

*3rd International Society of Advance Care Planning
and End of Life care Conference*

**Disability Perspectives on Public Policy
In Advance Care Planning**

NOT DEAD YET

Diane Coleman, JD, President/CEO

497 State Street

Rochester, New York 14608

(585) 697-1640

ndycoleman@aol.com

www.notdeadyet.org

CASE STUDY: Terrie's Story

“At the age of 19, I had an automobile accident. . . . While I was lying [unconscious] in the hospital bed . . . , the doctors would come in and ask my mom if she was ready to pull the plug on me. ‘Why would I want to do that?’ she would ask? The doctors answered, ‘What kind of life will she have— she won’t. She won’t be able to dance, walk, work, have a social life, or be independent.’”

How We Die, Values, Choices, Conflicts

<http://stories-2.com/HowWeDie/story?sid=4>

Terrie's Story

“ . . . The next day when the doctor came in my dad was there with my mom. The doctor informed [them] that I was going to be in a veggie state for the rest of my life. . . . [M]y dad asked what veggie I was going to be because I hated green beans and would be mad if I was one.”

Terrie's Story

“The doctor said he didn’t find that funny and felt it was inappropriate. My mom said she felt he was being inappropriate by coming in every day and telling her to pull the plug on her daughter. The doctor responded that any good mother would pull the plug instead of seeing their baby suffer. . . .”

Terrie's Story

“Over the weeks I got worse and worse. Pneumonia was causing my lungs to fill and I was constantly flat lining. . . . [Weeks later] I was spending hours a day off the ventilator and the doctors were still asking if I wanted to live the rest of my life with this condition. If I chose no, they would keep me off the ventilator and I would die. I could get injected with Morphine so I couldn't feel it.”

Terrie's Story

“They’d work at my parents, saying things like: ‘Your daughter was so active before this accident and now she’s nothing. She’s just like Christopher Reeve, she will need help with everything, . . .’

Then they’d work on me. . . ‘Are you sure this is something you can live with? Do you want to spend the rest of your life on a ventilator?’”


Terrie's Story

“When I returned for my follow-up appointment a year later I made it a priority to see that team of doctors. When I rolled into the offices pushing my own power chair, without a ventilator, and healthy as can be, their jaws dropped to the floor and their eyes began to fill with tears.”

Terrie & her daughter Khloe now

Khloe - 6 mos.
Birthday





How can we help ensure that
health care decisions reflect
the person's wishes?



A Disability Perspective:
The Quest for Balance

Are advance directives always to refuse treatment, never to request it?

A recent study in the Journal of Emergency Medicine:

- n Researchers from the University of Pittsburgh Medical Center
- n Survey responses from more than 700 physicians in 34 states
- 1) Found that over 50% of physicians misinterpreted a living will as having a "do not resuscitate" (DNR) order when it did not.
- 2) About the same percentage over-interpreted DNR orders as meaning no treatment except "comfort care" or "end-of-life" care.

Mirarchi, et al., TRIAD III: Nationwide Assessment of Living Wills and No Not Resuscitate Orders, Journal of Emergency Medicine, Volume 42, Issue 5 , Pages 511-520, May 2012

Futility Policies v. Advance Directives

- n State statute or medical provider policy
- n “Doctor knows best” in treatment withholding
- n Overrules patient decision, family decision
- n Denies life-sustaining treatment based on
 - medical predictions (often unreliable)
 - quality of life judgments (often biased)

3 Types of Futility Statutes

- n Requires continued treatment pending transfer by physician who judges treatment futile (about 10 states)
- n Requires continued treatment for a limited time (two states, VA and TX)
- n Allows physicians to act on futility judgments and withdraw treatment, but non-specific about efforts that must be made to transfer patient first

Futility by Due Process

“When there is a request for treatment that the physician feels is inappropriate, an ethics consultation may be requested. If the guidelines of the statute are followed, the law creates a legal safe harbor for both physicians and hospitals by granting immunity from civil and criminal liability.” Fine & Mayo, Resolution of Futility by Due Process: Early Experience with the Texas Advance Directives Act, *Ann Intern Med* 2003; 138: 743-746.

