

Medical Futility Treatment Disputes: Constraints, Best Practices, and Strategies

Thaddeus M. Pope, J.D., Ph.D.
 NAELA Elder & Special Needs Law
 Annual Conference (Las Vegas)
 May 20, 2011 at 3:45 p.m.





Thanks for inviting me - again

2006 NAELA Advanced Elder Law Institute


Re-Visioning the Practice

November 2-5, 2006
 Salt Lake City, Utah
 The Grand America Hotel



How providers avoid complying

How you can respond



What is a medical futility dispute?




- Patient
- Advance directive
- Proxy
- Agent
- Surrogate
- Conservator

Health care provider

“Continue to treat”


“Treatment is inappropriate”




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

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

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



Why do surrogates demand non-beneficial treatment?



Factual Mistakes



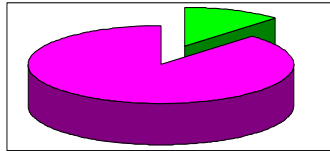
Absent
Late
Wrong
Bad
Inconsistent



Mistrust



Doubt prognostication



Zier, Critical Care Med. 2008



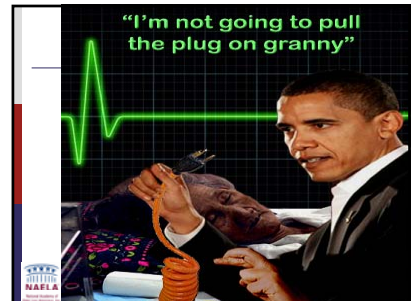
What Y'all Gon' Do With Me?

(Let's talk about it)



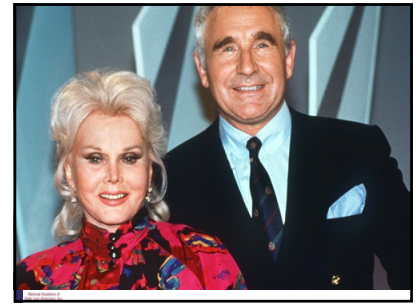

The African-American Spiritual and Ethical Guide to End of Life Care

By Gloria Thomas Anderson, MSW

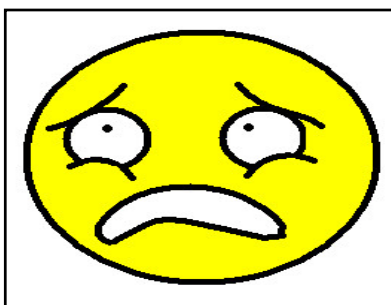



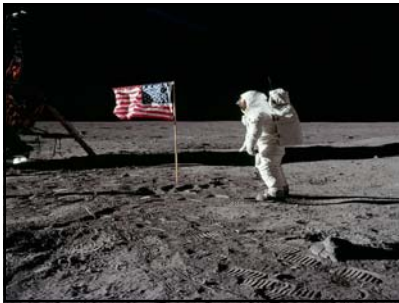


Emotional Barriers



Psychological Barriers





Externalization

- Costs
- Guilt

Religion



Table 5. Responses Regarding Race, Culture, Ethnicity, and Religion

Question and Responses ^a	Public, % (n = 1006)	Professionals, % (n = 774)	P Value
If the doctors treating your family member said futility had been reached, would you believe that divine intervention by God could save your family member?			
Yes	57.4	19.5	<.001
No	35.5	61.1	<.001

“religious grounds
 were more likely to request continued life support in the face of a very poor prognosis”

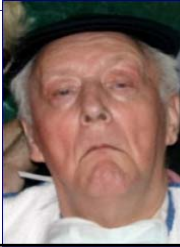


Zier et al., 2009 *Chest* 136(1): 110-117

Why do providers resist surrogate requests?

Avoid patient suffering

“abomination”

“tantamount to torture”

“This is the Massachusetts General Hospital,

Moral distress



Category: futile care

1. Follow the family's wishes for the patient's care when I do not agree with them but do so because hospital administration fears a lawsuit	41 (93)	29 (66)
2. Follow the family's wishes to continue life support even though it is not in the best interest of the patient	42 (95)	39 (89)
3. Carry out a physician's order for unnecessary tests and treatment	43 (98)	32 (73)
5. Initiate extensive life-saving actions when I think it only prolongs death	44 (100)	38 (86)
12. Carry out the physician's orders for necessary tests and treatments for terminally ill patients	43 (97)	30 (68)
19. Prepare an elderly man for surgery to have a gastrostomy tube put in, who is severely demented and a "No Code"	42 (95)	18 (41)

