

# Testimony to the Minnesota Senate Committee on Health, Human Services and Housing

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Thank you for allowing me to testify on S.F. 1880, the Minnesota Compassionate Care Act. This bill, modeled on Oregon's 1997 Death with Dignity Act, clarifies the legality of medical aid in dying in Minnesota for certain patients with less than six months to live.

More than two decades ago, the Minnesota Legislature confirmed the right of Minnesotans to refuse life-sustaining medical treatment.<sup>1</sup> Since then, every day, chronically and critically ill patients across the state hasten their deaths by withholding or withdrawing mechanical ventilation, dialysis, and other interventions. But some patients are not dependent on any such technologies. This bill gives such terminally ill, competent, adult patients the freedom to accelerate their imminent death.

Since the Committee will be hearing from a variety of witnesses, I have not prepared a comprehensive analysis of the bill. Instead, I focus on just a few important points that will supplement and complement other testimony.

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## 1. Background of the Witness

I am the Director of the Health Law Institute and a Professor at Mitchell Hamline School of Law.<sup>2</sup> In addition to being a lawyer, I also have a Ph.D. in philosophy and bioethics from Georgetown University. My primary area of scholarship and consulting for the past 15 years has been legal and ethical issues surrounding end-of-life medical treatment.

I have published over 100 articles in this area, including in the *New England Journal of Medicine*, *JAMA*, *Chest*, and the *New York Times*.<sup>3</sup> I have also published, delivered invited

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<sup>1</sup> Chapter 312, S.F. 40 (1993).

<sup>2</sup> I am happy to report that, this morning, *US News and World Report* ranked Mitchell Hamline's Health Law Institute the 12<sup>th</sup> best program in the country.

<sup>3</sup> My full CV is available at <http://thaddeuspope.com/cvbio.html>.

lectures, and otherwise seriously focused on medical aid in dying in particular.<sup>4</sup> For example, in December 2015, I was invited to San Francisco, to work with the End of Life Option Task Force. This expert group convened to promote thoughtful deliberation on topics relevant to healthcare systems as they create patient-centered policies to respond to California's aid in dying law (which becomes effective in June 2016).<sup>5</sup> More recently, here in Minnesota, I have participated in several public listening sessions on S.F. 1880 (in Mankato, Saint Paul, and Brooklyn Park).

## 2. Lessons Learned from Oregon

The bill that you are considering, today, has been extensively tested. A basically identical law has been in effect in Oregon since 1997, in Washington since 2008, and in Vermont since 2013. It becomes effective in California in June 2016. That is 30 years of combined experience. There is no better or more relevant evidence or data on which to evaluate the bill before you.

## 3. Overwhelming Safeguards Are Built into S.F. 1880

There are an overwhelming number of safeguards built into S.F. 1880. These safeguards limit which patients are eligible to request the medication. These safeguards also limit and control the manner in which patients must request the medication.

**First**, the patient must be **terminally ill**. This means that the patient is in the final stage of an incurable and irreversible medical condition that is anticipated to produce death within six months. The patient's terminal illness must be confirmed by two physicians.

**Second**, the patient must be an **adult**, over 18 years of age.

**Third**, the patient must be a **resident** of Minnesota.

**Fourth**, the patient must have **decision making capacity**. She must have the ability to understand and acknowledge the nature and consequences of the aid in dying decision, including the benefits and disadvantages of treatment. And the patient must have the ability to communicate the decision to a health care provider.

**Fifth**, if either the attending physician or the consulting physician suspect that the patient is suffering from a psychiatric or psychological condition or depression that is causing impaired judgment, they **must refer** the patient for counseling by a psychiatrist or a psychologist to determine whether the patient is competent to request aid in dying.

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<sup>4</sup> *Clinical Criteria for Physician Aid-in-Dying*, 19(3) JOURNAL OF PALLIATIVE MEDICINE 259-262 (2016) (with David Orentlicher & Ben Rich); *The Changing Legal Climate for Physician Aid-in-Dying*, 311(11) JAMA 1107-1108 (2014) (with David Orentlicher and Ben A. Rich); *Oregon Shows that Assisted Suicide Can Work Sensibly and Fairly*, NEW YORK TIMES - ROOM FOR DEBATE, Oct. 7, 2014; *Legal Briefing: Medical Futility and Assisted Suicide*, 20(3) JOURNAL OF CLINICAL ETHICS 274-286 (2009).

<sup>5</sup> <http://www.eoloptionacttaskforce.org/>

**Sixth**, the attending physician must **fully inform** the patient of: (1) her medical diagnosis and prognosis; (2) the potential risks associated with self-administering the medication to be prescribed; (3) the probable result of taking the medication to be prescribed; and (4) the feasible alternatives and health care treatment options, including but not limited to palliative care.

**Seventh**, the patient must make a **contemporaneous, voluntary** expressed wish for aid in dying. (This cannot be done through an advance directive, health care agent, surrogate, or guardian.) The bill requires **two signed written requests** for aid in dying. Each request must be witnessed by at least two persons who attest that the patient is: (1) of sound mind; and (2) acting voluntarily and not being coerced to sign the request. The patient's second request must be submitted at least 15 days after the first request.

**Eighth**, once the patient obtains the aid in dying medication, she must **ingest it herself**. No physician or other person may inject or otherwise administer the medication. That is why this is properly referred to as medical “aid” in dying and not “euthanasia.” The patient **herself** takes the final overt act causing her death.

These are the very same safeguards that are already built into the statutes in Oregon, Washington, Vermont, and California. Multiple independent studies have examined these safeguards. Those studies have uniformly concluded that they are **effective** and that there has not been any abuse.