Oklahoma has pending legislation titled the "Nondiscrimination in Treatment Act" (SB 1695).

A health care provider shall not deny to a patient a life-preserving health care service the provider provides to other patients, the provision of which is directed by the patient or a person authorized to make health care decisions for the patient:

- n 1. On the basis of a view that treats extending the life of an elderly, disabled, or terminally ill individual as of lower value than extending the life of an individual who is younger, non-disabled, or not terminally ill; or
- n 2. On the basis of disagreement with how the patient or person authorized to make health care decisions for the patient values the tradeoff between extending the length of the patient's life and the risk of disability.

Surrogate Decision-Making

Withholding or Withdrawing Life-Sustaining Treatment based on the decision of:

- n A surrogate (proxy) chosen by individual
- n A Surrogate designated under a statutory scheme or appointed by a court

Statutory Surrogates

- n (1) the spouse, unless legally separated;
- n (2) an adult child;
- n (3) a parent; or
- n (4) an adult brother or sister.

**UNIFORM HEALTH-CARE DECISIONS ACT
(1993)**

The Top 2 Statutory Surrogates Are the Top 2 Elder Abuse Perpetrators

In a telephone survey of nearly 6,000 elderly individuals, victims of elder physical mistreatment reported that:

- n A majority (57 percent) of perpetrators of physical abuse were partners or spouses.

Acierno R., M. Hernandez-Tejada, W. Muzzy, K. Steve.
National Elder Mistreatment Study (pdf, 183 pages),
NCJ 226456, March 2008, Grant Report.

The Top 2 Statutory Surrogates Are the Top 2 Elder Abuse Perpetrators

“Adult children are the most frequent abusers of the elderly, Other family members and spouses ranked as the next most likely abusers of the elderly.”

Toshio Tatara, PhD. and Lisa M. Kuzmeskus, M.A. for the National Center on Elder Abuse Grant No. 90-am-0660 (Washington, DC: May 1996)

Surrogate Decisions – What would the person want for him/herself?

Psychiatric News July 16, 2004

Volume 39 Number 14 © 2004 American Psychiatric Association p. 32

"The caretakers generally rated the patients' quality of life lower than the patients themselves had done.

"To find out why, the investigators used results from the Mini-Mental State Exam, Geriatric Depression Scale, Caregiver Burden Questionnaire, and other questions caretakers had answered.

Surrogate Decisions – What would the person want for him/herself?

"The reason, it turned out, is not that the patients lacked the mental capacity to assess their own quality of life, but rather that the caretakers felt burdened. In other words, it looks as though the caregivers had transferred their feelings about their own poor quality of life to the patients."

The study, "What Explains Differences Between Dementia Patients' and Their Caregivers' Ratings of Patients' Quality of Life?," is posted online at <

Rush To Judgment

CASE STUDY: Haleigh Poutre

- n Massachusetts case of 11-year-old girl injured by parental abuse
- n Withdrawal of a feeding tube sought by the state less than two weeks post-injury
- n Abusive father went to court to keep feeding tube (to avoid murder charges against himself)
- n State legal papers described her as almost “brain dead”
- n The judge in the case ruled that Poutre should “pass away with dignity”
- n The day after the ruling the news was released that Poutre had clearly recovered some level of consciousness
- n Poutre was transferred to rehabilitation

Rush To Judgment

CASE STUDY: Jesse Ramirez

- n 2007 car accident during argument between Mr. and Mrs. Ramirez in Arizona
- n Mr. Ramirez in coma and doctors can't say if he'll wake up
- n Nine days after accident, Mrs. Ramirez wants to remove feeding tube and fluids
- n Parents must go to court to stop her
- n Three weeks after accident, he wakes up

Rush to Judgment

“Reliable information about the character of an injured person’s future may be especially hard to find at those times during the course of treatment when there may be a ‘convenient’ window of opportunity to stop interventions and allow the patient to die.”

