Brain Death Is Broken
Status Shift and Implications

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November 2003

Georgia Perimeter College

Apnea test
10

11


12

13

14

Birth  03/16/04
W/D   03/18/04

15

Without consent

16

17

“tortious termination of life support”

18
Dead
Medical futility conflict
Family decision

Alive
Straightforward Clinician decision

2006 - 2011

What’s different today?

Roadmap

2
Medical futility
Brain death

Medical futility conflicts
Most visible cases from UK

Charlie Gard

Alfie Evans

Clinician
CMO

Surrogate
LSMT

Appropriate

Inappropriate

Beneficial
Non-beneficial

Proportionate
Disproportionate

Not therapeutically obstinate
Therapeutically obstinate

If we can help little #CharlieGard, as per our friends in the U.K. and the Pope, we would be delighted to do so.
Charlie Gard

Alfie Evans

European Court of Human Rights

Exceptions

95%

Medical Association of Georgia

5%

RESOLUTION

Subject: 2017-2018 Policy Statement: Responding to Requests for Potentially Inappropriate Treatments

Submitted By: Medical Association of Atlanta

Referred To: Reference Committee A
Options in intractable conflicts

Clinician may proceed without consent
Clinician may not proceed without consent

No permission
No prohibition

Green lights
Red lights
Why more red
Stop LSMT without consent

any reason if hospital review committee agrees

2018

20 years

“conflict remains unresolved, . . . make a reasonable effort to transfer the patient . . . not less than 14 days”

Day 15 ?
“end of the 14-day period . . . conflict remains unresolved . . . unable to identify . . . facility willing . . .”

“may cease to provide the treatment”

VA = TX

2018

30 years

“health care provider . . . may decline to comply . . . health care decision that . . .”

“requires medically ineffective health care”

“health care contrary to generally accepted health care standards”

PLUS
not subject to civil or criminal liability or to discipline for unprofessional conduct

BUT

Scared, reluctant to use

Elizabeth Alexander
70 years old
end-stage pancreatic cancer

“Clearly an individual who should not undergo aggressive resuscitation”

“She is frail, debilitated, and . . . metastasis . . . extensive.”

Advance directive
POLST
Agent

“all measures to prolong life”

Appropriate care committee
DNR

Elizabeth dies

Family sues & loses

“immune from liability under section 4740”

CA = TX
“immune from . . . liability for refusing to provide . . . treatment requested”

Procedures weaker than TX, VA, CA

Obtain another medical opinion

or

Obtain an opinion from a committee

or

Transfer the patient

That’s enough green lights

Consent always
Nondiscrimination in Treatment Act
November 2013

“health care provider shall not deny . . . life-preserving health care . . . directed by the patient or [surrogate]”

Medical Treatment Laws Information Act
November 2014

“If surrogate directs [LST] . . . provider that does not wish to provide . . . shall nonetheless comply . . .”
Discrimination in Denial of Life Preserving Treatment Act

“Health care . . . may not be . . . denied if . . . directed by . . . surrogate”

2018 Kansas Simon’s Law

2018 Kansas Simon’s Law

Simon Crosier

DNR without parents’ consent or knowledge
Simon’s Law addresses this

“No do-not-resuscitate order or similar physician’s order shall be instituted . . . if . . . refusal of consent”

2019

Not even a court may order withdrawal of LSMT over parental objections

Already passed House
Long held as paradigm green

1999

MV dialysis

CPR CANH

H.B. 3074 (2015)

artificially administered nutrition & hydration
2

DNR

3

MV dialysis

CPR CANH

More red lights

Why?

Mar. 19 2019

Court of Appeals
First District
301 Fannin Street
Houston, Texas 77002-2066

Sept. 2018

Chris Dunn constitutional challenge

Mar. 19 2019

Why?
Disputed treatment **might** keep patient alive.

At issue

Is that chance or outcome **worthwhile**

Not a medical judgment

Value judgment

That question is for patients & families

Withdrawal w/o consent okay
Already dead

Still true today?

Medical futility Brain death

1968

LIFE Picasso
Only 1 way to determine death

irreversible cessation of circulatory & respiratory functions

BUT
An individual . . . . is dead . . . who has sustained either (1) irreversible cessation of circulatory and respiratory functions, or (2) irreversible cessation of all functions of the entire brain.

Brain death = Death

All 56 US jurisdictions


Legally settled since 1980s
Collected 1000 pounds; moon rocks late 1960s.
Part 1
Resistance to BD is growing

Part 2

Consequences of resistance

Part 3
5 legal attacks on BD

Growing resistance More families dispute BD

NEUROLOGY Aug. 2016

(200)
50% report families request organ support after BD

"reject this diagnosis"
"deviate from standard procedures"

Not just USA

Conflict: 10%
56 BD cases 2014-2016

More conflict

Many cases to court
2016 - 2018

Why?

