A Disability Rights and Social Justice Perspective Against Assisted Suicide

NOT DEAD YET
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Major U.S. Disability Groups Opposed To Assisted Suicide

- ADAPT
- American Assn. of People with Disabilities
- Association of Programs for Rural Independent Living
- Autistic Self Advocacy Network
- Disability Rights Education & Defense Fund
- National Council on Disability
- National Council on Independent Living
- TASH
- The Arc of the United States
- United Spinal Association
What’s Disability Got To Do With It?

Some question the legitimacy of disability groups "meddling" and trying to "take away" what they see as the general public's right to choose assisted suicide in the face of terminal illness.
How U.S. Disability Groups Got Involved

Two-thirds of Jack Kevorkian’s body count was people with non-terminal disabilities. He was our biggest wake up call.
“At the age of 19, I had an automobile accident. While I was lying in the hospital bed, the doctors would come in and ask my mom if she was ready to pull the plug on me. ‘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.’ Then they’d work on me. ‘Are you sure this is something you can live with? 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.’

How We Die, Values, Choices, Conflicts
Terrie’s Story
CASE STUDY: Bill’s Story

Bill, a paraplegic anthropology professor who teaches at Syracuse University, was hospitalized for a stage 4 pressure sore. One night, a “hospitalist” visited him: “He grimly told me I would be bedbound for at least six months and most likely a year or more. That there was a good chance the wound would never heal. If this happened, I would never sit in my wheelchair. I would never be able to work again.”

Excerpt from Bad Cripple blog by Bill Peace, later in the Hastings Center Report.
http://badcripple.blogspot.com/2012_04_01_archive.html
CASE STUDY: Bill’s Story

“His next words were unforgettable. ... He informed me I had the right to forego any medication, including the lifesaving antibiotics. If I chose not to continue with the current therapy, I could be made very comfortable. I would feel no pain or discomfort at all. Although not explicitly stated, the message was loud and clear. ... A physician, a person who is highly educated, and I would hope free of any bias, considered my life not worth living.”
## Most “Reasons” For Assisted Suicide Are Disability Issues

<table>
<thead>
<tr>
<th>Oregon Reporting Form Language</th>
<th>1998-2016</th>
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<tbody>
<tr>
<td>His Or Her Terminal Condition Representing A Steady Loss Of Autonomy.</td>
<td>91.4%</td>
</tr>
<tr>
<td>The Decreasing Ability To Participate In Activities That Made Life Enjoyable.</td>
<td>89.7%</td>
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<tr>
<td>A Loss Of Dignity</td>
<td>77.0%</td>
</tr>
<tr>
<td>The Loss Of Control Of Bodily Functions, Such As Incontinence And Vomiting.</td>
<td>46.8%</td>
</tr>
<tr>
<td>The Physical Or Emotional Burden On Family, Friends Or Caregivers</td>
<td>42.2%</td>
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<tr>
<td>Inadequate Pain Control Or Concern About It</td>
<td>26.4%</td>
</tr>
<tr>
<td>The Financial Cost Of Treating Or Prolonging His Or Her Terminal Condition</td>
<td>3.4%</td>
</tr>
</tbody>
</table>
What is the Disability Role?

The disability experience makes us experts in both:
- The concerns that lead people to request assisted suicide, and
- The dangers of legalizing assisted suicide.

We live on the front lines of the healthcare system in a society that devalues old, ill and disabled people. We are the proverbial canaries in the coal mine, who understand and can explain the dangers to everyone of a public policy of assisted suicide.
A Deadly Mix:
The deadly combination of assisted suicide and our broken, profit-driven US health care system
What’s Cost Got To Do With It?

"...economics, not the quest for broadened individual liberties or increased autonomy, will drive assisted suicide to the plateau of acceptable practice."

Barbara Wagner, a 64-year-old great-grandmother, had recurring lung cancer, and Randy Stroup had prostate cancer. Their physicians prescribed chemotherapy, for Wagner to extend her life and for Stroup to help relieve pain.
But the Oregon Health Plan sent each a letter saying the Plan would not cover the beneficial chemotherapy treatment “but … it would cover … [among other things,] physician-assisted suicide.”
New California Case – Stephanie Packer

“A terminally ill California woman says her insurance company denied her coverage for chemotherapy treatment but offered to pay for her to kill herself, shortly after California passed a law permitting physician-assisted suicide.”

Elder & Disability Abuse

• Under the Oregon & Washington laws, a friend or relative – even an heir – can “encourage” an elder to make the request, sign the forms as a witness, pick up the prescription, and even administer the drug (with or without consent) because no objective witness is required at death, so who would know?

• One in 10 elders are abused in the U.S. (NEJM)
In about half the cases, the Oregon Health Division reports that no health care provider was present at the time of ingestion of the lethal drugs or at the time of death. Therefore, although “self administration” is touted as one of the key “safeguards”, in about half the cases, there is no independent witness to self-administration of the lethal drugs nor to consent at that time.
Can another speak for you?

