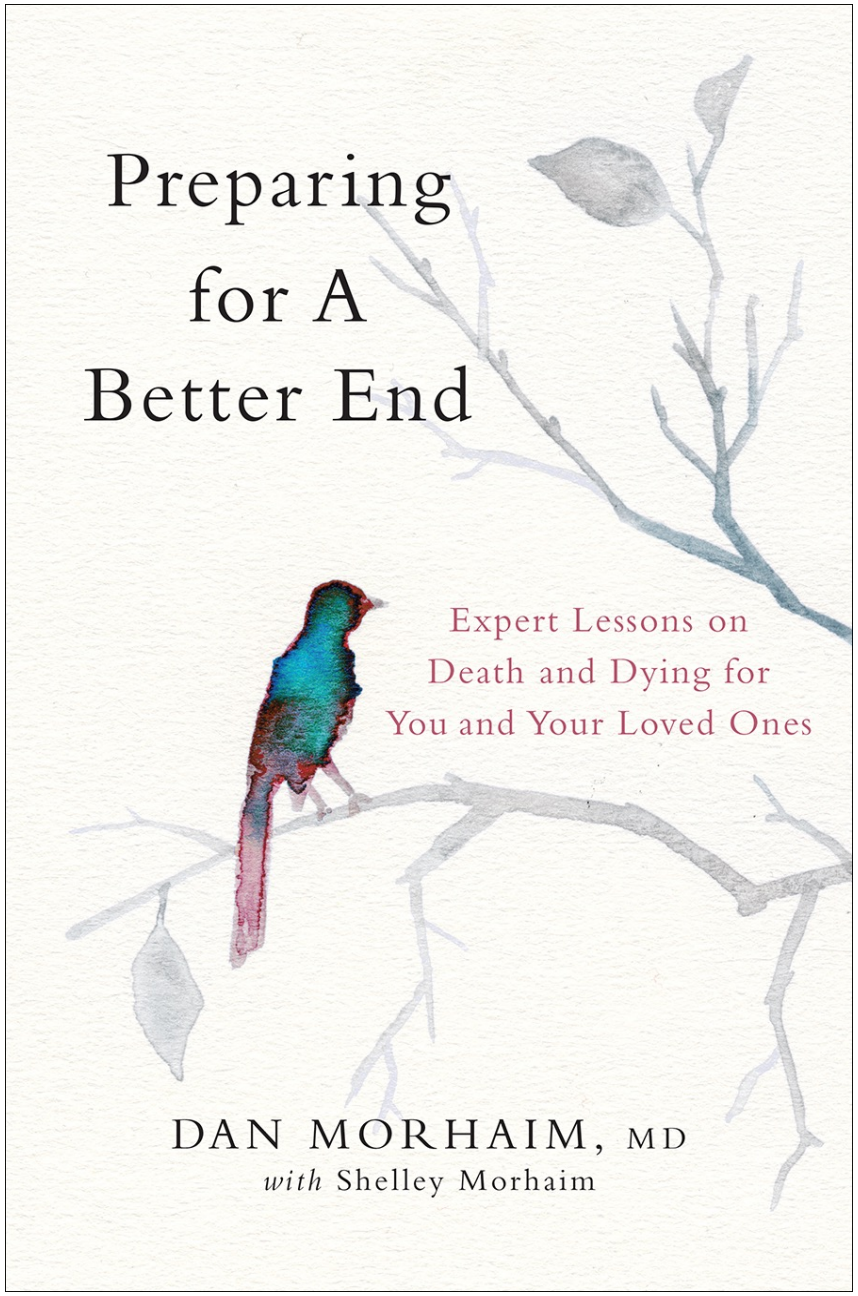
Eleanor Shelstrop from “The Good Place” TV show

Your role?

- Can you be the one to bring this up to friends, family, colleagues, co-workers?
- Almost everyone wants to have this discussion, but someone has to be the one to break the ice and start the conversation.

Live as if you were to die tomorrow. Learn as if you were to live forever.

- Mahatma Gandhi



www.thebetterend.com

- Summary, reviews, reviews, ordering
- Endorsements from Maya Angelou, US Senator Ben Cardin, Dr. Leana Wen, Dr. Leon McDougle (OSU), Hopkins Dean Dr. Michael Klag, and many others from medical, legal, and faith communities.
- Johns Hopkins Press: https://www.press.jhu.edu (go to Browse All, then Search, and enter ”Morhaim”)
- Amazon (of course)
- Bookshop.org and your local bookstore
- Contact information: danmorhaim@gmail.com

Available for presentations and discussions

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MY TIPS FOR AVOIDING MALPRACTICE LAWSUITS IN THE ER (and elsewhere)

- Self-introduction with my first and last name
  (and sometimes: “Call me Dr. Dan”)
- Introduction for everyone in the room
- Ask open-ended question: What brings you in today? How can I help you? What’s going on?
- THEN: listen without interruption for 2-3 minutes by the clock
- Establish physical presence
- No screens – keep focus on the patient
- Suggest time frames for evaluation, tests, discharge/admit with generous estimates
- Check in periodically so patient knows they have not been forgotten; keep the patient informed even if there’s nothing new to say
- Express concern beginning, middle, end
- 100% follow-up at discharge

- And, of course, document well!