ICGN

The relationship between moral distress and perception of futile care in the critical care unit
 Reardon, J., Gattipati, K., Rosemont, T., Berry, C., Stewart, L., Schumaker



Integrity of the profession



Stewardship





Distrust surrogate accuracy

66%

accurate

50% = pure chance



Moorman & Carr 2010	62%
Barrio-Catelejo et al. 2009	63%
Shalowitz et al. 2006	58%

Even lower

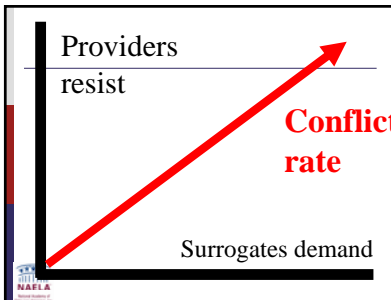
when most needed:
intermediate zones

e.g. PVS v. MCS

**Growing
rate of
conflict**

Population or percent, sex, and age	2000	2010	2020	2030	2040	2050
PERCENT OF TOTAL						
TOTAL	100.0	100.0	100.0	100.0	100.0	100.0
0-4	6.8	6.9	6.8	6.7	6.7	6.7
5-19	21.7	20.0	19.6	19.5	19.2	19.3
20-44	36.9	33.8	32.3	31.6	31.0	31.2
45-64	22.1	26.2	24.9	22.6	22.6	22.7
65-84	10.9	11.0	14.1	17.0	16.5	15.7
85+	1.5	2.0	2.2	2.6	3.9	5.0

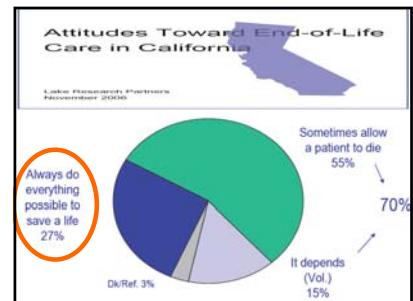
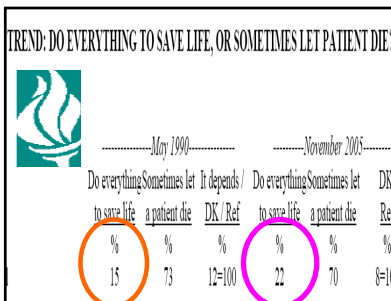
Source: U.S. Census Bureau, 2004, "U.S. Interim Projections by Age, Sex, Race, and Hispanic Origin." <http://www.census.gov/ipeds/data/interimproj/>




**Increasing
surrogate
requests**

20%: "More important to prolong life."


National Journal (Mar. 2011)
Archives Surgery (Aug. 2008)






THUR: End of Life and Family Views

"most fight with everything they've got to hold onto life as long as possible."



Increasing provider resistance



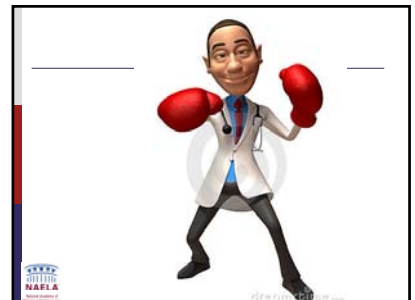
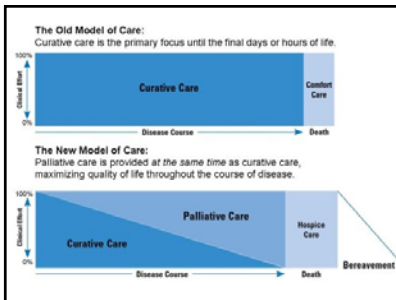
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ELNEC CONNECTIONS - WINTER 2011
Advancing End-of-Life Nursing Care


