Lessons from Seville: Identifying and Reducing Inappropriate End-of-Life Treatment in New Jersey

Thaddeus Mason Pope, J.D., Ph.D.
Z. Stanley Stys Memorial Lecture
Princeton University Medical Center
May 10, 2011

1

Delighted

Honored

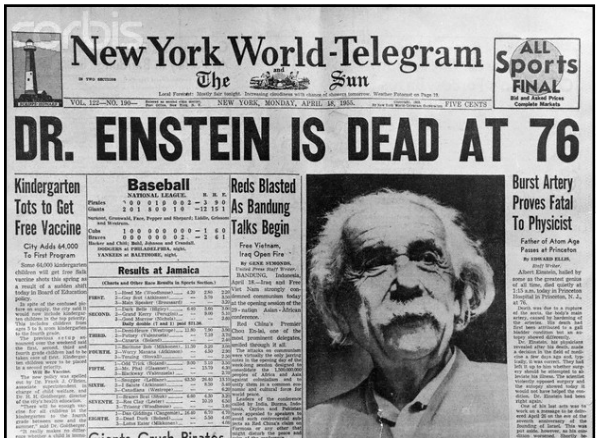
Z. Stanley Stys
Danuta Buzdygan

2

April 18, 1955

Princeton, NJ

3



New York World-Telegram
The Sun
VOL. 122—NO. 190— NEW YORK, MONDAY, APRIL 18, 1955. FIVE CENTS

ALL Sports FINAL
Bid and Asked Prices
Complete Markets

DR. EINSTEIN IS DEAD AT 76

Kindergarten Tots to Get Free Vaccine

City Adds 64,000 To First Program

Baseball

NATIONAL LEAGUE.

Results at Jamaica

Giants Crush Pirates

Reds Blasted As Bandung Talks Begin

Free Vietnam, Iraq Open Fire

Burst Artery Proves Fatal To Physicist

Father of Atom Age Passes at Princeton

Albert Einstein, hailed by some as the greatest genius of all time, died quietly at 1:15 a.m. today in Princeton Hospital in Princeton, N. J., at 76.

I want to go when **I** want. It is tasteless to prolong life artificially.

I have done my share, it is time to go. I will do it elegantly.

CPR

Dialysis

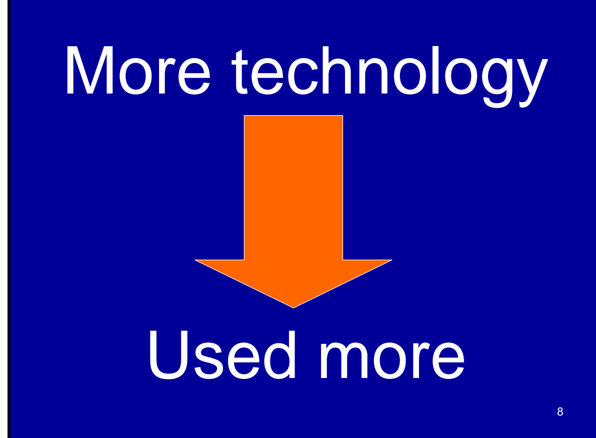
Mech. ventilation

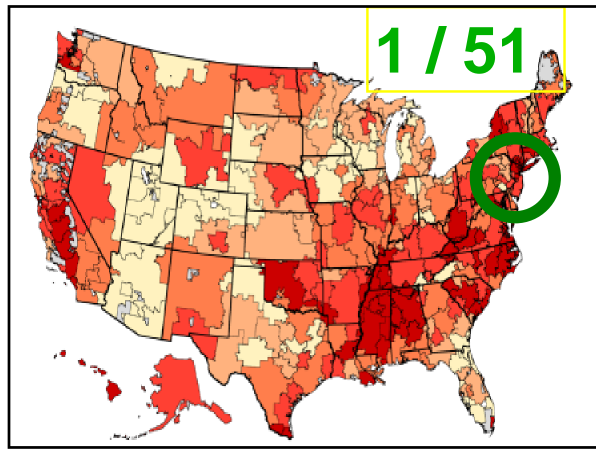
ICUs

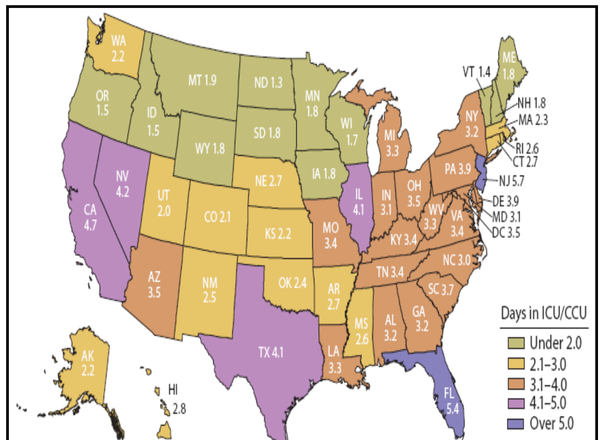
May

2011

7







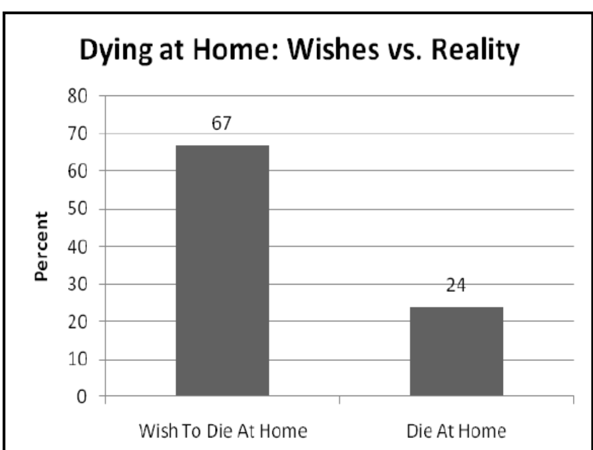
Value = Quality / Cost

$$\text{Value} = \frac{\text{Quality}}{\text{Cost}}$$

71%: "More important to enhance the **quality** of life for seriously ill patients, even if it means a **shorter life.**"

National Journal (Mar. 2011)

Question and Responses[a]	Public, % (n=1006)	Professionals, % (n=774)
If doctors believe there is no hope of recovery, which would you prefer?		
Life-sustaining treatments should be stopped and should focus on comfort	72.8	92.6
All efforts should continue indefinitely	20.6	2.5



