

Withholding and Withdrawing Treatment

Presentation by Diane Coleman

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[Slide 1]

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The first thing I want to say is thank you for giving your valuable time to this Institute. The second thing is that I really feel that we need a lively opening and those of you who know me realize, as I do, that I'm a bit too wonky for that. Throughout the Institute I'll be turning to so many of you for help, so I want to start off with a brilliant piece by Norm Kunc.

[Slide 2]

Euthanasia Blues – Video
<http://www.youtube.com/watch?v=8Mwj8TUrbWg>

[Slide 3]

People often asked about how I got into this, so let me give a little Pre-History leading up to the Formation of Not Dead Yet.

[Slide 4]

I was an attorney in Los Angeles in 1985 and volunteered as a member of the Board of a large center for independent living. The center's Executive Director contacted me about attending a protest over the case of Elizabeth Bouvia, explaining that Elizabeth was a 26-year-old woman with cerebral palsy who had been through a miscarriage, marriage break up and other setbacks in her personal life, including the state rehabilitation agency taking back her accessible van and effectively blocking her plans to attend a master's degree program. She had gone to a local hospital, asking to be allowed to starve herself to death while receiving comfort care and pain medication. A Hemlock Society lawyer took her so called "right to die" case. The California appellate court ultimately compared Ms. Bouvia, not to a suicidal person needing suicide prevention, but to a terminally ill person in a "helpless," "hopeless" condition, but by then she didn't go through with it. This case served as a wake u call to the disability community.

[Slide 5]

Also in the 1980's, several cases went through the courts involving young men with quadriplegia on ventilators. These men were stuck in nursing facilities against their will, or feared winding up in a facility as their support systems failed. They wanted to be free of the facility or else pull the plug. In each case, the court found that their liberty rights included the liberty to die, but apparently not the right to live free. In only one case, that of Larry McAfee, were ADAPT disability advocates able to intervene and help him get out of the facility. We call these the "give me liberty or give me death" cases, and they were another wake up call. While we don't oppose the right to refuse treatment based on informed consent, we question the devaluation and coercive pressures placed on these men and others.

[Slide 6]

Over the next few years, concerns grew yet disability advocates were ignored, and the idea arose that an organization that included street action tactics like ADAPT was needed. On the day that ADAPT leader Bob Kafka said "I've got a name for your group!" from Monty Python and the Holy Grail, Not Dead Yet began – 18 years ago this Sunday.

My job today is to talk about a few issues under the topic of "Withholding & Withdrawal of Life Sustaining Treatment."

There are quite a few people in this room who know more than I do about the topics I'll be touching on, which is personally intimidating but also exactly what we need and want, so that together we can make this a very productive gathering that moves us forward. For now, let me just thank you for your patience.

[Slide 7]

Not Dead Yet works toward:

- Ensuring that health care decisions are voluntary and based on informed consent, and are not pressured
- Ensuring that surrogate decisions are consistent with the person's wishes and their civil rights and
- Opposing involuntary, unilateral decisions by doctors, hospitals and other providers (aka futility policies)

[Slide 8 & 9]

First, turning to "Surrogate Decision-Making", there are two kinds of surrogates who have the potential power of withholding or withdrawing life-sustaining treatment:

- A surrogate chosen by the individual or
- A surrogate designated under a statutory scheme or appointed by a court.

We think that a person chosen by the individual should have more latitude than someone chosen by law or court, who should be clearly bound by civil rights constraints.

[Slide 10]

The 1990 U.S. Supreme Court decision in the landmark Cruzan case ruled:

- that a surrogate may decide to withdraw treatment
- that food and water by tube is medical treatment that can be withdrawn by a surrogate and
- that State law determines the specific rights and limitations.

As implemented, all indications are that the rights of surrogates to remove life-sustaining treatment from people with disabilities are being massively abused.

[Slide 11]

The Pennsylvania case of David Hockenberry involved a man who was age 53 with an intellectual disability who had resided in a facility most of his life. He got aspiration pneumonia in 2007 and was hospitalized, where doctors treated him with a ventilator for several weeks. His parents asked the courts to allow them to refuse the ventilator and other treatments but the court denied the parents' request. Mr. Hockenberry improved and no longer needed the ventilator, returning to his living situation. But his parents appealed up to the state Supreme Court so they could try again the next time he got sick.

[Slide 12]

The protection and advocacy agency, Not Dead Yet and others filed a friend of the court brief opposing them. The Pennsylvania Supreme Court held that:

“where . . . life-preserving treatment is at issue for an incompetent person who is not suffering from an end-stage condition or permanent unconsciousness, and that person has no [self-selected] health care agent, the Act mandates that the care must be provided.”

[Slide 13]

Another case was recently brought to our attention by Disability Rights Wisconsin. It arose in response to the death of a 13-year-old boy with I/DD who had pneumonia. It was Easily treatable by antibiotics and his long-term facility was providing the antibiotics. But the Doctor encouraged his parents to transfer him to the University of Wisconsin Hospital so that he could be taken off of antibiotics, as

well as artificial nutrition and hydration. Then the boy was transferred to hospice care, where he died after being administered morphine.