More organized opposition

208 209 210 211 212 213 214 215 216
More pro bono
217

More crowdfund
219

More vulnerable
221

Jahi McMath
222

McMath shadow effect
223

Families hear about these cases — makes brain death seem uncertain
224

Consequences of resistance
225
5 Types of dispute

Least
Most serious

Attack 1 of 5

Confusion
Mistrust

Lots of these cases

Just 1 example

Lisa Avila

Ectopic Pregnancy
“No”

Wrong before
Wrong now

Injunction against removing ventilator

Law buys time - to accept or confirm
That’s 1st attack on BD

Want religious exemption

“[D]eath . . . shall not be declared . . . neurological criteria . . . violate . . . personal religious beliefs . . .”

Religious objection → No death by BD

Pt may satisfy BD criteria

BUT

May not declare death
Until death by CP criteria

Rejected everywhere outside NJ

Still asked for

CHOP had 2 cases summer 2018

Areen Chakrabarti

Jayden Auyeing

River Styx in Hades, border between underworld and world of the living

Motl Brody (DC)
AMENDED IN ASSEMBLY APRIL 10, 1986
CALIFORNIA LEGISLATURE--80TH REGULAR SESSION
ASSEMBLY BILL
No. 3311

Introduced by Assembly Member Hilk Katz
February 16, 1986

An act to amend Section 1355.5 of the Welfare and Institutions Code, relating to Medical. (An act to amend Section 1280 of the Health and Safety Code, relating to The Uniform Determination of Death Act.)

LEGISLATIVE COUNCIL REPORT
Ontario cases

Shalom Ouounouno

Rejected everywhere outside NJ

BUT

New cases

1

Taquisha McKitty

Apostolic Pentecostal

BD guidelines “failed to . . . accommodate . . . religious beliefs, . . . violate . . . constitutional and human rights”
Israel Stinson

“Plaintiffs are Christians with firm religious beliefs . . . heart is beating . . . is alive.”

“removal of CP support . . . unconstitutional . . . interferes with . . . freedom of religion . . . first amendment”

Oral arg. Jan. 14, 2019
Hospitals must establish written procedures for the reasonable accommodation of the individual’s religious or moral objections to use of the brain death standard to determine death.

May see more of these cases

That’s 2nd attack on BD

Must clinicians obtain consent for BD tests?

Attack 3 of 5
Some try to prevent BD diagnosis

Why? this strategy

Clinic duties after BD

Limited

“After a patient... brain dead... medical support should be discontinued.”

Consent not required

Dead → Not a patient

American College of Physicians Ethics Manual
Sixth Edition
Los Angeles, CA, for the American College of Physicians Ethics, Professionalism, and Human Rights Committee

“Really, most SINCERELY dead Policy and procedure in the diagnosis of death by neurologic criteria
D.A. Shamos, MD, D.H. Day, MD, G. T. Droegemueller, PhD, IV, R. R. Hinder, MD, and R. Segeal, MD

“All medical interventions should be withdrawn.”
Not a patient → No Tx duty

No post-BD treatment rights

So, Focus on pre-BD rights

Apnea test

Final confirmatory test

Evidence-based guideline update: Determining brain death in adults
BUT

Almost all pediatric
Parental refusals

No apnea test
No BD

No BD
Treatment duties continue until CP

More family refusals

Practically, same as NJ religious exemption
Opt out
BD

No apnea test → ancillary tests

But same consent question

Must clinicians honor the refusal?

Do clinicians need consent for apnea test?

Yes
Allen Callaway

Billings, Montana
6-year-old
“Drowned” July 22, 2016

Mom: “no”

“mother has sole authority to make medical decisions . . . including . . . brain functionality examinations”

“request . . . permitting . . . testing . . . is denied”

Transferred home
Do clinicians need consent for apnea test?

MT said “yes”

KS also said “yes”

Brett Shively
2 yo “drown” Wichita, 2006

Forbid brain viability exam
TRO - 02/01/06
D/C home - 03/17/06

Do clinicians need consent for apnea test?

CA also said “yes”

Alex Pierce - drowned
Do clinicians need consent for apnea test?

MT, KS, CA said “yes”

Plausible
Normally, may not do things to patient without consent

Med Mal

No

Miranda Lawson

Richmond, Virginia

2-year-old Choked popcorn - May 11, 2016
Dad: “no”

Hospital "is ... allowed to administer the apnea test"

Do clinicians need consent for apnea test?

