

Implementation and implications of Physician-Assisted Death: It's All about Disability

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CONTEXT: People with serious illnesses and terminal conditions are disabled



**PEOPLE WITH
TERMINAL
CONDITIONS**

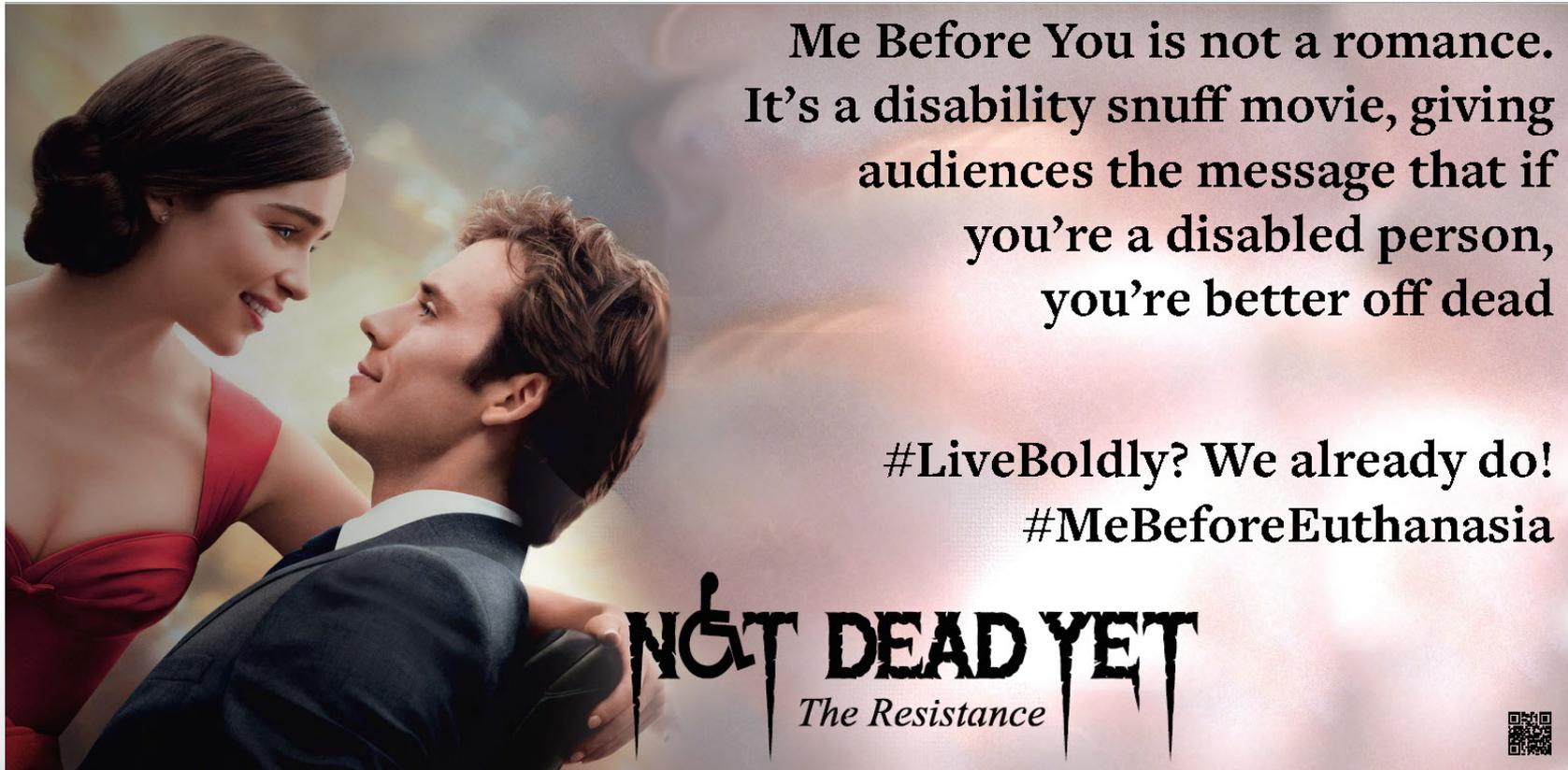
Disability = Terminal: Jack Kevorkian

- Two-thirds of Jack Kevorkian's body count were people with non-terminal disabilities.
- When 34-year-old Annette Blackman died at the hands of Jack Kevorkian, "Kevorkian's lawyer Geoffrey Fieger identified Blackman for police and said she suffered from multiple sclerosis causing 'total incontinence.'"