Harm to family

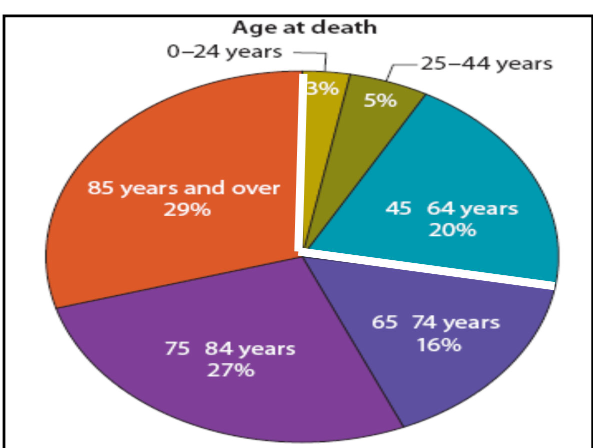
Emotional

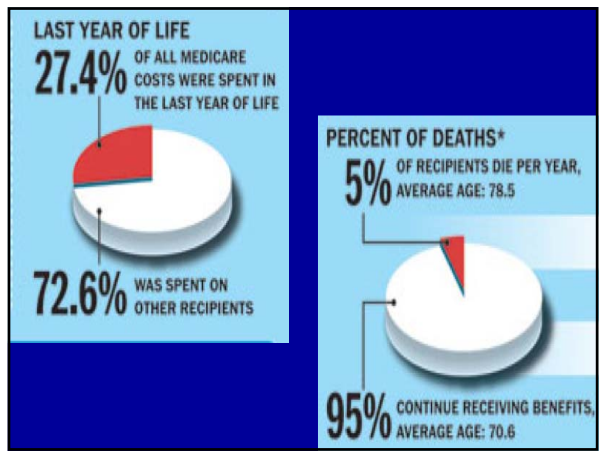
Economic

Harm to others

- Limited ICU beds
- ER boarding
- Antibiotic resistance
- Moral distress

16





Why

How to fix

19

Patients

Surrogates

Providers

Payers

20

Patient Problem

21

Associations Between End-of-Life Discussions, Patient Mental Health, Medical Care Near Death, and Caregiver Bereavement Adjustment

Alexi A. Wright; Baohui Zhang; Alaka Ray; et al.

JAMA. 2008;300(14):1665-1673 (doi:10.1001/jama.300.14.1665)

EOL discussion

less aggressive medicine

22

Arch Intern Med. 2009;169(5):480-488

Variable	Discussed EOL Care Preferences With Physician: Yes (n=75)	Discussed EOL Care Preferences With Physician: No (n=70)
Medical care received during the last week of life, No. (%)		
Intensive care unit stay	2 (2.7)	10 (14.3)
Ventilator use	1 (1.3)	10 (14.3)
Resuscitation	1 (1.3)	6 (8.6)
Chemotherapy	4 (5.3)	7 (10.0)
Inpatient hospice used	8 (10.7)	5 (7.1)
Inpatient hospice stay ≥1 wk	4 (5.3)	2 (2.9)
Outpatient hospice used	58 (77.3)	40 (57.1)
Outpatient hospice stay ≥1 wk	52 (69.3)	34 (48.6)
Place of death, No. (%)[b]		
Intensive care unit	2 (2.9)	9 (13.2)
Hospital	15 (21.7)	18 (26.5)
Inpatient hospice	5 (7.2)	3 (4.4)
Home	47 (68.1)	38 (55.9)

Associations Between End-of-Life Discussions, Patient Mental Health, Medical Care Near Death, and Caregiver Bereavement Adjustment

Alexi A. Wright; Baohui Zhang; Alaka Ray; et al.

JAMA. 2008;300(14):1665-1673 (doi:10.1001/jama.300.14.1665)

EOL discussion

Earlier hospice referral

Better patient QOL

Better family bereavement

24

Not completed

Not found

Not informed

Not clear

ABA

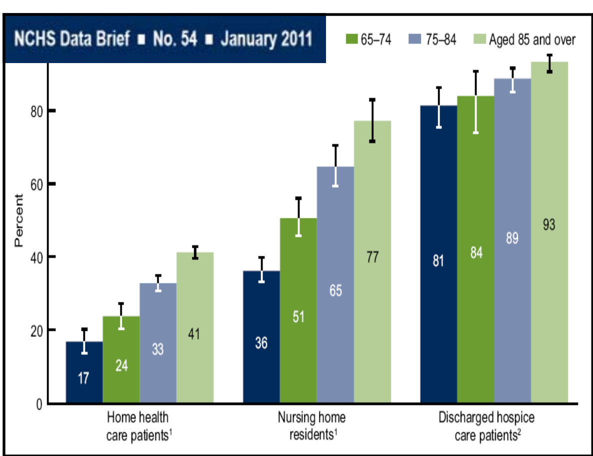
AMERICAN BAR ASSOCIATION

30%

AARP

28% 35-50

50% 50+



65-76% of physicians whose patients have advance directives do not know they exist

U.S. Department of Health and Human Services
Assistant Secretary for Planning and Evaluation
Office of Disability, Aging and Long-Term Care Policy

Enough

The Failure of the Living Will

by Angela Fagerlin and Carl E. Schneider

In pursuit of the dream that patients' exercise of autonomy could extend beyond their span of competence, living wills have passed from controversy to conventional wisdom, to widely promoted policy. But the policy has not produced results, and should be abandoned.

HASTINGS CENTER REPORT March–April 2004

Trigger terms vague

"Reasonable expectation of recovery"

75% 51%

25% 10%

Plus: prognosis uncertain

30

Preferences vague

"No ventilator"

Ever

Even if temporary

31

More technology is the **default**

Patient must **opt out**

32

Patient Solution

33

More ACP

Better documentation

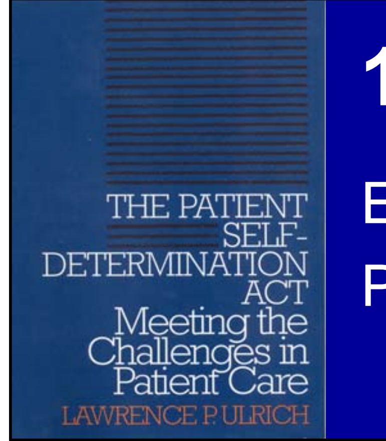
Equalized safeguards

34

Prompt

Providers

35



1991

Enforce PSDA

36

Voluntary
Advance
Care
Planning
Blumenauer
H.R. 3200
Sec. 1233

TODAY
I WAS TOLD I WAS
TOO OLD...
I WAS
CANCELED
RATIONED HEALTHCARE
FOR THE GOOD OF THE COUNTRY
OBAMA-CARE

RED FLAG
THIS PRODUCT
IS TOXIC
OBAMA
CARE
© Flag_This 2009
SENIORS CHECK IN...
BUT THEY DON'T CHECK OUT!

PPACA silent on ACP. But does cover **annual wellness visits**.