END-OF-LIFE NURSING EDUCATION CONSORTIUM

EPEC[®]
Education in Palliative and End-of-life Care

EPERC End of Life / Palliative Education Resource Center




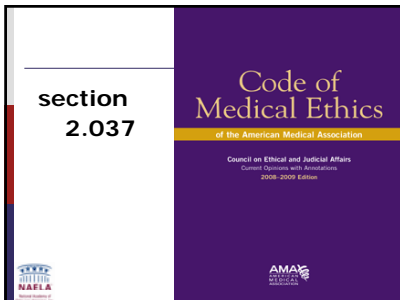
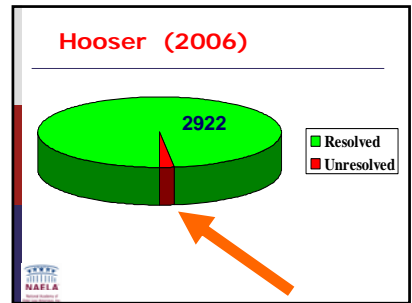
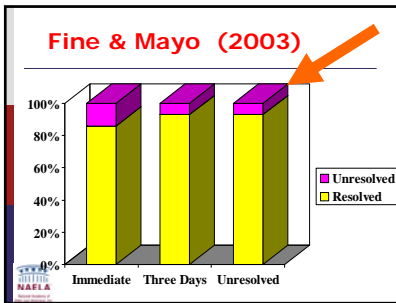
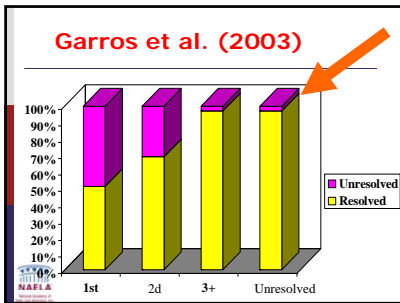
Typical dispute resolution pathway



Prendergast (1998)

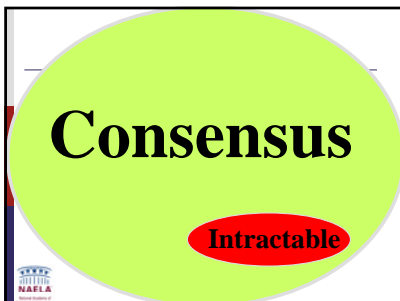
- 57% surrogates immediately agree
- 90% agree within 5 days
- 4% continue to insist on LSMT



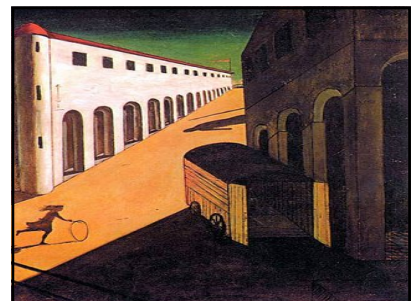


1. Earnest attempts . . . **deliberate over and negotiate** prior understandings . . .
2. **Joint decision-making** should occur . . . maximum extent possible.
3. Attempts . . . **negotiate . . . reach resolution . . . with the assistance of consultants** as appropriate.
4. Involvement of . . . **ethics committee** . . . if . . . irresolvable.

5.
6. If the process supports the physician's position and the patient/proxy remains unpersuaded, **transfer**. . . .
7. If transfer is not possible, the **intervention need not be offered**.



How physicians & hospitals handle **intractable** disputes



Surrogate selection



Act in accord

directive, decisions
preferences, wishes
best interests



Wis. Stat. 155.20(5)

[A]gent **shall act** in good faith **consistently** with the desires of the principal . . . with any valid declaration . . . in the best interests of the principal



Wis. Stat. 155.60(4)

The **court may . . .**
"direct the . . .
agent to act in
accordance . . . [or]
rescind all powers"

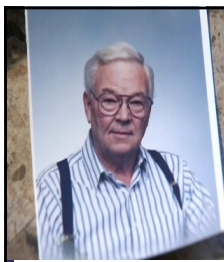


Famous failure

Helga Wanglie
(Minn. 1991)



Increasingly
proven

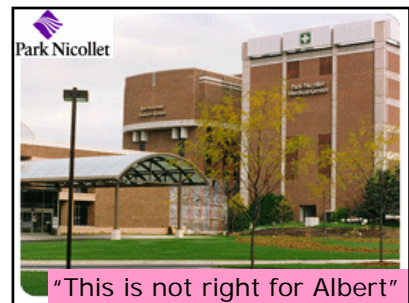


Albert Barnes

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



SDM
Lana Barnes
"Continue"



"This is not right for Albert"


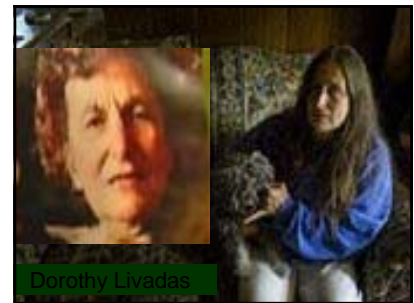


**MINNESOTA
JUDICIAL BRANCH**

Feb. 4, 2011



Surrogate	Advance directive
A	B

Material COI




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

"Refocus your assessment"





Barbara Howe



Daughter
Carol Carvitt





Bernstein v. Superior Court of Ventura County (Feb. 2, 2009).