Oregon law, model for most bills, says: "Capacity" means that in the opinion of an individual's attending physician, consulting physician, psychiatrist, or psychologist the individual has the ability to make and communicate an informed decision to healthcare providers, including communication through a person familiar with the individual's manner of communicating if that person is available. (Emphasis added.)
Failures of “Safeguards”

Fundamental loophole: Terminal Illness Prognosis.

• Many people are misdiagnosed.
• “Terminal” predictions are unreliable.
• Oregon’s law and most bills include people with conditions that cause death without treatment, like diabetes.
• Some bills define “terminal” as “incurable” and “irreversible.”
Jeanette Hall of Oregon was diagnosed with cancer in 2000 and told she had six months to a year to live. She knew about the assisted suicide law, and asked her doctor about it, because she didn’t want to suffer.
Her doctor encouraged her not to give up, and she decided to fight the disease. She underwent chemotherapy and radiation. Eleven years later, she wrote, “I am so happy to be alive! If my doctor had believed in assisted suicide, I would be dead. ... Assisted suicide should not be legal.”
Data Show Non-Terminal People Get Lethal Prescriptions

The law’s definition of “terminal” requires that the doctor predict that the person will die within six months. The reports do not reveal how many people outlived the 180-day “terminal” prediction, but give the median and range of the number of days between the request for a lethal prescription and death.
Data Show Non-Terminal People Get Lethal Prescriptions

In 2016, at least one person lived 539 days; across all years, the longest was 1009 days. In every year except the first year, the upper end of the range is significantly longer than 180 days.
Doctor-shopping is when, if you ask for lethal drugs and your doctor says “No, you don’t qualify,” you or your family shops for another doctor who will say “yes.”
It’s important to know that Compassion & Choices, known earlier as the Hemlock Society, facilitates the overwhelming majority of reported Oregon deaths in some way. They can refer you to a doctor if yours says no.
Percentage of Reported Oregon Deaths Through C&C Assistance

(examples of particular years)

- Through 2002: “About 75%”
- In 2003: 79%
- In 2008: 88%
Duration of Physician-Patient Relationship in Reported Oregon Assisted Suicide Cases

The median reported duration of the physician-patient relationship in the Oregon assisted suicide cases over the years 1998-2016 is:

13 weeks.

(Range: 0 – 1905 weeks)
Failures of “Safeguards” (cont’d.)

People with depression and psychiatric disabilities are at a significant risk.
Michael Freeland obtained lethal drugs in Oregon, despite a 43-year history of severe depression, suicide attempts and paranoia. His prescribing doctor said a psychological consult was not “necessary.” Yet, when finally provided high-quality medical and social services, his desire for assisted suicide vanished. He was able to reconcile with his estranged daughter and lived two years post-diagnosis until he died a natural death.
If Oregon’s safeguards are strong, how did someone like Michael Freeland obtain lethal drugs?

Oregon’s statistics show that, in recent years, less than 4% of patients are being referred for psychological evaluations. Over all the years, only 5.1% have been referred.
Psychological Issues Untreated

Moreover, the consulting doctor only gives an opinion about whether the person’s depression or other psychological factors result in impaired judgment. No treatment for diagnosed depression is required.
Assisted suicide creates a double standard. If you’re non-disabled and want to kill yourself, you get suicide prevention services. If you have a disability and want to die, you get assisted suicide.
The safeguards do work for someone: The doctors!

• Doctors are not held liable if they act in “good faith,” an impossible standard to disprove.
• The “good faith” standard makes all the other “safeguards” unenforceable.
• For all other procedures, doctors are liable if they are negligent.
Minimal Data & Fatally Flawed Oversight

• Reporting requirements lack teeth
• Non-compliance is not monitored
• No investigation of abuse
• Underlying data is destroyed annually
Not “Slippery Slope,” But An Incremental Strategy

“One safeguard – that physician-assisted death be restricted to the terminally ill – has proven to be especially controversial even among supporters of physician-assisted death. . . . The arguments against the terminal illness requirement illustrate the force of gravity that pulls the policy of physician-assisted death down the slope, and attempts to answer those objections force us to deal with problems of line-drawing on the slope.”

Gunderson, Martin and Mayo, David J., "Restricting Physician-Assisted Death to the Terminally Ill" (PDF) Hastings Center Report, November-December 2002. (pp. 17-23)
Not “Slippery Slope,” But An Incremental Strategy

“[I]t is reasonable to proceed incrementally and extend physician-assisted death initially only to terminally ill patients. Thus the restriction of physician-assisted death to terminally ill patients should not necessarily be regarded as a permanent restriction.”

Gunderson, Martin and Mayo, David J., "Restricting Physician-Assisted Death to the Terminally Ill" (PDF) Hastings Center Report, November-December 2002. (pp. 17-23)
“If assisted suicide is legal, some people’s lives will be ended without their consent, through mistakes and abuse. No safeguards have ever been enacted, or even proposed, that can prevent this outcome, which can never be undone.”

Marilyn Golden, Disability Rights Education & Defense Fund
Questions