## 4. Oregon and Washington Demonstrate a 27-Year Safety Record

The health authorities in Oregon and Washington have been collecting and reporting significant data on the usage of aid in dying laws, since the laws were first effective in those states in 1997 and 2008 respectively.<sup>6</sup> This data shows that the safeguards work. This data also shows that there have not been any other abuses or concerning trends.

**First**, very few patients use the law. In 2015, 218 Oregon patients received aid in dying prescriptions. But only 132 of the 218 ingested the medication. Consistent with experience over the entire 18 years of aid in dying in Oregon, only two-third of the patients who obtain prescriptions find it necessary to actually ingest the medication. Since the law was passed in 1997, a total of 1,545 people have had prescriptions written. But only 991 patients have died from ingesting the medications.<sup>7</sup>

Since Minnesota is a more populous state, an extrapolation of the Oregon data suggests that 182 terminally ill Minnesotans might choose to ingest aid in dying medication. That is less than one-

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<sup>6</sup> Oregon Health Authority, *Death with Dignity Act Annual Reports*, <https://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Pages/ar-index.aspx>; Washington State Department of Health, *Death with Dignity Act*, <http://www.doh.wa.gov/YouandYourFamily/IllnessandDisease/DeathwithDignityAct>. The Vermont Department of Health is not required to start reporting until 2018.

<sup>7</sup> The Washington and Oregon data on all these points is substantially similar.

**half of one percent** (0.4%) of the 41,000 Minnesotans who die each year.<sup>8</sup> Legalizing aid in dying would not impact over 99% of deaths in Minnesota. As I demonstrate in the table below, it is an option for only a very narrow population of Minnesotans.

<b>Oregon</b>	
Population	4,000,000
Annual deaths	34,000
AID medications ingested in 2015	132
AID as percent of all deaths	0.4%

**Second**, not only do very few patients use aid in dying but also the demographics of those few patients show that aid in dying is not being foisted onto minorities or the vulnerable. Instead, it is overwhelmingly used by **educated, insured, white cancer patients**.

<b>Who uses aid in dying</b>	
Health insurance	99%
White	97%
In Hospice	91%
Age > 65	90%
College educated	72%

<b>Terminal illness</b>	
Cancer	77%
ALS	8%
COPD	5%
Other	10%

<b>Reason for aid in dying</b>	
Decreasing ability to participate in activities that made life enjoyable	96%
Loss of autonomy	92%
Loss of dignity	75%

**Third**, this data (and similar data from Washington) show that aid in dying is not seen or used as an alternative to hospice and palliative care. Instead, it is nearly universally used **concurrent with hospice care**. Indeed, this surely explains why one-third of patients who get aid in dying prescriptions never ingest the medication.

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<sup>8</sup> CDC National Center for Health Statistics, *Deaths: Final Data for 2013*, 64(2) NATIONAL VITAL STATISTICS REPORTS (Feb. 16, 2016), [http://www.cdc.gov/nchs/data/nvsr/nvsr64/nvsr64\\_02.pdf](http://www.cdc.gov/nchs/data/nvsr/nvsr64/nvsr64_02.pdf).

## 5. Participation is Entirely Voluntary

Not only is participation by patients completely voluntary but also is participation by physicians and facilities. S.F. 1880, like its analogs in Oregon, Washington, Vermont, and California, does not require any Minnesota healthcare provider to participate in aid in dying. The bill provides opt-outs to accommodate physicians who have a conscientious objection or simply do not wish to participate.

The voluntary nature of aid in dying does not mean that all the prescriptions will be written by just a small handful of Minnesota physicians. Recent surveys show that a majority of physicians support aid in dying.<sup>9</sup> Indeed, the 218 prescriptions written in Oregon, during 2015, were written by **106 different physicians**.

## 6. Varying Experience in Belgium Is Irrelevant

Opponents to medical aid in dying point out that cases in Belgium fall outside the parameters in U.S. aid in dying statutes. For example, Belgian patients have obtained aid in dying even though they are not terminally ill. They were just “suffering” in some vague way. Opponents contend that this indicates U.S. safeguards like those in S.F. 1880 may get ignored or relaxed. But this argument is misplaced.

**First**, no U.S. state has relaxed the 1997 safeguards. S.F. 1880 is basically identical to already existing statutes in Oregon, Washington, Vermont, and California. No U.S. state has ever enacted legislation with different, fewer, or weaker safeguards.

**Second**, there is no evidence that physicians have failed to comply with the safeguards. There is not a single criminal case. There is not a single health licensing board action from Oregon, Washington, Vermont, or California, pertaining to aid in dying. Neither has Disability Rights Oregon, the state’s Protection and Advocacy System, received any complaint of exploitation or coercion of any individual with disabilities in the use of Oregon’s law.

**Third**, this argument has been specifically rejected by independent and neutral tribunals like the Supreme Court of Canada.<sup>10</sup> Belgium is a very different medico-legal culture. Assisted death was already prevalent before the practice was legalized there. Belgium never “slipped” from being less permissive to being more permissive of aid in dying. Instead, Belgium was always more permissive.

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<sup>9</sup> <http://www.medscape.com/features/slideshow/public/ethics2014-part1#2>

<sup>10</sup> *Carter v. Canada*, [2015] 1 SCR 331, <https://scc-csc.lexum.com/scc-csc/scc-csc/en/item/14637/index.do>.

## **7. Contact Information**

I am happy to answer any questions and to serve as a resource to the Committee or to any individual legislator.

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