Not just an **option** but sometimes a **duty**





USC University Hospital



More than a hospital. An academic medical center.


USC University Hospital has established its place as one of the nation's preeminent academic medical centers. Part of Southern California and located on the historic campus of USC, USC University Hospital is a nationally recognized leader in health care and teaching. It is the only hospital in the world to be called by the faculty of the renowned USC School of Medicine of the University of Southern California.



Pascentia McDonald, 74yo

Advance directive:

1. Bobby Miles - agent
2. Cynthia Cardoza - alternate
3. "Do No prolong life if incurable condition"




Aug. 14

PM: surgery thoracoabdominal aneurysm
 PM: post-op infections

Aug. 30

PM: sepsis, non-cognitive




Aug. - Sept.

BM: continued LSMT
 BM: 3 more surgeries
 CC: Disagrees w/ brother

Sept. 17


CC: threatens to sue
 USC stops
 PM dies



CC still sues (for damages)

USC & providers argue:


Probate Code 4740
immunizes providers who
 “in good faith comply with a health care decision made by one whom they believe authorized.”



California Court of Appeals:


“Operation of the immunity here is not so certain.”

“Compliance with an agent’s decision that is **at odds** with the patient’s own expressed decision, in her AHCD, would probably not qualify as in good faith.”




The agent was not authorized to depart from the patient’s AD.

USC should have known that.



Train surrogates




EMANUEL MEDICAL CENTER
 Technology to Heal. Compassion for Life.

The Role of the Substitute Decision-Maker (SDM)

Guide For Healthcare Agents & Surrogate Decision-Makers


Making decisions for patients who can't speak for themselves

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



Be sure, as well as the appropriate, to arrange for the health care of someone else. This handbook can guide you through this decision, you may have to make and provide resources for your information.

UPOAA **Statement to Agent**

Agent's Duties


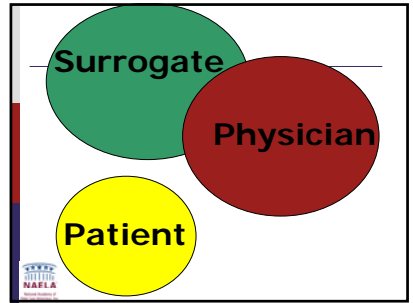
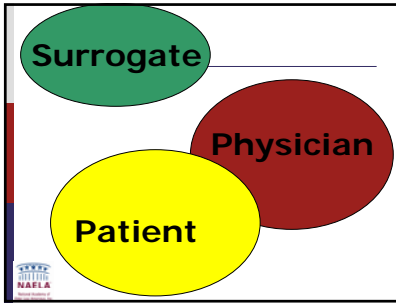
When you accept the authority granted under this power of attorney, a special legal relationship is created between you and the Principal. This relationship imposes upon you legal duties that continue until you resign or the power of attorney is terminated or revoked. You must:

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 _____

Limits of
surrogate
replacement





Providers cannot
show deviation

But absence of evidence
means objective best
interest standard

Healthcare providers get
more deference



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

In the name of Allah most generous most merciful

I Samir Swaid born March 20 1945 declare that there is only one god and Mohammed is the messenger of god, I practice and believe in the true religion of Islam and follow all Islamic rules including the sharia Law (Islamic Law).

I know that I have been sick and in and out of the hospital for a long time now, if something was to happen to me my wishes are to follow all Islamic law (the sharia law), in whatever comes my way.

Thank you (Shamek) to He (Allah) whose hands in the Creation, and He has Power over all things, He who created death and life and He who will be most kind of you are dead in short, and He is Everlasting (Al-Forgiving) (Quran 02: 1-2)

Samir Swaid *Samir Swaid*

IN THE COURT OF APPEAL OF THE STATE OF CALIFORNIA

SECOND APPELLATE DISTRICT

DIVISION EIGHT

CYNTHIA L. CARDOZA, B195092
Plaintiff and Appellant, (Los Angeles County
Super. Ct. No. BC338034)

v.

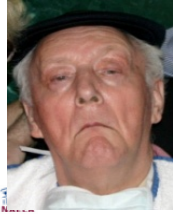
USC UNIVERSITY HOSPITAL et al., **August 2008**
Defendants and Respondents.