[Slide 14]

Disability Rights Wisconsin, the designated disability protection and advocacy agency, filed suit against the University of Wisconsin Hospital and Clinics, and six physicians including Dr. Norman Fost, to prevent them from denying life-sustaining medical treatment to people with developmental disabilities. Not Dead Yet is partnering with the Autistic Self Advocacy Network on an Amicus Brief in this case which will be filed early next month. Samantha Crane, who will be speaking with you tomorrow, is writing the brief.

[Slide 15]

The disability protection and advocacy system is a tremendous resource for addressing surrogate cases. And I'd like to thank the National Disability Rights Network, and David Carlson and Nachama Wilker, who are with us at this Institute, for issuing their report in 2012 on Devaluing People with Disabilities: Medical Procedures that Violate Civil Rights, documenting the abuses and loss of life of people with disabilities at the hands of medical decision makers.

[Slide 16]

I'd next like to talk about what we call "Rush to Judgment" cases.

[Slide 17]

A good example is the case of Haleigh Poutre. Haleigh was an 11-year-old girl in Massachusetts, allegedly injured by parental abuse. Less than two weeks post-injury, the state sought to withdraw her feeding tube. The abusive father went to court to keep the feeding tube, not wanting to face murder charges. The State's legal papers described her as almost "brain dead." The judge in the case ruled that she should "pass away with dignity" in 2008. But the day after the ruling, the news was released that she had clearly recovered some level of consciousness so she was transferred to rehabilitation. By the way, Wikipedia says that during the father's trial in 2008, she was shown to have recovered the ability to walk 100 feet and eat independently.

[Slide 18]

Sometimes the press refers to people who wake up from a vegetative state as "miracles," but in most cases the person woke up in the time frames laid out by the American Academy of Neurology as the appropriate waiting period before giving a prognosis of permanent unconsciousness. According to the Academy, a vegetative

state can be judged to be permanent 12 months after *traumatic* injury, and to be permanent for *non-traumatic* injury through oxygen deprivation after 3 months.

[Slide 19]

Studies also show a high rate of misdiagnosis of persistent vegetative state. While that rate was 43% in a widely reported 1996 study, the commonly accepted figure is 30% misdiagnosis.

[Slide 20]

The problem with the mistaken or rushed diagnosis is that doctors are combining it with a recommendation to withdraw life support. One 2004 article referred to this as “ a ‘convenient’ window of opportunity to stop interventions and allow the patient to die.”

[Slide 21]

A leading national expert on consciousness, Dr. Joseph Fins, was interviewed for a New York Times article about drugs that were found to wake up people thought to be in a vegetative state. He said, “Once a patient progresses to minimal consciousness, we can’t predict what’s going to happen,” (he’s referring to what doctors call “minimally conscious state”, which some doctors began distinguishing from the vegetative state during the 1990’s).

[Slide 22]

He said, “It is not uncommon for doctors to assume the worst and advise family members to withdraw care early. . . . 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” but it’s happening, he says it’s not uncommon, and we don’t know how many people with disabilities are having their lives ended in this way rather than having the chance to recover.

[Slide 23]

Interestingly, Dr. Fins has also been involved in the organ transplant system, and reported in an AMA journal article several years ago that he resigned from the board of an organ procurement organization because of it’s overly aggressive practices in approaching families in the ICU.

[Slide 24]

Beginning two years ago, Not Dead Yet submitted comments on proposed protocols for organ donation after cardiac or circulatory death, which generally involves people on ventilators who may be removed from them. We were concerned about

the transplant system's failure to protect individuals and families from being contacted and even pressured about organ donation prior to a decision that life support will be withdrawn, and about the system's failure to ensure that organs are not procured before a conscious potential donor has received appropriate psychological counseling and support to live. (I can't help but think about the recent media flurry about the hunter who fell from a tree, though I don't know if organ donation was part of his case.)

[Slide 25]

After two years of letters regarding the protocols, including many by you, the Organ Procurement and Transplantation Network adopted a protocol requiring that organ donation discussions must not begin before a decision to withdraw life support has been made.

[Slide 26]

Of course, that success really needs follow through. The U.S. Dept. of Health and Human Services should ensure that the transplant network carries out its responsibility to monitor and discipline organ procurement organizations. HHS could also require support counseling for people who acquire severe disabilities.

[Slide 27]

Another organ donation issue is discrimination in eligibility for organ transplants. I'm sure that many of you heard two years ago about Amelia Rivera's story when her mother wrote a blog about a doctor at the Children's Hospital of Philadelphia who said that her daughter did not have the "right to a transplant, because she is developmentally delayed."

[Slide 28]

Following a national petition drive and negative publicity, the hospital's position changed and their public statement was quoted in USA Today:

"While we can unequivocally state that we do not disqualify transplant patients on the basis of intellectual ability... this event underscores the importance of our responsibility to effectively communicate with families."

[Slide 29]

I see this as an example of effective disability rights advocacy and would like to refer everyone interested in these issues to the Autistic Self Advocacy Network's Policy Paper & Toolkit.