Roscoe, Lori A., at al, Gerontologist, Vol 41: 4, 8/1/2001
Story, Kristin, Detroit news, 10/14/1997

Disability = Death: “Better Dead than Disabled”

- Popular culture romanticizes the death of people like me. From films like “Whose Life Is It Anyway?,” “Million-Dollar Baby,” “The Sea Inside,” and last year’s hit “Me Before You,” people are taught that lives like mine are a humiliating burden calling out for death.



ELIGIBILITY

Terminal Illness Prognosis

- Oregon model bills define “terminal” as “incurable” and “irreversible” even if that is based on non-treatment or denial of treatment by insurers.
- Thousands of people are misdiagnosed as terminal every year.
- Misdiagnosis threatens EVERYONE.

Oregon Data Show Non-Terminal People Get Lethal Prescriptions

In 2017, at least one person lived 603 days; across all years, the longest was 1009 days. In every year except the first year in Oregon, people outlived the terminal prognosis they were given.

Oregon Health Authority, DWDA Year 20, 2017

MISTAKEN PROGNOSIS: Jeanette Hall

- **From her letter to the editor, Boston Globe, October 4, 2011**
- I didn't want to suffer. I wanted to do what our law allowed, and I wanted my doctor to help me. Instead, he encouraged me not to give up, and ultimately I decided to fight the disease. I had both chemotherapy and radiation.
- I am so happy to be alive! It is now 11 years later.
- If my doctor had believed in assisted suicide, I would be dead. I thank him and all my doctors for helping me to choose "life with dignity."



NEJM: “EXISTENTIAL DISTRESS”

- **Review of hospital-based program in Canada**
- “Those who received MAiD [Medical Aid in Dying] tended to be white and relatively affluent and indicated that loss of autonomy was the primary reason for their request.
- “Other common reasons included the wish to avoid burdening others or losing dignity and the intolerability of not being able to enjoy one’s life.
- “Few patients cited inadequate control of pain or other symptoms.”

Li, Madeleine, et al, Medical Assistance in Dying — Implementing a Hospital-Based Program in Canada, NEJM

Reported reasons for assisted suicide: Oregon 1998-2017

End of life concerns	1998-2017
HIS OR HER TERMINAL CONDITION REPRESENTING A STEADY LOSS OF AUTONOMY .	91 %
THE DECREASING ABILITY TO PARTICIPATE IN ACTIVITIES THAT MADE LIFE ENJOYABLE.	90 %
A LOSS OF DIGNITY .	76%
THE LOSS OF CONTROL OF BODILY FUNCTIONS, SUCH AS INCONTINENCE AND VOMITING.	46%
THE PHYSICAL OR EMOTIONAL BURDEN ON FAMILY, FRIENDS OR CAREGIVERS.	44%
INADEQUATE PAIN CONTROL OR CONCERN ABOUT IT.	26 %
THE FINANCIAL COST OF TREATING OR PROLONGING HIS OR HER TERMINAL CONDITION.	4%

BAIT & SWITCH

- C & C president Barbara Coombs Lee told the Washington Post about disability scenarios she considered “worse than death.” Lee described one assisted suicide who considered her emotional distress over incontinence “more painful than any of the pain from the cancer.”
- Proponent Dan Diaz said in the same article that if he found himself dependent on others for toileting and positioning, “I would then submit, ‘is that really living?’” As a California doctor summed up, “It’s almost never about pain. It’s about dignity and control.”
- Dr. Ira Byock, a leading palliative care expert, told the Post, “it’s a bait and switch. We’re actually helping people hasten their deaths because of existential suffering. That’s chilling to me.” Almost all pain is controllable, Byock said.

Szabo, Liz, ‘Death with dignity’ laws and the desire to control how one’s life ends, Washington Post, October 24, 2016

Economics of Assisted Suicide

Assisted suicide makes for a deadly combination
With our broken, profit-driven US health care
system.

Derek Humphry, founder of the Hemlock society, the
precursor to Compassion & Choices, wrote in 2000
**"...economics, not the quest for broadened
individual liberties or increased autonomy, will
drive assisted suicide to the plateau of acceptable
practice."**

Derek Humphry & Mary Clement, "Freedom to Die:
People, Politics and the Right to Die Movement" (2000).

Failure of “Safeguards”: Elder & Disability Abuse

- One in 10 elders are abused in the U.S.
- 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?