FILED
LOS ANGELES SUPERIOR COURT

1 SCOTT B. McFALL, State Bar No. 80396
2 Donald Oshida, Jr., State Bar No. 207430
3 AGAJANIAN, McFALL, WEISS, TETREAULT & CHEN
4 140 North Leimerton Boulevard
5 Los Angeles, California 90004
6 Telephone: (323) 993-0598
7 Facsimile: (323) 993-0599
8 DEC 15 2008
9 FILING WINDOW
10 JESSICA C. JAMES, CLERK
11 BY MARIA FERRER, DEPUTY

1 CYNTHIA L. CARDOZA, CASE NO.: BC338034
2 Plaintiff, [PROPOSED] JUDGMENT RE: USC UNIVERSITY
3 vs. HOSPITAL'S MOTION FOR SUMMARY
4 USC SCIENCE HOSPITAL, DR. FRED JUDGMENT/ADJUDICATION
5 WEAVER, KECK SCHOOL OF DATE: December 9, 2009
6 MEDICINE, DR. MICHAEL LEKE, DR. TIME: 8:10 a.m.
7 DOUGLAS WOOD, BOBBY G. MILES, DEPT: 331
8 Defendants. **File by Fax**

Surrogates often faithful



If cannot
replace
surrogate,
then provide
the
treatment



Truog

Dispute resolution
mechanisms for
intractable cases in
which surrogates are
“irreplaceable”



Ontario

Consent
and
Capacity
Board



Hassan Rasouli




Unilateral
withdrawal

“Remove
the ____,
and I will
sue you.”

Perceptions of "futile care" among caregivers in intensive care units

Robert Sibbald MSc, James Downar MD, Lesra 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.**"



Resolution 505-08 TITLE: LEGAL SUPPORT FOR NONBENEFICIAL TREATMENT DECISIONS

Author: H Hugh Vincent, MD, William Anderson, MD


Introduced by: District 8 Delegation

Endorsed by: District 8 Delegation Reference Committee

October 4-6, 2008


This resolution constitutes a proposal for consideration by the California Medical Association House of Delegates and does not represent official CMA policy.

WHEREAS, it is still common for physicians who feel non-beneficial or futile treatments are being provided or considered to feel threatened by legal action by the patient's family or other surrogates, and thus continue to provide such care against their best medical judgment; and



Exposure to civil liability


- State HCDA
- Battery
- Medical malpractice
- Informed consent
- EMTALA




Criminal liability

e.g. homicide

Licensure discipline




Providers have **won** almost every single damages case for unilateral w/h, w/d



Providers typically lose only claims for **IIED**

- Secretive
- Insensitive
- Outrageous



Luce is confirming the trend of **un**successful lawsuits against providers




- Barber (Cal. 1983)
- Manning (Idaho 1992)
- Rideout (Pa. 1995)
- Bland (Tex. 1995)
- Wendland (Iowa 1998)
- Causey (La. 1998)



Risk > 0



"It is **not** settled law that, in the event of disagreement . . . **the physician** has the final say."

Golubchuk v. Salvation Army Grace Gen. Hosp., 2008 MBQB 49 (Feb. 13, 2008).



"The only fear a doctor need have in denying heroic measures to a patient is the **fear of liability** for negligence"

Child & Fam. Svcs. v. Lavallee (Man. App. 1997).



Process itself can be punishment

Even prevailing parties pay transaction costs
Time
Emotional energy



Liability averse

Litigation averse too



J Am Geriatr Soc 58:533-538, 2010.

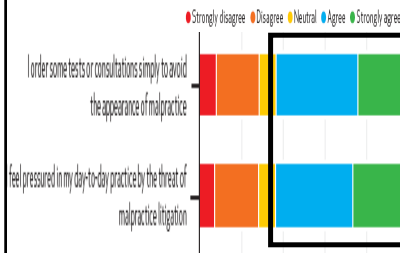
Factor	Extremely or Very Important	Most Important of All Factors Listed
Patient's prognosis	98.5	12.0
What was best for the patient overall	98.1	33.2
Respecting the patient as a person	96.6	5.4
Patient's pain and suffering	94.6	12.5
What the patient would have wanted you to do	81.8	29.4
Providing the 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

Mass. Med. Society (Nov. 2008)

DOCTOR SURVEY

Action	% ordered for defensive reasons
Hospital admissions	13.0%
Lab tests	17.9%
X-rays	21.9%
Ultrasound studies	24.0%
MRI studies	27.4%
CT scans	27.6%
Specialty referrals	28.4%