Section 4103

40

DHHS: “Notice of Proposed Rulemaking: Physician Fee Schedule” (July 2010)

41

Final Rule (Nov. 2010)

Defined “VACP” as element of annual wellness visit

42

Lie of the Year:

"Death Panels"

A "**quiet**" victory

"The longer this goes **unnoticed**, the better our chances of keeping it."

Jan. 2011: Rescind VACP

"We did not have an opportunity to consider . . . the wide range of views . . . held by a broad range of stakeholders"

H. R. 6331

One Hundred Tenth Congress
of the
United States of America

AT THE SECOND SESSION

(1) IN GENERAL.—Section 1861(ww) of the Social Security Act (42 U.S.C. 1395x(ww)) is amended—

"(3) For purposes of paragraph (1), the term 'end-of-life planning' means verbal or written information regarding—

"(A) an individual's ability to prepare an advance directive in the case that an injury or illness causes the individual to be unable to make health care decisions; and

"(B) whether or not the physician is willing to follow the individual's wishes as expressed in an advance directive.".

112TH CONGRESS
1ST SESSION

H. R. 1589

To amend the Social Security Act to provide for coverage of voluntary advance care planning consultation under Medicare and Medicaid, and for other purposes.

IN THE HOUSE OF REPRESENTATIVES

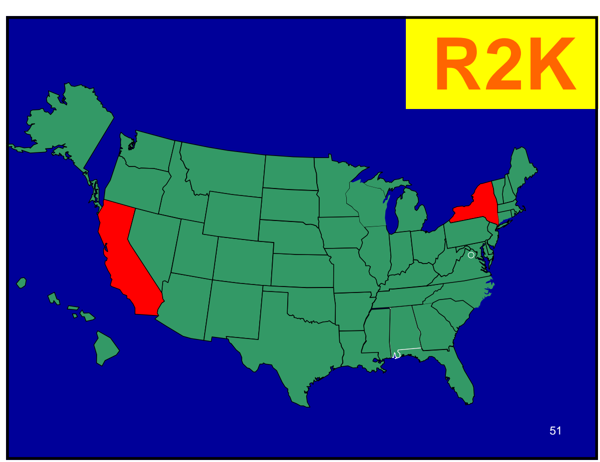
APRIL 15, 2011

SECTION 1. SHORT TITLE; FINDINGS; TABLE OF CONTENTS.

(a) SHORT TITLE.—This Act may be cited as the "Personalize Your Care Act of 2011".

Derecho a la información asistencial

Deberes respecto a la información clínica



Benefits

Risks

Alternatives

Financial

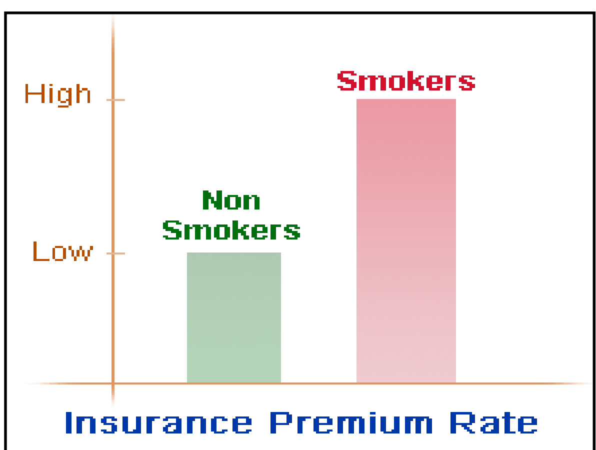
52

Prompt Patients

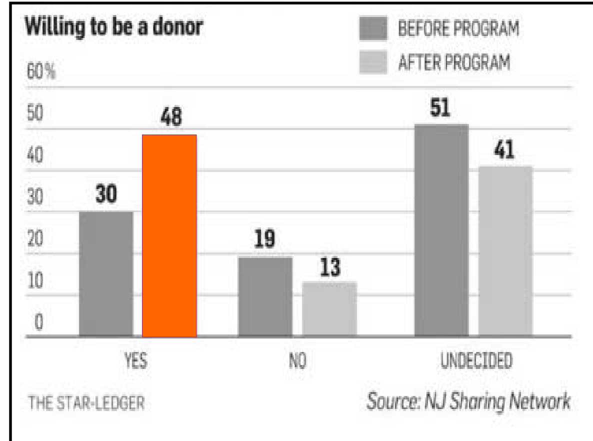
53

54

INTRODUCING...
VANISHING
DEDUCTIBLE
Watch your deductible start vanishing.
Get an auto quote
Safe Driver
RECOGNITION


High
Low
Smokers
Non
Smokers
Insurance Premium Rate

Nudge



Content agnostic

59

Make AD available

60

Registries

Organ donation

NOK

61

Make AD effective

62

POLST

Closes gap between what people **want** and what they **get**

64

FORM SHALL ACCOMPANY PATIENT/RESIDENT WHEN TRANSFERRED OR DISCHARGED

Physician Orders for Scope of Treatment (POST)

This is a Physician Order Sheet based on the person's medical condition and wishes. Any section not completed indicates full treatment for that section. When need occurs, first follow these orders, then contact physician.

Last Name

First Name/Middle Initial

Date of Birth

Section A — Check One Box Only

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

- ☐ Resuscitate (CPR)
- ☐ Do Not Attempt Resuscitation (DNR/no CPR)

When not in cardiopulmonary arrest, follow orders in B, C, and D.

Section B — Check One Box Only

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

- ☐ **Comfort Measures** Treat with dignity and respect. Keep clean, warm, and dry. Use medication by any route, positioning, wound care and other measures to relieve pain and suffering. Use oxygen, suction and manual treatment of airway obstruction as needed for comfort. **Do not transfer to hospital for life-sustaining treatment. Transfer only if comfort needs cannot be met in current location.**
- ☐ **Limited Additional Interventions** Includes care described above. Use medical treatment, IV fluids and cardiac monitoring as indicated. Do not use intubation, advanced airway interventions, or mechanical ventilation. **Transfer to hospital if indicated. Avoid intensive care.**
- ☐ **Full Treatment** Includes care above. Use intubation, advanced airway interventions, mechanical ventilation, and cardioversion as indicated. **Transfer to hospital if indicated. Include intensive care.**

Other Instructions:

Section C — Check One Box Only

ANTIBIOTICS

- ☐ No Antibiotics
- ☐ Antibiotics

Other Instructions:

Section D — Check One Box Only in Each Column

Medically Administered Fluids and Nutrition: Oral fluids and nutrition must be offered if medically feasible.

