

Cover Page and Summary for Margaret Carter's Testimony on HB0933

The End-of-Life Options Act

I am a cancer survivor, a disability advocate, and a caregiver for two people with life-altering disabilities, my daughter Lucy Carter and my 94-year-old mother who has dementia. I urge you to vote against this act because it represents a threat to vulnerable people and to the medical profession itself. Doctors must be dedicated to preserving life—not taking it. Laws requiring them to make value judgements based on their patients' "quality of life" will inevitably lead to a devaluation of human life in general. Ultimately this will destroy the medical profession as we now know it—as well as the lives of many vulnerable people.

I am including the following documents which I will refer to in my oral testimony.

Pages 1-3: An obituary for Sheryl Grossman who testified against Physician Assisted Suicide in Annapolis in 2019. Sheryl lived with a rare "terminal illness" known as Blooms disease for many years. She cannot testify today, but she should be remembered as a silent witness for vulnerable people today.

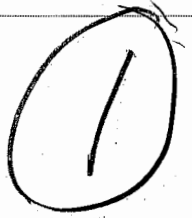
Pages 4-5 A definition of "terminal illness" from the Patients' Rights Council that Sheryl Grossman would have referred to had she been here today. When I met her in 2019, she noted that she fit that definition.

Pages 6-9 An op-ed by Theo Boer, a Dutch euthanasia advocate who finally realized that once euthanasia is normalized, it inevitably expands.

Pages 10-14 A report from the US Conference of Catholic Bishops which shows that euthanasia, particularly in Europe, where it first began, has expanded to include "involuntary euthanasia."

Page 15 A photo of my daughter Lucy Carter, who was described many years ago as "hopeless" by a family member. It took me many years to realize that while by the world's standards she has a low quality of life, she is indeed a remarkable person. And she is only alive today because of remarkable medical advancements.

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Disability rights activist Sheryl Grossman, 2015. Courtesy of the Jewish Orthodox Feminist Alliance.

Death of Jewish disability activist Sheryl Grossman

March 28, 2022

On March 28, 2022, Jewish disability activist Sheryl Grossman died at the age of 46. She was a fierce advocate and activist for the rights of the disabled and served as a role model and source of empowerment for disabled people both within and beyond the Jewish community.

Grossman was born on December 30, 1975, in Chicago. When she was fourteen, she learned that she had Bloom's Syndrome, a rare genetic condition characterized by short stature, immune deficiency, and an increased susceptibility to many cancers. Fewer than 300 people have been diagnosed with Bloom's Syndrome since it was named in 1954, and about a quarter of them, like Grossman, have Ashkenazi Jewish ancestry.

In her junior year of college, in 1996, Grossman launched Bloom's Connect, an organization that provided crucial resources to people with the condition around the world. In 2008, the group held its first conference in Chicago, hosting 35 families from five countries.

Grossman spent over 20 years in disability rights advocacy, working on issues ranging from access to education and appropriate medical care to voting rights, housing, and employment. As a Community Living Advocate for the National Council on Independent Living, she worked on housing rights for the disabled, facilitating the National Organizing Project. Between her own hospital visits, she advocated for community integration on Capitol Hill. At the Job Accommodation Network, she worked on making the workplace accessible to the disabled. She also served as a board member of Yad Hachazakah, the Jewish Disability Empowerment Center.

Grossman later focused on advocating for those with rare conditions. Since most doctors had never treated anyone with Bloom's, she saw it as her duty to educate

them about the inner workings of the disease. In 2020, Grossman was nationally recognized for her dedication to the rare disease community, and she received a RareVoice Award for her federal advocacy work. She also advocated for those with multiple minority group status, speaking frequently about inclusion in Jewish spaces and coaching Jewish organizations and communities about how to adopt practices that would fully include people with disabilities. 2

In the last years of her life, Grossman worked on making the Covid vaccine accessible to aged, disabled, and homebound people in Maryland. She also raised awareness about accessibility and privacy issues in the American elections process and how they affect disabled people.

Grossman was an observant Jew who found herself drawn to Orthodoxy in college. As Dana Marlowe, a fellow disability advocate from Silver Spring, told *Washington Jewish Week*, "Though her advocacy was important, religion always came first."