[Slide 30]

Another healthcare decision-making issue focuses not on decisions by individuals and their surrogates, but unilateral decisions by healthcare providers.

[Slide 31]

What is futility?

Futile care is designated by State statute or medical provider policies that basically say that the “Doctor knows best,” overruling a patient or family decision in favor of treatment and denying life-sustaining treatment based on:

- medical predictions (which are often unreliable) and
- quality of life judgments (which are often biased).

[Slide 32]

There are basically three types of futility statutes. One requires continued treatment by the physician until the patient can be transferred (AL, FL, KS, MD, MA, MN, NH, NY, OH, WY) or otherwise protects the person (ID and OK). Two states require continued treatment for a limited time (VA 14 days and TX 10 days). The third and most common type allows or appears to allow physicians to act on futility judgments and withdraw treatment, but are not specific about the efforts that must first be made to transfer the patient to another willing provider.

[Slide 33]

The most infamous and widely discussed futility statute is the one in Texas which requires a review process by an ethics committee, and then allows life-sustaining treatment to be withdrawn after the 10th day after the written decision of that committee. A court is only authorized to extend the time if a preponderance of the evidence shows that another willing provider can be found.

So these policies involve involuntary passive euthanasia. There are at least two types of challenges to futility policies that disability advocates can pursue in their home states.

[Slide 34]

Oklahoma has legislation entitled the "Nondiscrimination in Treatment Act." It says that:

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

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

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. We're interested in trying this in Virginia, the state with the 14 day limit.

[Slide 35]

The second strategy is from our colleagues at Texas Not Dead Yet, a proposal for ethics committee accountability which would require ethics committee composition to be at least one quarter non-hospital staff, to include members of both disability and aging advocacy organizations, and require an independent oversight committee to adjudicate when individuals or families are in conflict with the decision of the ethics committee. One possible slogan would be: "End the UNethics Committees."

This type of effort could be undertaken in every state. It's a "Nothing About Us Without Us" campaign. There's a handout about this, and I would encourage disability advocates who are interested to email me after the Institute.

[Slide 36]

My final topic this morning is Physician/Medical Orders on Life-Sustaining Treatment (POLST/MOLST). I'd like to share part of a training video from California, modeling what is represented to be a good conversation between a doctor and patient.

[Slide 37]

POLST: Having the POLST Conversation (Uncaptioned Video)

<http://www.ucsd.tv/search-details.aspx?showID=18360&subject=health>

My feeling about that dialogue is that it's called "steering." No trial period on the feeding tube was offered, but they offered a trial period on the vent. I haven't seen that often. The doctor, Dr. Yee, tried to talk the patient into "no" ventilator, but she wanted to try, so he had to back off. Dr. Yee is getting a big award from the California Compassionate Care Coalition because of this work on POLST.

[Slide 38]

There are a number of disability community concerns about POLST. First, POLST is being used with non-terminal people who's situations and needs require more flexibility that POLST allows with it's rigid yes/no format. POLST conversations tend to show bias against life-sustaining technologies. The resulting POLST form may not reflect person's wishes, but the doctor's.

Most research on POLST has been done by POLST advocates, not independent researchers. Medical professionals have not been held accountable for compliance

with POLST procedures and safeguards. There may be a risk of over-interpretation of POLST orders (just as there is with do not resuscitate orders, where researchers say that 50% of doctors mistakenly deny other treatments besides CPR).

[Slide 39]

As an example of the fact that POLST is often overused, in Maryland, facilities have a duty to complete the MOLST form for residents of nursing homes, assisted living programs, kidney dialysis centers, home health agencies and hospices.

[Slide 40]

Another important issue is whether POLST requires the individual's or authorized surrogate's signature? The American Bar Association Commission on Law and Aging has analyzed the issue in states that have POLST laws.

- States that require patient/surrogate signature: CA, CO, GA, HI, ID, IL, IN, IA, LA, MT, NC, NV, NJ, PA, RI, UT, WA and WV
- States that don't: MD, MN, NY, OR, TN and VT

[Slide 41]

In the face of these concerns, we can look to the disability advocates in Connecticut, including Cathy Ludlum who's with us at the Institute, for negotiating POLST legislation that we can live with.

The bill which has passed the Connecticut Senate provides that POLST is:

- For a person at end stage of serious illness
- That the state POLST Advisory group includes disability advocates
- That the Signature of the patient or surrogate is required
- That the POLST Discussion with patients involves methods for presenting choices for end-of-life-care without steering patients toward particular options and
- That the discussion includes fully informing patients about both the benefits and risks of entering an immediately effective medical order for life sustaining treatment

There's a handout with the full bill language and if you'd like to be involved in a project to introduce or improve the POLST law in your state, please email me after the Institute.

[Slide 42]

- Nothing About Us Without Us!!!!
- Financial constraints pose a threat in the medical system.
- The medical system resists accountability.

- Bias against people with disabilities permeates society and medical providers.
- “Fear and loathing” of disability drives pro-euthanasia advocacy.

In closing, I've noted some central themes and messages that we'll be talking about throughout our time here, but I'd like to open things up to questions now.