- ☐ No IV fluids (provide other measures to assure comfort)
- ☐ IV fluids for a defined trial period
- ☐ IV fluids long term if indicated
- ☐ No feeding tube
- ☐ Feeding tube for a defined trial period
- ☐ Feeding tube long term

Other Instructions:

Section E

Discussed with:

- ☐ Patient/Resident
- ☐ Spouse
- ☐ Other (Specify)

The Basis for These Orders Is: (Must be completed)

- ☐ Patient's preferences
- ☐ Patient's best interest (patient's preferences unknown)
- ☐ (Other)

Physician Name (Print)

Physician Phone Number

Office Use Only

Physician Signature (Mandatory)

Date

FORM SHALL ACCOMPANY PATIENT/RESIDENT WHEN TRANSFERRED OR DISCHARGED

Actionable orders

More likely honored

No need to "translate"

66

Portable

Travels with the patient in **all** treatment settings

Home	LTC
Hospital	EMS

67

Surrogate Problem

69

Surrogate must comply

Written instructions

Values & preferences

Best interests

66% accurate

50% = pure chance

Moorman & Carr 2010 **62%**

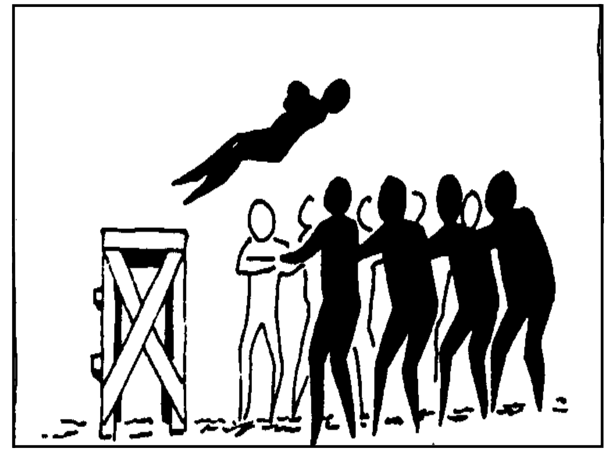
Barrio-Catelejo et al. 2009 **63%**

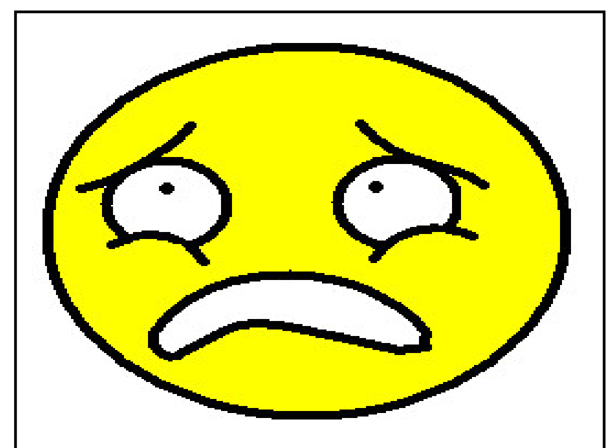
Shalowitz et al. 2006 **58%**

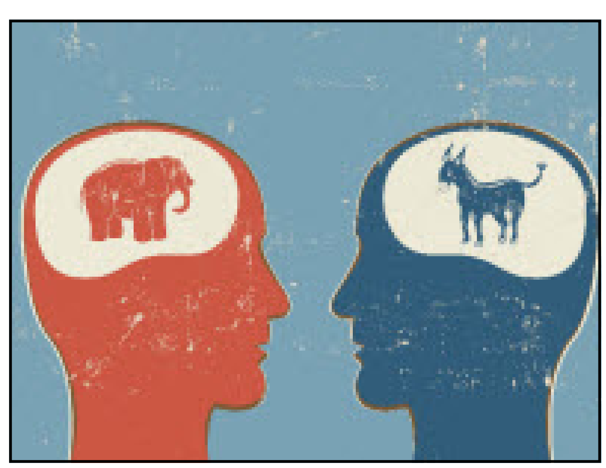
Even lower

when most needed:

intermediate zones

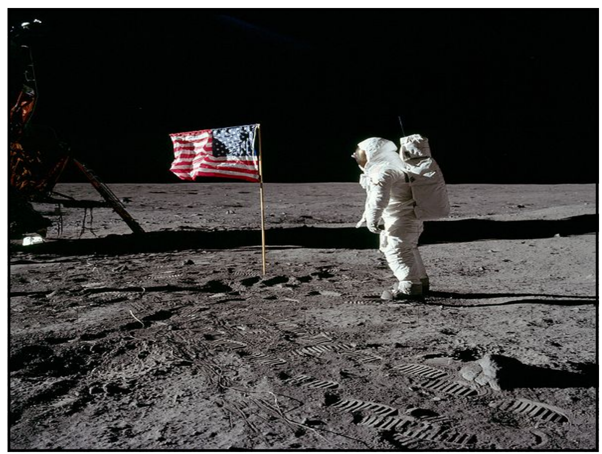


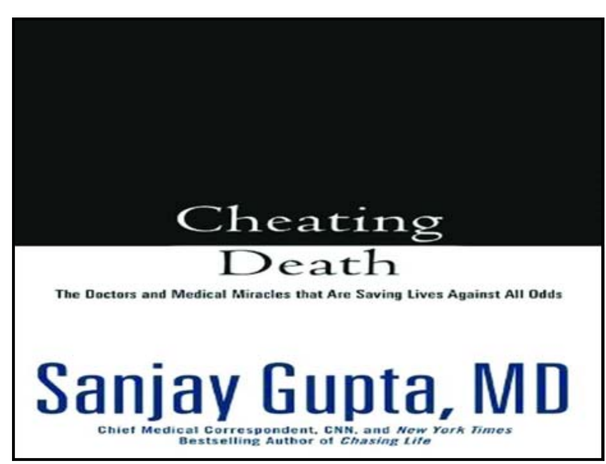




GUILT

Ceci n'est pas une pipe.




Cheating
Death
The Doctors and Medical Miracles that Are Saving Lives Against All Odds
Sanjay Gupta, MD
Chief Medical Correspondent, CNN, and New York Times
Bestselling Author of Chasing Life

More

aggressive treatment

85

	D: Palliative	D: Curative
P/S: Palliative		
P/S: Curative	**Futility**	

86

Surrogate Solution

87

Educate

Mediate

Replace

Override

88

Educate

89

Guide For Healthcare Agents & Surrogate Decision-Makers

Making decisions for patients who can't speak for themselves

The Role of the Substitute Decision-Maker (SDM)

Making Healthcare Decisions for Others

London Health Sciences Centre

Making Medical Decisions for Someone Else:
A How-To Guide

The American Bar Association
Commission on Law and Aging

Making Medical Decisions
For Someone Else

A New Hampshire Handbook

Are you, or will you be, responsible for managing the health care of someone else? This handbook can guide you through the decisions you may have to make and provide resources for more information.