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Jewish Women's Archive. "Death of Jewish disability activist Sheryl Grossman." (Viewed on March 8, 2023) <<https://jwa.org/thisweek/mar/28/2022/death-jewish-disability-activist-sheryl-grossman>>.

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Terminal: What Does It Mean

DID YOU KNOW – YOU COULD BE CONSIDERED TERMINALLY ILL EVEN IF YOU FOR DECADES?

Under current doctor-prescribed suicide laws and proposals, a person who could 1 years is eligible to receive a prescription for a lethal overdose of drugs.

Proponents of doctor-prescribed suicide invariably point to the requirement that a person must obtain the prescription for what they call “death with dignity.” They further explain that the person has been diagnosed with a six-month or less life expectancy. They call this a safeguard.

What they omit is the fact that, in all the assisted-suicide laws that have passed in the various states, and those that have been proposed this year – the definition of “terminal” allows doctors to prescribe to individuals even if the patients could live for many years.

This is because the laws and proposals define “terminal” as an illness or condition that will result in death within six months, *but do not specify whether the person could survive with appropriate treatment.*

There is documentation that this has occurred under Oregon’s assisted suicide law. In official reports from Oregon, diabetes is noted as the underlying terminal condition that made the patient eligible for a lethal prescription.^[1] If insulin-dependent diabetics do not take insulin, they will die within six months. If they take the medication, they can live for many years.

Dr. Charles Blanke, an oncologist and professor of medicine at Oregon Health and Science University, described another case of a young woman with Hodgkin lymphoma who had a 90 percent chance of living if she received the recommended treatment. The woman, however, refused the treatment. “That was a very challenging case,” he said. “You have to ask yourself, ‘Why doesn’t that patient want to take relatively non-toxic treatment for another seven decades?’” Blanke ended up prescribing the deadly overdose for the woman and she died.
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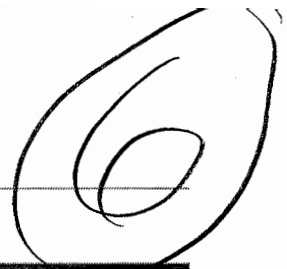
[1] Official report for 2016 deaths under Oregon’s Death with Dignity Act, Oregon Public Health Division, “Oregon’s Death with Dignity Act – 2016,” pg. 11, fn. 2. Available at: <http://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Documents/year19.pdf>. (8/17/17.)

[2] Tara Bannow, "Rural Oregonians Still Face Death with Dignity Barriers," *Bend Bulletin*, Aug
Available at: <http://www.bendbulletin.com/health/5512373-151/oregonians-can-choose-how-th>
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Opinion



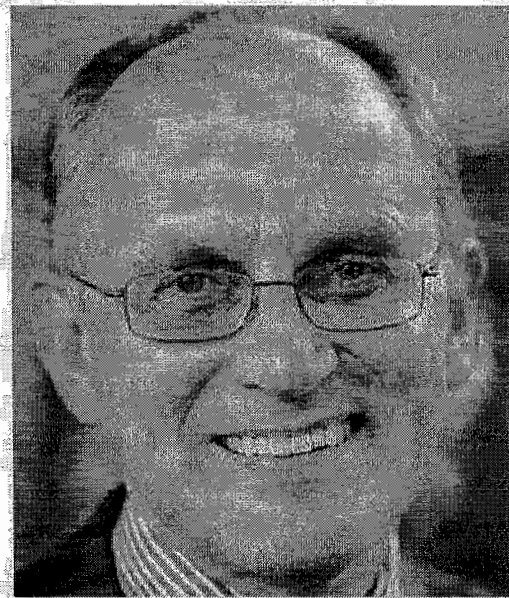
Boer: I was wrong – euthanasia has a slippery slope

In 2001, the Netherlands was the first country in the world to legalize euthanasia and, along with it, assisted suicide. Various safeguards were put in place to show who should qualify, and doctors acting in accordance with these safeguards would not be prosecuted.

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Published Jul 17, 2014 • 3 minute read

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Theo Boer

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In 2001, the Netherlands was the first country in the world to legalize euthanasia and, along with it, assisted suicide. Various safeguards were put in place to show who should qualify, and doctors acting in accordance with these safeguards would not be prosecuted.