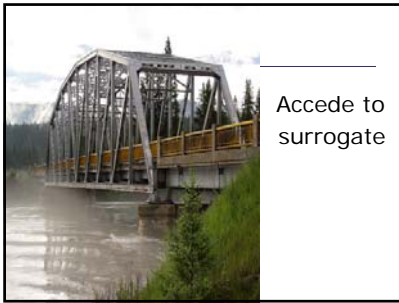
HEALTH AFFAIRS 29, NO. 9 (2010): 1585-1592



Bad law



Override

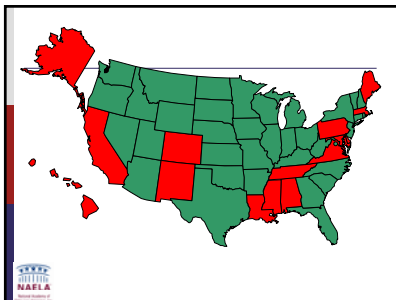


Typical response to
"bad law" claims

Safe harbor immunity

**UHCDA
model**

- New Mexico (1995)
 - Maine (1995)
 - Delaware (1996)
 - Alabama (1997)
 - Mississippi (1998)
 - California (1999)
 - Hawaii (1999)
 - Tennessee (2004)
 - Alaska (2004)
 - Wyoming (2005)
-



16 Del. Code 2508(f)

Provider may decline to comply

"medically ineffective treatment"

"contrary to generally accepted health-care standards"

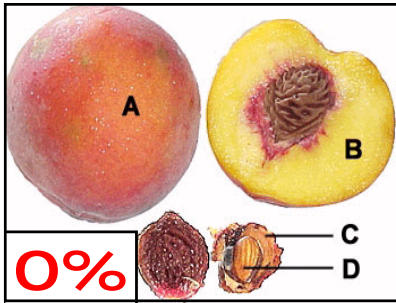
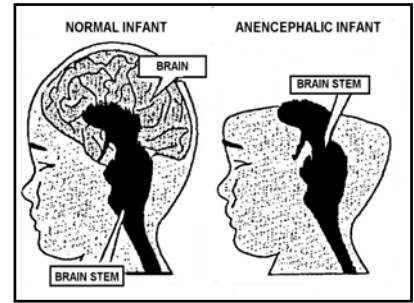
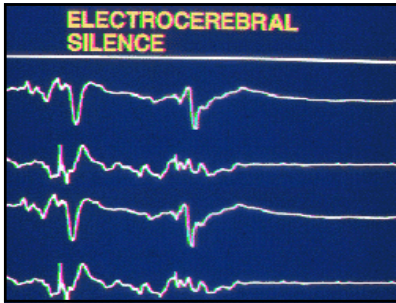
16 Del. Code 2510(a)(5)

A provider . . . in good faith
and in accordance with
generally accepted health-care
standards . . . is **not subject
to civil or criminal liability**
or to discipline for
unprofessional conduct for . . .
declining to comply . . .

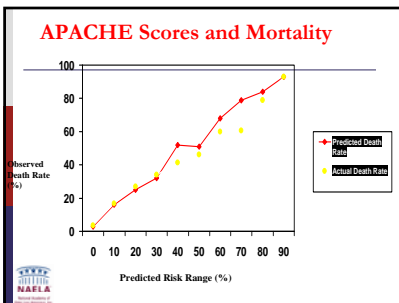
Safe harbor attributes

- Clear
- Precise
- Concrete
- Certain

"generally
accepted
health care
standards"



No
quantitative
measures



Wide variation on threshold

- Some: 0%
- Some: 1%
- Others: 13%

Lantos, Am. J. Med. 1989



Uncertainty in
extrapolating from
populations to
individuals



No qualitative measures



Goals of Medicine

- Cure disease
- Alleviate pain & suffering
- Restore function
- Prevent disease
- Prolong corporeal existence

