

A Disability Rights and Social Justice Perspective Against Assisted Suicide

NOT DEAD YET

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Terrie's Story – How some doctors write people off

“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

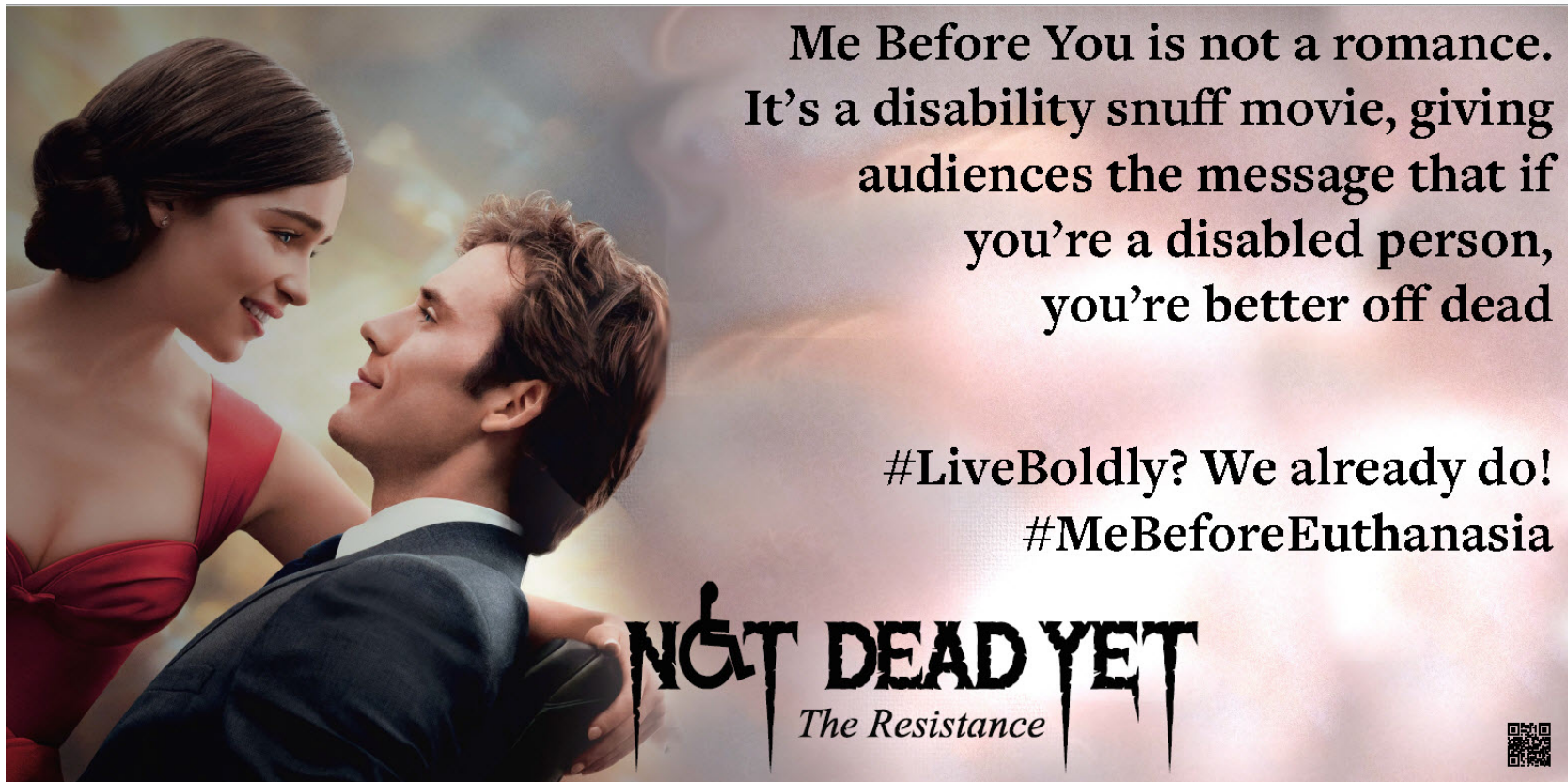
<http://stories-2.com/HowWeDie/story?sid=4>

Terrie's Story



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.



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

Question

So why do all the major national disability rights groups that have taken a position on the issue break ranks with our progressive allies concerning bills to legalize assisted suicide?

How U.S. Disability Groups Got Involved

- Two-thirds of Jack Kevorkian's body count in the 1990's was people with non-terminal disabilities. He was our biggest wake up call.
- And the 1996 assisted suicide cases that went up to the U.S. Supreme Court.

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%

CONTEXT: People with serious illnesses and terminal conditions are disabled

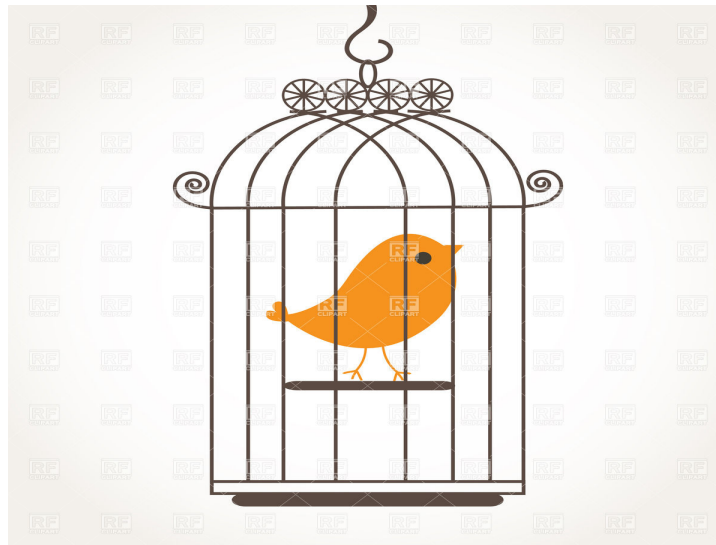


**PEOPLE WITH
TERMINAL
CONDITIONS**

What is the Disability Role? Proverbial Canary in the Coal Mine

The disability experience makes us experts in both:

- The concerns that lead people to request assisted suicide, and
- The dangers of legalizing assisted suicide.