Because each case is unique, five regional review committees were installed to assess every case and to decide whether it complied with the law. For five years after the law became effective, such physician-induced deaths remained level — and even fell in some years. In 2007, I wrote that “there doesn’t need to be a slippery slope when it comes to euthanasia. A good euthanasia law, in combination with the euthanasia review procedure, provides the warrants for a stable and relatively low number of euthanasia.”

Most of my colleagues drew the same conclusion.

But we were wrong — terribly wrong, in fact. In hindsight, the stabilization in the numbers was just a temporary pause. Beginning in 2008, the numbers of these deaths show an increase of 15 per cent annually, year after year. The annual report of the committees for 2012 recorded 4,188 cases (compared with 1,882 in 2002). Last year saw a continuation of this trend, and I expect the 6,000 line to be crossed this year or the next. Euthanasia is on the way to becoming a default mode of dying for cancer patients.

Alongside this escalation, other developments have taken place. Under the name End of Life Clinic, the Dutch Right to Die Society NVVE founded a network of travelling euthanizing doctors. Whereas the law presupposes (but does not require) an established doctor-patient relationship, in which death might be the end of a period of treatment and interaction, doctors of the End of Life Clinic have only two options: administer life-ending drugs or send the patient away.

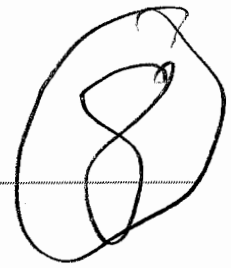
Testimony on SB 0845 From Margaret Carter

I am a cancer survivor, disability advocate and a caregiver for two vulnerable individuals, one with dementia and the other with developmental disabilities. I oppose this legislation for the following reasons:

1. It normalizes suicide, a social anathema.
2. It normalizes the killing of patients by physicians—who must be dedicated to healing.
3. The six month terminal diagnosis is nebulous at best. Many people who receive that diagnosis live well beyond it.
4. It will force physicians who are morally opposed to Physician Assisted Suicide to take part in it.
5. Once physician assisted suicide is normalized in the U.S, it will eventually morph into involuntary euthanasia—as it has in Europe.

I am including two documents that support my points.

Thank you, Margaret Carter



On average, these physicians see a patient three times before administering drugs to end their life. Hundreds of cases were conducted by the End of Life Clinic. The group shows no signs of being satisfied even with these developments. They will not rest until a lethal pill is made available to anyone over 70 years who wishes to die. Some slopes truly are slippery.

Other developments include a shift in the type of patients who receive these treatments. Whereas in the first years after 2002, hardly any patients with psychiatric illnesses or dementia appear in reports, these numbers are now sharply on the rise. Cases have been reported in which a large part of the suffering of those given euthanasia or assisted suicide consisted of being aged, lonely or bereaved. Some of these patients could have lived for years or decades.

Whereas the law sees assisted suicide and euthanasia as an exception, public opinion is shifting toward considering them rights, with corresponding duties on doctors to act.

A law that is now in the making obliges doctors who refuse to administer euthanasia to refer their patients to a "willing" colleague. Pressure on doctors to conform to patients' (or in some cases, relatives') wishes can be intense. Pressure from relatives, in combination with a patient's concern for the well-being of his beloved, is in some cases an important factor behind a euthanasia request. Not even the review committees, despite hard and conscientious work, have been able to halt these developments.

I used to be a supporter of legislation. But now, with 12 years of experience, I take a different view. At the very least, wait for an honest and intellectually satisfying analysis of the reasons behind the explosive increase in the numbers. Is it because the law should have had better safeguards? Or is it because the mere existence of such a law is an invitation to see assisted suicide and euthanasia as a normality instead of a last resort?

Before those questions are answered, don't go there.

Once the genie is out of the bottle, it is not likely to ever go back in again.

Theo Boer is professor of ethics at the Protestant Theological University at Groningen, Netherlands. For nine years, he was a member of a regional euthanasia review committee. The views expressed in this article, which was written for Britain's Daily Mail, represent his views as a professional ethicist, not of any institution.