Lachs, Mark S., M.D., and Karl A. Pillemer, Ph.D., NEJM, “Elder Abuse,”
November 12, 2015

UNPROTECTED PATIENTS

- Neither doctors nor witnesses need know the patient more than superficially. Witnesses can simply check the person's ID.
- Doctors who decline to prescribe for medical reasons are not interviewed.
- People can simply doctor shop until they find a prescriber.

Violations of the Law Go Unpunished

- Oregonian Wendy Melcher, a trans-woman, was terminally ill with throat cancer, and was receiving hospice services but had not enrolled in the assisted suicide program.
- Her hospice nurse and another nurse – who was allegedly having an affair with Wendy’s partner– tried to kill her with massive morphine suppositories. They said they were following Wendy’s instructions, disputed by the family.
- By claiming their act was assisted suicide, they were not charged with a crime, but rather dealt with in secret by the Oregon nursing board. A 30 day license suspension for one, two years probation for the other.
- The Portland Tribune wrote: “If nurses — or anyone else — are willing to go outside the law, then all the protections built into the Death With Dignity Act are for naught.”

Korn, Peter, "Assisted suicide's on trial again," Portland Tribune, 7/5/07
Portland Tribune Editorial, "Another case for nursing reform," 7/9/07

Wash. State Elder Law Attorney Margaret Dore says:

Assisting persons can have their own agendas:

- an adult child wanting an inheritance;
- a financial predator seeking financial gain;
- or a doctor wanting to hide malpractice.

Dore, Margaret, “Assisters Can Have Their Own Agendas; Patient Choice Not Assured,” Choice Is an Illusion Website, March 5, 2017

Failure of Safeguards: No Witness At the Death

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. So there is no independent witness to self-administration of the lethal drugs nor to consent at that time.

Oregon Health Authority, DWDA Year 20, 2017

SAFEGUARD: CAPABILITY

Oregon's statistics show that, in 2017, only five out of 143 patients were referred for psychological evaluations, 3.5%. Over all the years, only 4.9% have been referred.

Oregon Health Authority, DWDA Year 20, 2017

The safeguards do work for doctors and other suicide assisters

- 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.

MAJOR DISABILITY RIGHTS GROUPS OPPOSED

All the major national disability rights groups that have taken a position on assisted suicide against prevailing progressive views.

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

SUMMARY

“If assisted suicide is legal, some people’s lives will be ended without their consent, through mistakes, coercion 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

Golden, Marilyn, “Assisted suicide is bad medicine,” Sacramento Bee, November 1, 2014

CITATIONS, p. 1

“Better Dead than Disabled”

- Coleman, Diane, “Face To Face: Challenging the ‘Better Dead Than Disabled’ Message,” Not Dead Yet website, September 1, 2016.

<http://notdeadyet.org/2016/09/face-to-face-challenging-the-better-dead-than-disabled-message.html>

- Center for Disability Rights, “Live On. Disabled Lives Are Worth Living,” Video PSA, June 3, 2016.

<https://www.youtube.com/watch?v=PLPAzs0A5-Q>

Assisted Suicide Eligibility

- Oregon revised statute:

<http://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Pages/ors.aspx>

Non-terminal people dispensed lethal drugs

- Oregon Health Authority (OHA), Public Health Division, Center for Health Statistics, “Year 20: Oregon DWDA annual statistical report 2017,” February 8, 2018:

<http://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Documents/year20.pdf>

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- Jeanette Hall, “She pushed for legal right to die, and - thankfully - was rebuffed,” letter to the editor, Boston Globe, October 4, 2011:
http://archive.boston.com/bostonglobe/editorial_opinion/letters/articles/2011/10/04/she_pushed_for_legal_right_to_die_and_thankfully_was_rebuffed/

NEJM: “Existential Distress.”

- Li, Madeleine, et al, “Medical Assistance in Dying — Implementing a Hospital-Based Program in Canada,” N Engl J Med 2017; 376:2082-2088
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Bait and Switch

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Economics of Assisted Suicide

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Failure in Safeguards: Elderly and Disabled Abuse

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Violations go Unpunished

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portlandtribune.com/component/content/article?id=89065
- Portland Tribune Editorial, "Another case for nursing reform," July 9, 2007:
portlandtribune.com/component/content/article?id=89126
- 'Dore, Margaret, "Assisters Can Have Their Own Agendas; Patient Choice Not Assured," March 5, 2017.
<http://www.choiceillusion.org/2017/03/assisters-can-have-their-own-agendas.html#more>

Summary

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<http://www.sacbee.com/opinion/california-forum/article3480794.html>