A Deadly Mix:

The deadly combination
of assisted suicide
and our broken, profit-driven
US health care system

Disabled protesters dragged out of healthcare bill hearing



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."

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

Example: 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.”

Washington Times, Oct. 20, 2016

Racial Disparities

Due to racial disparities in our healthcare system, Blacks and people of color receive inferior healthcare compared to Whites, especially in cardiac care, diabetes and pain management.

Failure of “Safeguards”: Elder & Disability Abuse

- The 2 doctors who certify “no coercion” don’t actually have to know the person or family well enough to identify coercion.
- The 2 witnesses to the assisted suicide request form need not know the person at all and can simply check their ID.

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 1998-2017 is:

13 weeks.

(Range: 0 – 1905 weeks)

Failure of “Safeguards”: 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)**

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.)

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.

Failure of “Safeguards”

Terminal Illness Prognosis

- Many people are misdiagnosed.
- “Terminal” predictions are unreliable.
- Oregon model bills define “terminal” as “incurable” and “irreversible” even if that is based on non-treatment due to lack of insurance

Failure of “Safeguards”

Terminal Illness Prognosis

- “disease or condition that ...will result in death within the foreseeable future” (NM bill)
- “disease that will, within reasonable medical judgment, produce or substantially contribute to a patient's death” (OR bill)

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.



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.

Failure of “Safeguards”

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.

No Effort Needed To Address Psychological or Attendant Service Issues

Moreover, in the few cases referred, the psychological consultant only gives an opinion about whether the person's depression or other psychological factors result in impaired judgment. The law allows assisted suicide without any treatment for diagnosed depression, or any effort to address the patient's reported concerns.

Doctor Shopping

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.”

No “Light of Day” - Fatally Flawed Oversight

- Oregon’s reports summarize a form filed by prescribing doctors
- Doctors’ self reports are not verified
- No investigation of error or abuse
- Underlying data is destroyed annually

The safeguards do work for doctors and other suicide assisters

- Doctors are not held liable if they say they acted 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.
- ASSISTED SUICIDE LAWS ARE IMMUNITY STATUTES for everyone involved.



Assisted suicide creates a double standard. If you're non-disabled and want to kill yourself, you get suicide prevention. If you have a disability and want to die, you get suicide assistance. It's the ultimate discrimination.

A good 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

Communicating the message

Media Work

A. Working with the media

1. Give interviews
2. Issue media advisories explaining your Key Arguments
3. Issue press releases describing activities and responding to relevant news
4. Contact journalists who report on AS/E issues
 - a. Cold calls (Brrrrr)
 - b. Respond to articles they write.

A. Working with the media

5. Submit letters to the editor, and online comments on articles
6. Write and pitch opinion pieces to editorial pages of key publications
7. Meet with editorial boards to urge them to oppose legalization

B. Keep in mind

1. Make sure reporters have your information:
 - a. your name, phone, email, website, social media links.
 - b. the name of your group, phone, email, website, social media links, and
 - c. the Key Arguments

B. Keep in mind – Key Arguments

- Legalization is unnecessary.
- Assisted suicide is discriminatory.
- Choice is a slogan, not a reality.
- Safeguards don't work.

B. Keep in mind

2. Make sure to get important information from the journalist:

a. the name and contact information for the reporter,

b. the news outlet they're writing for,

c. the date of publication, and

d. an email copy or a link to the article or video report.

C. Social Media

1. Which media for which audience and what objective:
 - a. Website
 - b. Facebook
 - c. Twitter
 - d. Videos/YouTube, Email, blogs, and other Social media platforms

C. Social Media

2. Investment of time and effort

a. Set Up

b. Maintenance & updates

c. Participation (comments on others' posts, blogs & media articles)

3. Accessibility

D. Strategic Reminders

1. Put your best feet forward:
 - a. Disability rights advocates,
 - b. Palliative care professionals, and
 - c. People of color

D. Strategic Reminders

2. Moral / religious arguments are not helpful

a. Have a very narrow appeal

b. Generate heat without light

c. Bring negative attention / backfire

D. Strategic Reminders

3. When people get the facts, Assisted suicide is defeated.
4. Responding to the tragic individual story
 - a. If you only consider one person, AS might look OK, but as public policy it harms too many people
 - b. Some people's lives will be ended without their consent through mistakes and abuse; no safeguards can prevent this outcome

Working in Coalition

“All roads lead to Rome.”

A. All roads lead to Rome

1. We come from different places, with different beliefs and priorities.
2. We all want to get the same place.
3. We want to use the surest, most efficient route.
4. Associating with religious and moral groups can be harmful to disability groups.

B. Leave your baggage at home

1. Single-issue coalition
2. We agree to disagree on other issues.
3. Religious and moral beliefs, while dearly held, should not be shared, except when invited.

C. R-E-S-P-E-C-T

1. Policies have been made without the input of disabled people.
2. Our expertise on health care and assisted suicide has not been respected.
3. We have been denied leadership roles

C. R-E-S-P-E-C-T

4. We have been used as tokens.
5. Many disabled people find religious views about disability to be negative and discriminatory.

Questions