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Assisted Suicide and Euthanasia: From Voluntary to Involuntary

While promoted in the name of personal autonomy, physician-assisted suicide (providing lethal drugs so patients can take their own lives) and euthanasia (direct killing of patients by doctors) do not remain limited to cases in which the victim gave his or her voluntary consent. This agenda ultimately embraces coercion and the death of unwilling victims.¹

The Case of the Netherlands

Since 1973 a series of court decisions has established that Dutch doctors need not fear punishment or prosecution if they kill, or assist the suicides of, patients in “unbearable suffering” who make a voluntary request to die. When the Dutch government studied actual practice in 1991, it found: 2300 cases of voluntary euthanasia every year; 400 assisted suicides; and 1040 cases in which doctors killed patients without their knowledge or consent. In this last category, 72% of the patients had never expressed an interest in having their lives taken, and 14% were fully competent. In addition, 8100 patients died from overdoses of pain medications intended primarily to end life rather than relieve pain, and 61% of the time (4941 cases) this was done without the patient’s consent.

Patients Rights Council, *Background About Euthanasia in the Netherlands*, at www.patientsrightscouncil.org/site/holland-background/.

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In one recent case, A Dutch physician slipped a sedative into an elderly dementia patient’s coffee after deciding it was time for her to receive euthanasia. When the patient awoke and struggled against what was being done, the doctor told the patient’s family to hold her down while the lethal injection was administered. The doctor was “cleared of any wrongdoing” by a regional review committee, which said “the doctor acted in good faith.”

R. Roberts, “Doctor who asked dementia patient's family to hold her down while she gave lethal injection cleared,” *The Independent* (London), 5 February 2017, at <http://www.independent.co.uk/news/world/europe/doctor-netherlands-lethal-injection-dementia-euthanasia-a7564061.html>.

* * *

Writes one investigator into Dutch practice: “Some euthanasia advocates defend the need for doctors to make decisions to end the lives of competent patients without discussion with them. One euthanasia advocate gave me as an example a case where a doctor had terminated the life of

¹ On how assisted suicide laws in Oregon and Washington open the door to ending the life of people unable to give voluntary and informed consent, also see USCCB Secretariat of Pro-Life Activities, *Assisted Suicide Laws in Oregon and Washington: What Safeguards?*, at <http://www.usccb.org/issues-and-action/human-life-and-dignity/assisted-suicide/to-live-each-day/upload/OR-and-WA-Safeguards-FACTSHEET.pdf>.

a nun a few days before she would have died because she was in excruciating pain, but her religious convictions did not permit her to ask for death. He did not argue, however, when asked why she should not have been permitted to die in the way she wanted... Other advocates admit that a system in which doctors become used to playing a predominant role in making decisions about ending life encourages some to feel entitled to make decisions without consulting patients.”

H. Hendin, “Assisted Suicide, Euthanasia, and Suicide Prevention: The Implications of the Dutch Experience,” 25.1 *Suicide & Life-Threatening Behavior* 193-204 (Spring 1995) at 201-2. For other cases see R. Fenigsen, “Other People’s Lives: Reflections on Medicine, Ethics, and Euthanasia,” 26.3 *Issues in Law & Medicine* 239-79 (Spring 2011) at 278.

* * *

While patients with clinical depression or other mental disorders cannot be expected to make a rational request for assisted suicide, in Oregon and Washington only 4% of patients receive a psychological evaluation to exclude such cases (see documentation in note 1 above). In the Netherlands, Belgium and Switzerland, such mental illness can actually be the sole reason for a physically healthy patient to *receive* assisted suicide or euthanasia. A 2016 study reviewing 66 such cases in the Netherlands showed that most of the patients were women, most suffered from depression, and 35% had no independent psychiatric input or consultants had disagreed.

B. Carey, “Assisted Suicide Study Questions Its Use for Mentally Ill,” *The New York Times*, Feb. 10, 2016, at <https://www.nytimes.com/2016/02/11/health/assisted-suicide-mental-disorders.html>; S. Kim et al., “Euthanasia and Assisted Suicide of Patients With Psychiatric Disorders in the Netherlands 2011 to 2014,” 73.4 *JAMA Psychiatry* 362-8 (2016) at 362.