Statement to Agent

Agent's Duties

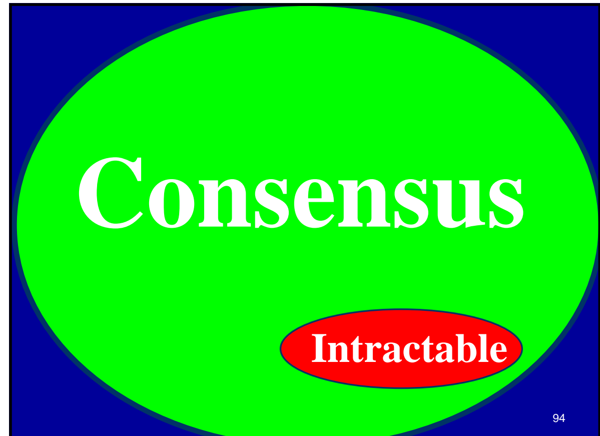
When you accept the authority granted under this power of attorney, a special legal relationship is created between you and the Principal. This relationship imposes upon you legal duties that continue until you resign or the power of attorney is terminated or revoked. You must:

Agent's Certification

I, ______________________, have read the attached durable power of attorney and the foregoing statement, and I am the person identified as the Agent for the Principal. To the best of my knowledge, this power has not been revoked. I hereby

___________________________ ___________________________
Agent Signature Date

Mediate



Earnest attempts . . . **deliberate over and negotiate** prior understandings . . .

Joint decision-making should occur . . . maximum extent possible.

Attempts . . . **negotiate** . . . **reach resolution . . ., with the assistance of consultants** as appropriate.

Involvement of . . . **ethics committee** . . . if . . . irresolvable.

95

Replace

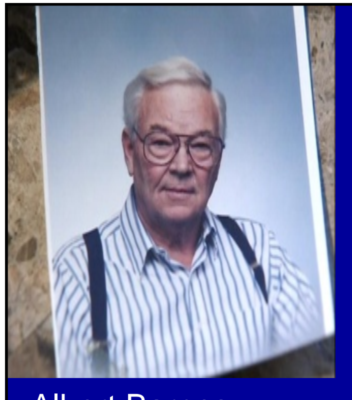
96

Early famous failure

Helga Wanglie

(Minn. 1991)

97



Albert Barnes

- 85-year-old
- End-stage kidney failure
- Chronic respiratory failure
- Dementia

98

Lana Barnes
SDM

"Continue"

99

Park Nicollet

MINNESOTA
JUDICIAL BRANCH
Feb. 4, 2011
101

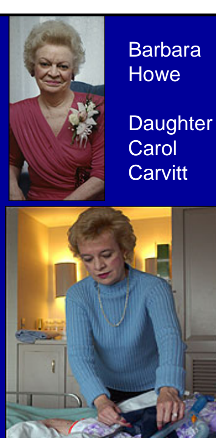
Dorothy Livadas

Material COI

103

Court: "Your own personal issues are "impacting your decisions"

"Refocus your assessment"



Barbara Howe

Daughter Carol Carvitt

Limits of surrogate replacement

105

Providers cannot show deviation

Surrogates often faithful

57%: God could heal patient even if physicians had pronounced further efforts futile

Religious Coping and Use of Intensive Life-Prolonging Care Near Death in Patients With Advanced Cancer

Andrea C. Phelps; Paul K. Maciejewski; Matthew Nilsson; et al.

JAMA. 2009;301(11):1140-1147 (doi:10.1001/jama.2009.341)

20%: "More important to prolong life."

National Journal (Mar. 2011)
Archives Surgery (Aug. 2008)
Pew Ch. (Nov. 2005)

If cannot replace surrogate, then provide the treatment

Truog

Capacity and Consent Board

Dispute resolution mechanisms for intractable cases in which surrogates are "irreplaceable"

Override

Physicians usually **cave-in** to surrogate demands

“Remove the __, and I will **sue you**.”

115

Perceptions of “futile care” among caregivers in intensive care units

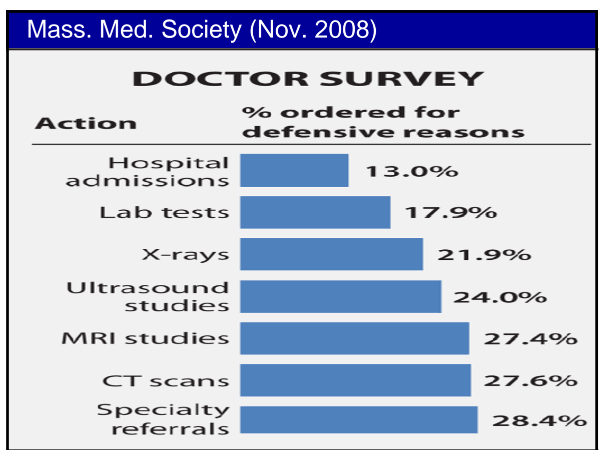
Robert Sibbald MSc, James Downar MD, Laura Hawryluck MD MSc

CMAJ 2007;177(10):1201-8

“Why they follow the instructions of SDMs instead of doing what they feel is appropriate, almost all cited a **lack of legal support.**”

116

Mass. Med. Society (Nov. 2008)



Providers have won almost **every single** damages case brought after unilateral withholding

118

HCP exposure = **IIED**

Secretive

Insensitive

Outrageous

119

Risk > 0

120

Betancourt v. Trinitas Hospital

- 73yo male
- PVS
- COPD
- End-stage renal disease
- Hypertensive cardiovascular disease
- Stage 4 decubitus ulcers
- Osteo-myeletitus
- Diabetes
- Parchment-like skin

"The only organ that's functioning really is his heart."

"It all seems to be ineffective. It's not getting us anywhere."

"We're allowing the man to lay in bed and really deteriorate."