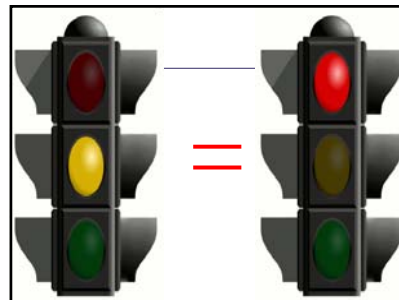


Know
it
when I
see it



Result of Ambiguity

Few futility policies
Rare "full"
implementation



Easier to ask for
forgiveness, than to
ask for permission



Get an
injunction



Courts almost
always grant
temporary
injunctions



Likelihood of success
on the merits

Substantial threat
of irreparable
damage or injury



Patients often **die** before
adjudication of merits

De jure loss

De facto win



73yo male

PVS

COPD

End-stage renal
disease

Hypertensive
cardiovascular
disease

Stage 4

decubitus
ulcers

Osteo-
myelitis

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



January 2009

Jacqueline files

Court issues TRO



February 2009

Evidentiary hearings

Medical experts

Family members



March 2009

Permanent injunction



April 2010

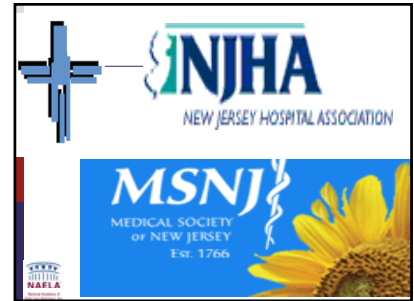
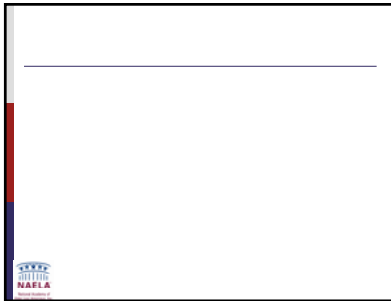
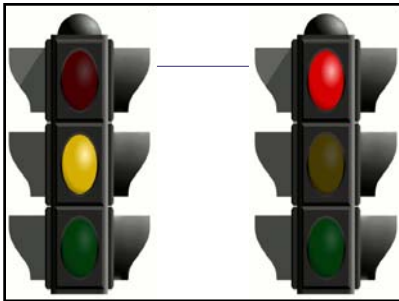
NJHA
MSNJ
NJP
GNYHA
CHPNJ

Disability coalition
Jewish coalition
Pope



August 2010

Appeal dismissed
No guidance
No clarity



Texas
H&S Code
166.046



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



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



1. 48hr notice
2. HEC meeting
3. Written decision
4. 10 days to transfer
5. Unilateral WH/WD



April 16, 2007
 Ms. Emillio Gonzalez
 407 Nexham St.
 Lockhart, Texas 78644

Step 1: Notice HEC meeting

Dear Ms. Gonzalez:

We, the physicians and other members of the healthcare team, appreciate you taking your time to attend the patient care conferences regarding your son.

At the last conference, your son's physician discussed his brain condition and the poor prognosis for any further neurological improvement. As you know, the physicians involved in the care of your son believe that his condition is irreversible and that to continue certain treatments will serve to prolong his suffering without the possibility of cure. We understand that you do not agree with this position and want the hospital to continue to provide all current treatments for your son.

When disagreements of this nature arise, Texas law allows hospitals to call the hospital ethics committee meeting to review whether certain treatments are medically appropriate. A meeting has been called for the Seton Faculty of Hospitals Pediatric Ethics Committee to consider Emillio Gonzalez's case. This meeting will be held on February 16, 2007 at 09:00 a.m. in the 3rd floor boardroom at Brackensridge Hospital of Austin. The physicians providing care for your son, as well as the ethics committee members will attend the meeting. Under Texas law you have the right to attend and participate in this meeting. While that is not legally required, we strongly encourage you to be present for this discussion. You will be given the opportunity to ask questions regarding your son's care and to provide input into the committee's decision-making process.

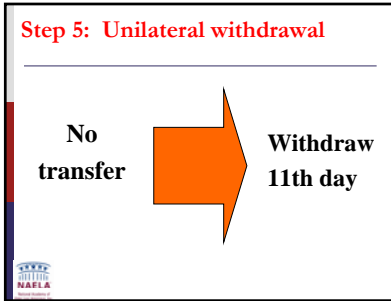


Step 3: HEC written decision

The Ethics Committee further recommends that

- The treatment plan for the patient be modified to allow only comfort measures (such as hydration, pain control and other interventions designed to decrease the patient's suffering.)
- New complications that develop should not be treated, except with additional palliative measures, as appropriate.
- The patient's code status be changed to a DNR.
- Appropriate spiritual and pastoral care resources should be provided to Emillio's mother and family members.

In summary, the consulted members of the Ethics Committee concur with the recommendation by the Attending Physician and patient care team to withdraw aggressive care measures, including use of the ventilator, and to allow palliative care only. The Attending Physician, with the help of the Children's Hospital of Austin, will continue to assist the patient's family in trying to find a physician and facility willing to provide the requested treatment. The family may wish to contact providers of their choice to get help in arranging a transfer.