VA said “no”

NV also said “no”

A.B. 424 (June 2, 2017)

Already amending NUNDA
“determination of the death . . . is a clinical decision that does not require the consent of the person’s . . . representative . . . .”

Do clinicians need consent for apnea test?

“The facility must make diligent efforts to notify the person closest to the patient that the process for determining brain death is underway. Consent need not be obtained . . .”

Conflict continues

YES
California
Kansas
Montana

NO
Nevada
Virginia
Georgia
New York
2 more recent cases in McKinley Hawkins Payton Summons

Not only neurologists say need consent

That’s 3rd attack on BD

Attack 4 of 5
Dec. 12, 2013
Declared dead

Lost lawsuits against hospital

Transferred to NJ
Sustained organ support 4.5 years!!

Mar. 2015
Med Mal lawsuit

future medical expenses

Dead people do not have medical expenses
Re-litigate status as alive


Does not attack medical criteria themselves

No longer meets criteria

If alive, must reexamine medical criteria for BD

Dead at T1

Not dead at T2

Problem

stay dead
Death should be irreversible

Collateral estoppel

Chance to prove

“Triable issue . . . whether changed circumstances”

That’s 4th challenge
Attack
5 of 5

Most serious attack

Are medical criteria for BD legally sufficient?

Reno, Nevada

Aden Hailu

April 1, 2015

Catastrophic anoxic brain injury during exploratory laparotomy

May 28, 2015

Met AAN criteria for brain death

Dad: “she is not dead”
Dad loses

Trial court
AAN criteria met
Aden is dead

Dad appeals
Nevada Supreme Court

Dad wins

Supreme Court of Nevada
November 2015

Irrelevant if Aden meets AAN criteria
NOT the “right” criteria

2 reasons

1

UDDA
“must be made in accordance with accepted medical standards”

BUT

Trial court did not consider whether AAN are “accepted medical standards”

AAN ≠ Hospital policies ≠ Clinicians

Number of physicians Qualifications How tests administered

Hailu = AAN

AAN ≠ UDDA
Court throws BD into **doubt**

Nevada legislature steps in

A.B. 424

“accepted medical standards”

AAN / AAP authoritative criteria

**AAN** does **not** measure what the **UDDA** requires

Supreme Court of Nevada
November 2015
“irreversible cessation . . . all functions of . . . entire brain”

BUT

Brain dead people do stuff

Gestate a fetus

AAN measures only cessation some functions of part of brain

Supposed to measure: “all functions” “entire brain”

Predictable
UDDA

“silent on . . .
diagnostic tests . . . procedures”

“medical profession remains free to
formulate acceptable . . . practices”

Defers to
medical profession

BUT

Discretion not unfettered

Medical criteria must measure legal standards

“irreversible cessation . . . all functions of . . . entire brain”

Medical criteria drifted too far from statute
UDDA requires Clinicians measure

Legal standard may demand more than medical criteria

January 2019

Brain death, the determination of brain death, and member guidance for brain death accommodation requests

AAN position statement

“neuroendocrine function may be present . . . not inconsistent with the whole brain standard of death.”

Supposed to measure:

“all functions”

“entire brain”
Medically dead ≠ Legal dead

Conclusion

Debate has been academic

“critics and skeptics have not gained much traction with lawmakers”
Courts and legislatures are tackling this not just more scrutiny more debate now it is a public policy question

U.S. hospitals will see more cases

"Determining whether a patient is alive or dead is the most fundamental aspect of providing medical care."

Life Death

Life Death

Life Death
But we’ve got to verify it legally, to see if she is morally, ethically spiritually, physically positively, absolutely undeniably and reliably dead

And she’s not only merely dead, she’s really most sincerely dead.

References

Materials from the cases discussed in this presentation are available at
http://thaddeuspope.com/braindeath
Medical Futility Blog

Since July 2007, I have been blogging, almost daily, to medicalfutility.blogspot.com. This blog focuses on reporting and discussing legislative, judicial, regulatory, medical, and other developments concerning medical futility and end-of-life medical treatment conflicts. The blog has received nearly 4 million direct visits. Plus, it is distributed through RSS, email, Twitter, and re-publishers like WestlawNext and Bioethics.net.


Brain Death and the Law, World Brain Death Project (in progress)


Brain Death: Legal Duties to Accommodate Religious Objections 147 CHEST e69 (2015).


Pregnant and Dead in Texas: A Bad Law, Badly Interpreted, LOS ANGELES TIMES (Jan. 16. 2014) (with Art Caplan).


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