Intramural process

No consensus

Unilateral withdrawal

DNR order written

Dialysis port removed

124

January 2009

Jacqueline files

Court issues TRO

125

February 2009

Evidentiary hearings

Medical experts

Family members

126

March 2009

Permanent injunction

SEAL OF THE SUPERIOR COURT OF NEW JERSEY

April 2010

NJHA
MSNJ
NJP
GNYHA
CHPNJ

Disability coalition
Jewish coalition
Pope

August 2010

Appeal dismissed

No guidance
No clarity

You can stop LSMT for **any reason** if your hospital ethics committee agrees

Tex. H&S Code 166.046

48hr notice

Ethics committee meeting

Written decision

10 days

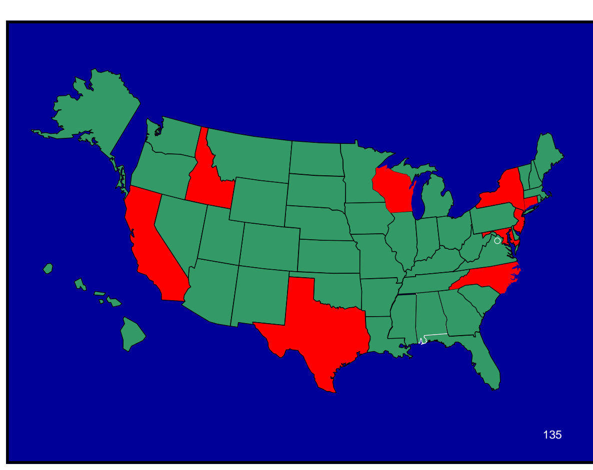
No judicial review

133

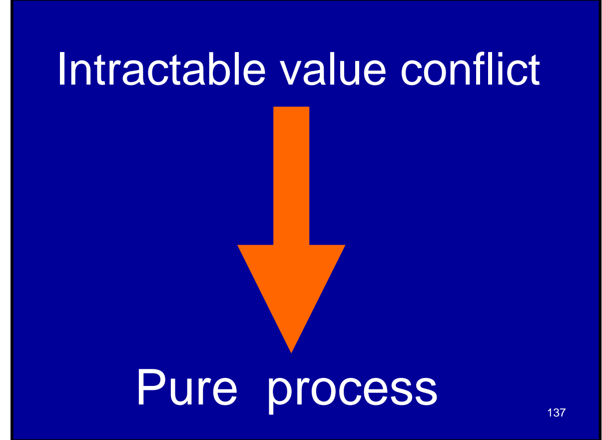
Tex. H&S Code 166.045

[N]ot civilly or criminally liable or subject to review or disciplinary action . . . complied with . . . **procedures**

134



135



If process is all you have, it must have **integrity and fairness**

Notice

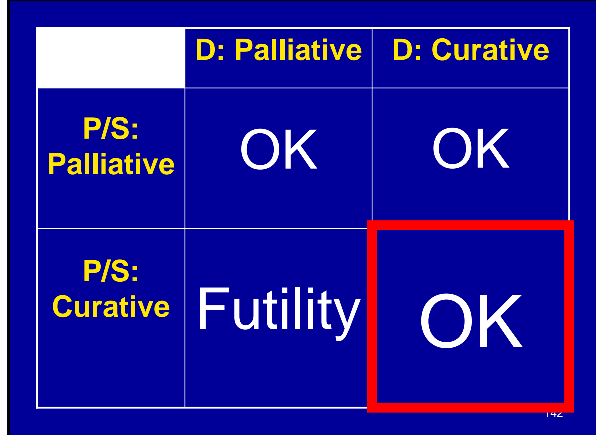
Independent, neutral decision-maker

Judicial review

139

Physician Problem

141



	D: Palliative	D: Curative
P/S: Palliative	OK	OK
P/S: Curative	Futility	OK

	D: Palliative	D: Curative
P/S: Palliative	OK	OK
P/S: Curative	Futility	Informed consent

EOL communication

Defensive medicine

Offensive medicine

144

Communication

145

Table 3—*Factors Associated With Patient/Surrogate Preference for Full Code Status*

Factor	Percentage Desiring Full Code Status	*P* Value
Estimated chance of survival following CPR, %		.012
0-25	33.3	
26-50	64.7	
51-75	82.9	
76-100	92.7	

CHEST 2011; 139(4):802–809

Absent

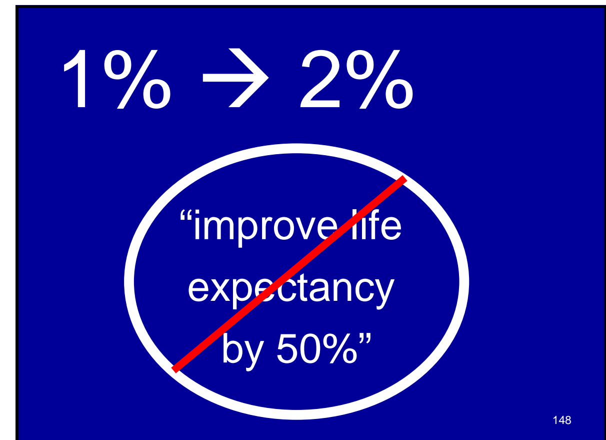
Late

Wrong

Bad

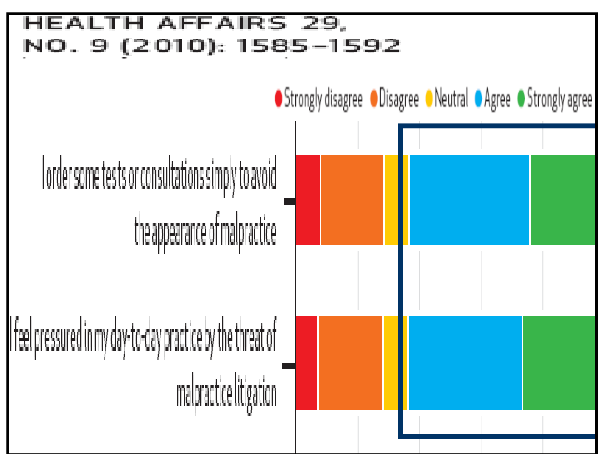
Inconsistent

147



Defensive Medicine

149



J Am Geriatr Soc 58:533–538, 2010. Factor	Extremely or Very Important	Most Important of All Factors Listed
Patient's prognosis	98.5	12.0
What was best for the patient overall	98.1	33.2
Respecting the patient as a person	96.6	5.4
Patient's pain and suffering	94.6	12.5
What the patient would have wanted you to do	81.8	29.4
Providing the standard of care	81.5	2.2
Respecting the wishes of the family or surrogate(s)	80.9	3.3
Following the law	68.6	1.1
The burden on the family	44.8	0
Religious beliefs of the patient	35.3	0
Religious beliefs of the family or surrogate(s)	28.6	0
Cost to society of caring for the patient	14.2	0
Physician's religious beliefs	10.7	0
Concerns about paying for medical care	9.3	0
Concern that the surrogate(s) might sue	8.4	1.1

Offensive Medicine

152

Would you recommend or give life-sustaining therapy when you judged it futile?