* * *

Newborn children, of course, cannot make a voluntary request for euthanasia. Yet in 1993, a Dutch physician was acquitted of wrongdoing after he gave a lethal injection to a four-day-old infant with spina bifida, because he allegedly faced a conflict between his duties to preserve life and to relieve suffering. By 1995, Dutch physicians had published an account of 22 similar cases. Parents had consented to the injections; however, in all but four cases it was the physicians who first made the proposal. That year the Dutch Association of Paediatrics approved the “Groningen Protocol,” which set standards for such nonvoluntary taking of life and found all 22 cases to be in accord with acceptable medical practice.

T. De Jong, “Deliberate termination of life of newborns with spina bifida, a critical reappraisal,” 24 *Child’s Nervous System* 13-28 (2008) at 15-17.

Killing Without Consent in Belgium

In Belgium, where voluntary euthanasia was legalized with supposed “safeguards” in 2002, a 2010 study showed that half of nurses involved in the practice – 120 out of 248 – had taken the lives of patients without their request or consent. “We should take a warning from this that

wherever you draw the line, people will go up to it and beyond it," said Dr. Peter Saunders of Great Britain's Care Not Killing campaign. "Once you have legalised voluntary euthanasia, involuntary euthanasia will inevitably follow."

S. Caldwell, "Warning to Britain as almost half of Belgium's euthanasia nurses admit to killing without consent," in *The Daily Mail* (London), June 10, 2010, at www.dailymail.co.uk/news/article-1285423/Half-Belgiums-euthanasia-nurses-admit-killing-consent.html.

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In a study of 208 deaths in Belgium in 2007 involving "the use of life-ending drugs," physicians reported that 66 of these deaths (about 32%) were "without an explicit request." The study notes: "Use of life-ending drugs without an explicit request mostly involved patients 80 years or older, those with a disease other than cancer and those in hospital. Of the deaths without an explicit request, the decision was not discussed with the patient in 77.9% of cases."

K. Chambaere et al., "Physician-assisted deaths under the euthanasia law in Belgium: a population-based survey," 182.9 *Canadian Medical Association Journal* 895-901 (June 15, 2010) at 895, <http://www.cmaj.ca/content/182/9/895.full>.

Children and Euthanasia

In 2014 Belgium became the first country to end age limits on euthanasia, extending the practice to terminally ill children of any age. The first child killed under this policy died in 2016. Since 2002 the Netherlands has allowed euthanasia for children aged 12 or older; but in 2015, the Dutch Paediatricians Association began urging that the Netherlands follow Belgium in rejecting any such "arbitrary age limit" so younger children can request euthanasia.

Y. Logghe, "First child dies by legal euthanasia in Belgium," *Associated Press*, Sept. 19, 2016, at <http://www.cbsnews.com/news/child-dies-by-euthanasia-in-belgium-where-assistance-in-dying-is-legal/>; J. Huggler, "Give children under 12 the right to die, say Dutch paediatricians," *The Telegraph* (London), June 19, 2015, at <http://www.telegraph.co.uk/news/worldnews/europe/netherlands/11686716/Give-children-under-12-the-right-to-die-say-Dutch-paediatricians.html>.

The Trend in the United States

The assisted suicide movement in the United States, as well, has shown that this agenda will not be limited to cases where a voluntary request is made by a competent patient.

Criticizing the murder conviction of Richard Rodriguez, a man who said he had fatally shot his ailing and elderly father out of sympathy, the executive director of Hemlock Society USA (now renamed "Compassion and Choices") stated: "A judicial determination should be made when it is necessary to hasten the death of an individual whether it be a demented parent, a suffering, severely disabled spouse or a child. Consultants should evaluate what other ways might be used

to alleviate the suffering and, if none are available or are unsuccessful, a non-violent, gentle means should be available to end the person's life."

Faye Girsh of Hemlock Society USA, "Mercy Killing: A Position Statement Regarding Richard Rodriguez," *PR Newswire*, December 3, 1997, quoted in Patients Rights Council, 12.1 *IAETF Update* (Jan.-March 1998), <http://www.patientsrightsCouncil.org/site/update012/>.

* * *

In 2014, Barbara Coombs Lee as president of Compassion & Choices reaffirmed this stand at a forum in Connecticut. Noting that current legislation in the U.S. does not cover patients with dementia or other conditions preventing an informed choice, she said: "It is an issue for another day *but is no less compelling*."