Nelson, Frader, “Brain Trauma and Surrogate Decisionmaking: Dogmas, Challenges and Response”, J Clin Ethics, Winter 2004, 15(4): 264-76.

Premature PVS Diagnosis

“The Multisociety Task Force on PVS (1994) proposed the term permanent vegetative state in cases where the probability of recovery from unconsciousness is extremely low (12 months for patients with traumatic brain injury and 3 months for patients with non-traumatic [anoxic] brain injury.)”

Katz, The Minimally Conscious State (MCS) and Related Disorders of Consciousness: Definitions, Diagnostic Criteria, Natural History and Prognosis.

Rush to Judgment

“Once a patient progresses to minimal consciousness, we can’t predict what’s going to happen,” says Dr. Joseph J. Fins, chief of medical ethics at Weill Cornell Medical College and author of a coming book, “Rights Come to Mind: Brain Injury, Ethics and the Struggle for Consciousness.”

- n A Drug That Wakes the Near Dead,
NYTimes Magazine, Jeneen Interlandi, Dec
1, 2011

Rush to Judgment

“Early on, when families have the option to pull the plug, it’s almost impossible to tell what the long-term prognosis will be,” says Dr. Soojin Park, a neurointensivist at the University of Pennsylvania Hospital, “And then later, when we have the certainty — that this is as good as it’s going to get — that option is gone. Because by then, the patient is breathing on their own. There’s no more plug to pull.” A Drug That Wakes the Near Dead, NYTimes Magazine, Jeneen Interlandi, Dec 1, 2011

Rush to Judgment

“At that point, families who want to end a loved one’s suffering must either have the feeding tube removed, or agree to let the next bacterial infection win out, unhindered by antibiotics. Many families find choosing these deaths much more difficult than turning off a ventilator. ...”

A Drug That Wakes the Near Dead, NYTimes Magazine, Jeneen Interlandi, Dec 1, 2011

Rush to Judgment

It is not uncommon for doctors to assume the worst and advise family members to withdraw care early. They do so in part because they see their duty as helping loved ones face reality. But Fins argues that this is a cop-out. "It's glossing over all the unknowns for the sake of a quicker, cleaner solution," he says. "It's wrong to be so uniformly fatalistic so early on, especially with all the data emerging about the prospects for later-stage recovery."

A Drug That Wakes the Near Dead, NYTimes Magazine,
Jeneen Interlandi, Dec 1, 2011

Translation/Restatement:

Leading neurologists admit that it is not uncommon for people with brain injuries, some of whom will recover, to have their lives ended through withdrawing ventilators before their prognosis is known. This is in order to ensure that others who will not recover (to an “acceptable” extent) will also have their lives ended, because by waiting the latter may be weaned from ventilators and only depend on feeding tubes, which families are often less willing to remove.

In today's health care system, would Terrie have survived?

Terrie & Khloe



5/24/12: National Disability Rights

Network issues groundbreaking report

In fact, there are times, as this report will describe where physicians recommend and family or other surrogate decision makers decide to not provide a needed transplant, to withhold medical treatment including hydration and nutrition of individuals without a terminal condition Applied in these ways, medical decision making and procedures are discriminatory and deny basic constitutional rights to individuals with disabilities including the rights to liberty, privacy, and other statutory and common law rights. [Page 11.]

Devaluing People with Disabilities: Medical Procedures that Violate Civil Rights, at www.ndrn.org

5/24/12: National Disability Rights

Network issues groundbreaking report

Hospitals, medical establishments and other medical entities' reliance on ethics committees and consultations are insufficient protections of patient's legal rights and they must, therefore, establish and implement due process protections to ensure the civil rights of a person with a disability are protected when ... there is a perceived or actual conflict between the desires of parents or guardians and the civil and human rights of a person with a disability. These due process procedures must ... be in place for instances of withholding necessary medical treatment including but not limited to nutrition, hydration or antibiotics.

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