Yes 23.6%

MedScape (Nov. 2010)

153

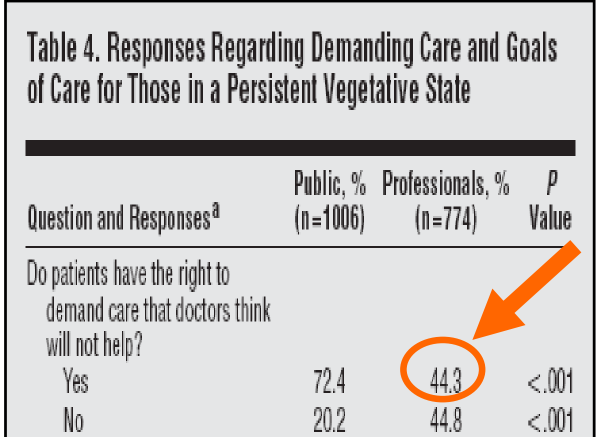


Table 4. Responses Regarding Demanding Care and Goals of Care for Those in a Persistent Vegetative State

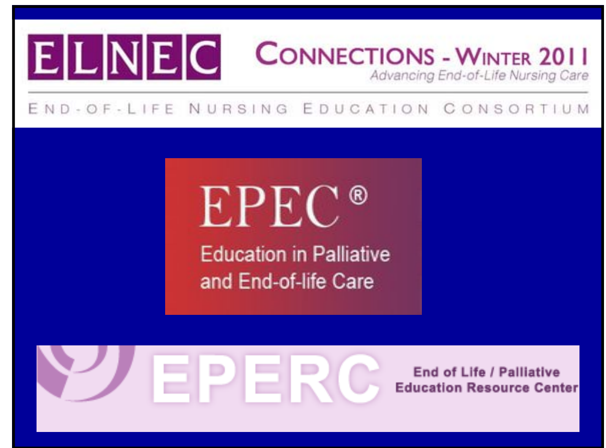
Question and Responses[a]	Public, % (n=1006)	Professionals, % (n=774)	P Value
Do patients have the right to demand care that doctors think will not help?			
Yes	72.4	44.3	<.001
No	20.2	44.8	<.001

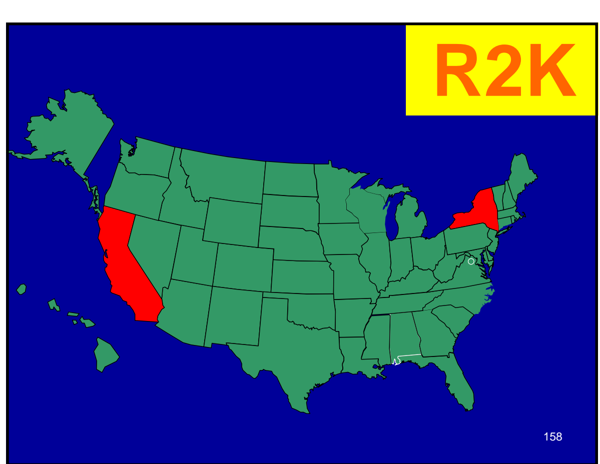
Physician Solution

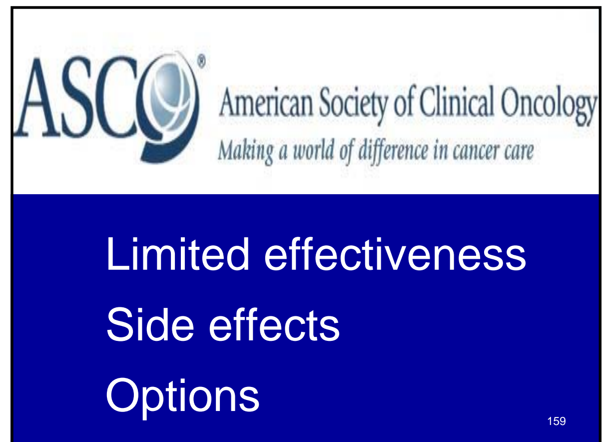
155

Communication

156

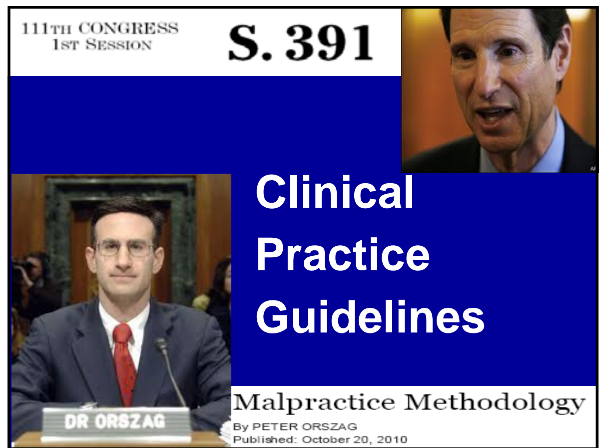

ELNEC
CONNECTIONS - WINTER 2011
Advancing End-of-Life Nursing Care
END-OF-LIFE NURSING EDUCATION CONSORTIUM
EPEC®
Education in Palliative and End-of-life Care
EPERC
End of Life / Palliative Education Resource Center

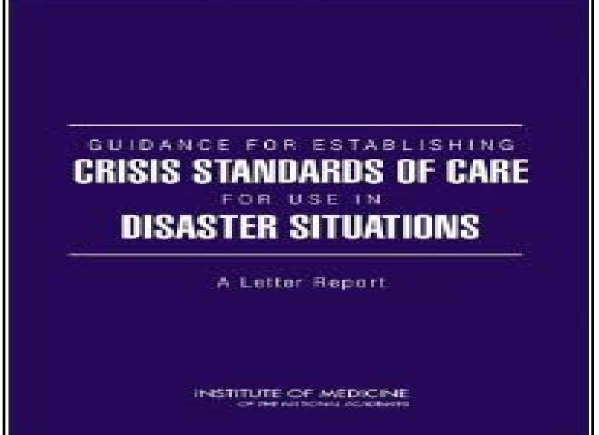

R2K
158


ASCO
American Society of Clinical Oncology
Making a world of difference in cancer care
Limited effectiveness
Side effects
Options
159

Defensive Medicine

160



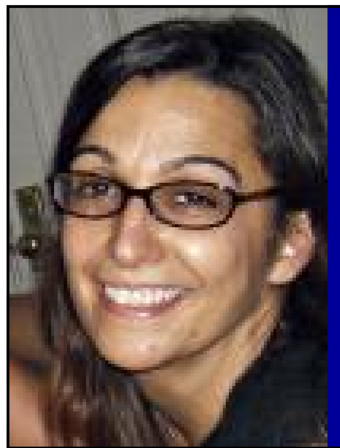


Offensive Medicine

163

164

El médico limitará el esfuerzo terapéutico, cuando la situación clínica lo aconseje, evitando la **obstinación terapéutica**



Hargett
v.
Vitas

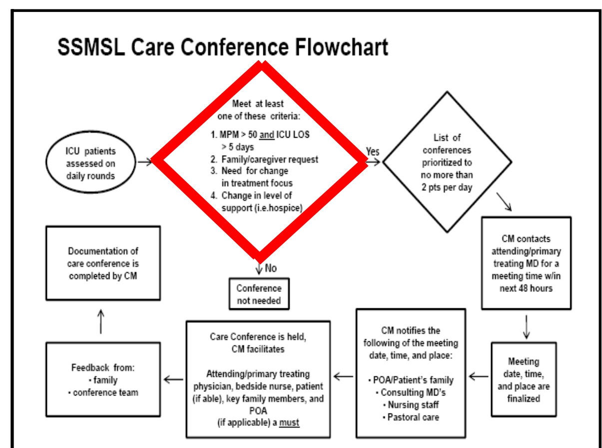
166

Strachan v.
John F. Kennedy
Memorial Hospital
(N.J. 1988)