L. Foster, "Compassion & Choices Draws Full House at Real Art Ways for Panel Discussion, Film," *CT News Junkie*, Oct. 10, 2014, at http://www.ctnewsjunkie.com/archives/entry/compassion_choices_draws_full_house_for_panel_discussion_film/ (emphasis added).

* * *

Writes the founder of the Hemlock Society: "In attempting to answer Why Now?, one must look at the realities of the increasing cost of health care in an aging society, because *in the final analysis, economics, not the quest for broadened individual liberties or increased autonomy, will drive assisted suicide to the plateau of acceptable practice....* Is there, in fact, a duty to die – a responsibility within the family unit – that should remain voluntary *but expected nevertheless?*"

D. Humphry and M. Clement, *Freedom to Die: People, Politics, and the Right-to-Die Movement* (St. Martin's Press 1998) at 313 (emphasis added).

* * *

Oregon has taken steps toward an "expected" earlier death for patients whose care costs the government money. In 1995, Oregon's State Health Services Commission voted 10-to-1 to include physician-assisted suicide as a form of "comfort care" for all low-income terminally ill patients covered by Oregon's Medicaid rationing program. In response to criticisms that Oregonians never voted to support assisted suicide with taxpayer money, the head of Oregon's Medical Assistance Program replied: "These are cheap prescriptions, and health care provider time will not be significant" (See Patients Right Council, *IAETF Update*, op. cit.). Since then, some patients on the Oregon Health Plan have received letters from the state saying it will not pay for drugs that may help stave off their death but will fully cover assisted suicide. "It was horrible," said one woman, cancer patient Barbara Wagner. "I got a letter in the mail that basically said if you want to take the pills, we will help you get that from the doctor and we will stand there and watch you die. But we won't give you the medication to live." Hemlock founder Derek Humphry responded that the Oregon Health Plan's approach is sound.

S. James, "Death Drugs Cause Uproar in Oregon," *ABC News*, August 6, 2008, at <http://abcnews.go.com/Health/story?id=5517492&page=1>.

* * *

California insurers have also begun exerting this economic pressure on patients. California cancer patient Stephanie Packer says her insurance company initially indicated it would cover a new chemotherapy drug, but after the state's assisted suicide law passed it rejected her claim, confirming that it would cover assisted suicide and "you would only have to pay \$1.20 for the medication." And Nevada physician Dr. Brian Callister testifies that when he tried to transfer patients to Oregon and California for treatments not available in his state, insurers in both states rejected his effort and instead volunteered, "would you consider assisted suicide?" Dr. Callister says both patients had good chances for a cure with treatment but will be terminal without it.

B. Richardson, "Assisted-suicide law prompts insurance company to deny coverage to terminally ill California woman," *The Washington Times*, Oct. 20, 2016, at <http://www.washingtontimes.com/news/2016/oct/20/assisted-suicide-law-prompts-insurance-company-den/>; Id., "Insurance companies denied treatment to patients, offered to pay for assisted suicide, doctor claims," *The Washington Times*, May 31, 2017, at <http://www.washingtontimes.com/news/2017/may/31/insurance-companies-denied-treatment-to-patients-o/>.

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According to the National Council on Disability, such cost pressures create an especially toxic environment when combined with longstanding social prejudice against the value of a life with disabilities: "The dangers of permitting physician-assisted suicide are large indeed. The pressures upon people with disabilities to choose to end their lives, and the insidious appropriation by others of the right to make that choice for them are already way too common in our society. These pressures are increasing and will continue to grow as managed health care and limitations upon health care resources precipitate increased 'rationing' of health care services and health care financing.... There is no doubt that people with disabilities are among society's most likely candidates for ending their lives. As the experience in the Netherlands demonstrates, there is also little doubt that legalizing assisted suicide generates strong pressures upon individuals and families to utilize that option, and leads very quickly to coercion and involuntary euthanasia."

National Council on Disability, "Assisted Suicide: A Disability Perspective," Position Paper of March 24, 1997, reprinted in 14.3 *Issues in Law & Medicine* 273-99 (Spring 1998) at 298.

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