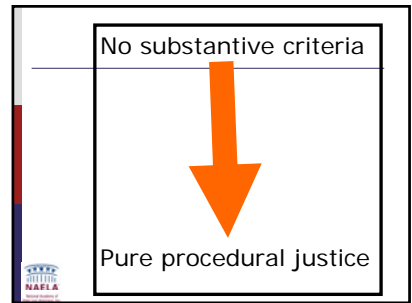
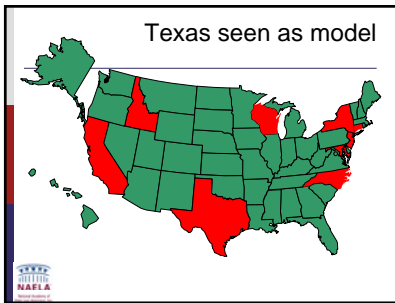
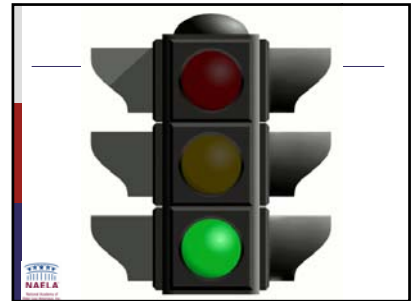
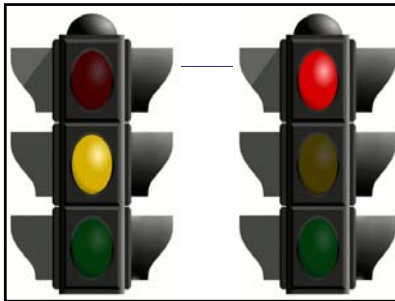


There is no step 6

There is no judicial review

The HEC is the forum of last resort

TX safe harbor	DE safe harbor
Measurable procedures	Vague substantive standards
Safe harbor protection certain	Safe harbor protection <u>uncertain</u>



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

- Due Process**
- Notice
 - Opportunity to present
 - Opportunity to confront
 - Assistance of counsel
 - **Independent, neutral decision-maker**
 - Statement of decision
 - **Judicial review**

Survived a "storm" of bills

2007

2009

2011

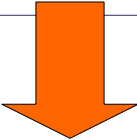


Make sure **dealt fairly**

Attend HEC
Get second opinion
Help find transfer

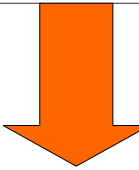
Conscientious Objection

No treatment relationship



May refuse to treat
for **any** reason

Existing treatment relationship



Must continue to treat

Termination: normally

Sufficient notice to find
alternative

Medical Board may require
~ 30 days

Life-and-death situation

"free to refuse . . . **upon**
providing reasonable
assurances that basic
treatment and care will
continue"

Couch (N.J.A.D. 2000).

Del. Code 2508(e)

". . . provider may
decline to comply . . .
for reasons of
conscience."

Del. Code 2510(a)(5)

. . . provider . . . not
subject to civil or
criminal liability or to
discipline . . . for . . .
[d]eclining to comply .
because . . . conscience

Del. Code 2508(g)

[If] decline to comply . . .

(2) Provide continuing care, including continuing life sustaining care, . . . **until a transfer can be effected**



Want to refuse → Try transfer

No transfer → Must comply



Not always

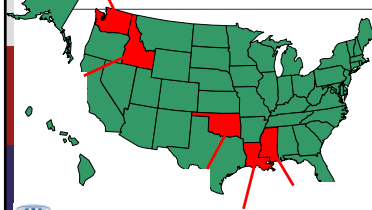


Cal. Probate Code 4736

(c) Provide continuing care . . . until a transfer can be accomplished **OR** until it appears that a transfer cannot be accomplished.



Comprehensive Conscience Clauses



Idaho Code 18-611

No health care professional . . . shall be civilly, criminally or administratively liable for . . . declining to provide health care services that violate his or her conscience



. . . in a **life-threatening situation** . . . professional shall provide treatment and care **until** an alternate health care professional capable of treating the emergency is found.



Not always



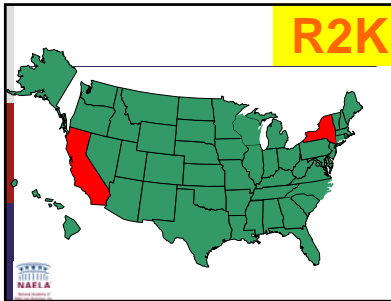
Miss. Code 41-107-5

A health care provider has the right not to participate, . . . violates his or her conscience. . . .

**No emergency exception
No duty to refer**



Offensive
medicine is
the far bigger
threat



Hargett
v.
Vitas

Select
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