167

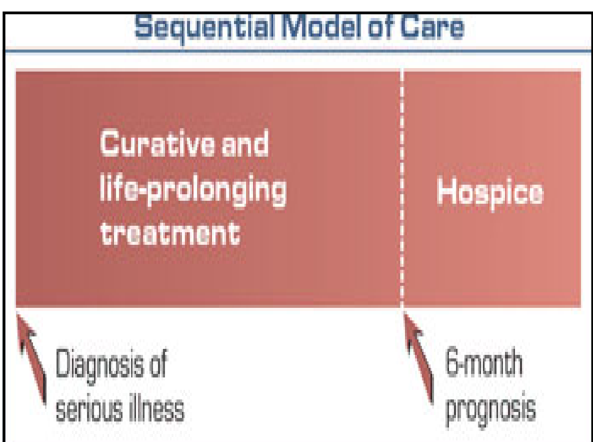
False
Claims
Act

168



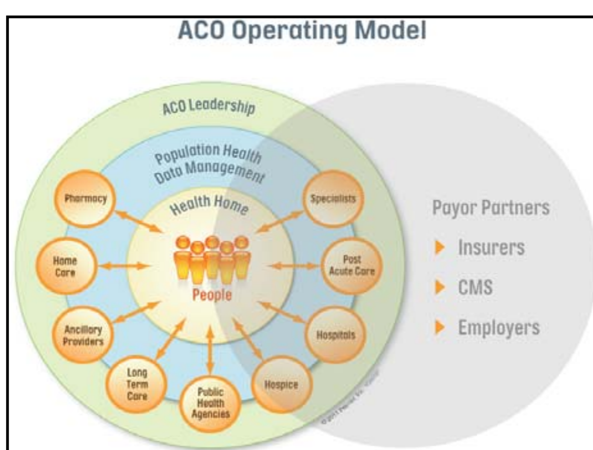
Medicare Problem

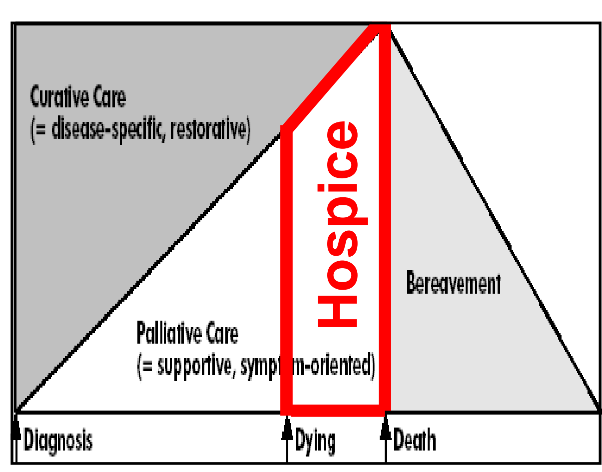
170

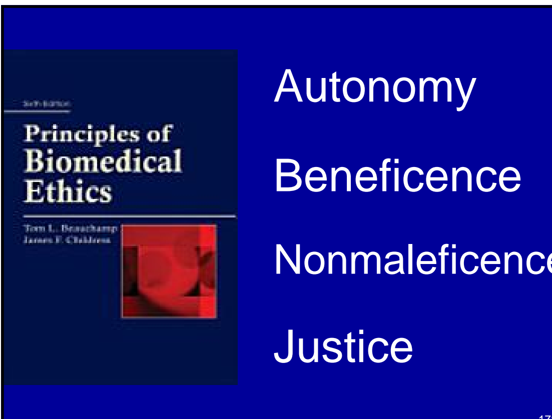


Medicare Solution

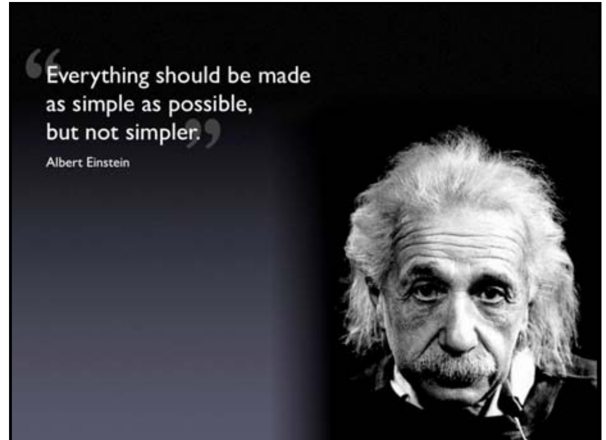
ONE DOLLAR


ACO Operating Model
ACO Leadership
Population Health Data Management
Health Home
People
Pharmacy
Home Care
Ancillary Providers
Long Term Care
Public Health Agencies
Hospice
Hospitals
Post Acute Care
Specialists
Payor Partners
Insurers
CMS
Employers

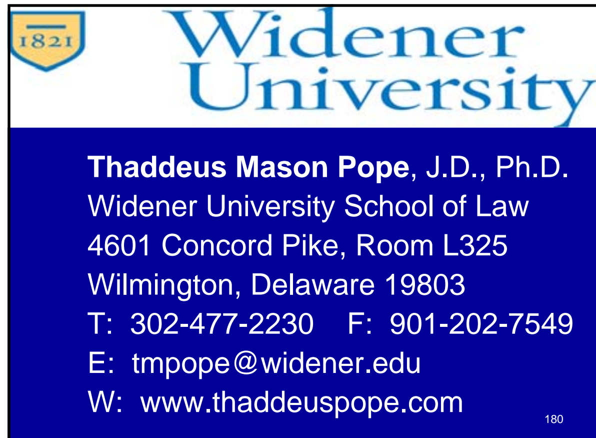

Curative Care
(= disease-specific, restorative)
Hospice
Bereavement
Palliative Care
(= supportive, sympt m-oriented)
Diagnosis
Dying
Death



Principles of Biomedical Ethics
Tom L. Beauchamp
James F. Childress
Autonomy
Beneficence
Nonmaleficence
Justice
178



"Everything should be made as simple as possible, but not simpler."
Albert Einstein



1821
Widener University
Thaddeus Mason Pope, J.D., Ph.D.
Widener University School of Law
4601 Concord Pike, Room L325
Wilmington, Delaware 19803
T: 302-477-2230 F: 901-202-7549
E: tmpope@widener.edu
W: www.thaddeuspope.com
180