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Public Health Committee
Connecticut General Assembly
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Hartford, Connecticut

Subject: Support for CT Bill 5236: Compassionate Aid in Dying 2014

Dear Committee Members:

It is an honor to share my experience with you. I hope it will be of help, as you consider the option of physician aid-in-dying in Connecticut.

My name is Ann Jackson. In June 2008, after 20 years, I retired as executive director and chief executive officer of the Oregon Hospice Association (OHA). In that role, I was OHA's primary spokesperson about physician-assisted dying, prior to and during the 1994 and 1997 elections, and after, when Oregon's Death With Dignity Act was implemented.

OHA is a 501(c)(3) charitable, not-for-profit membership organization whose goal is to make sure that all Oregonians can have excellent care as they—or their loved ones—approach the end of life. It is important to note that I no longer speak for the Oregon Hospice Association.

I am currently working with individuals and organizations about choices at the end-of-life, with a focus on decision-making; and in assisting governmental and other organizations in health care policy-making. I continue to present frequently to a variety of audiences about Oregon's experience as a "laboratory" of the states.

I am a co-investigator of IRB-approved and published research looking at hospice workers' experiences with people who have hastened death and with the POLST (physician orders for life-sustaining treatment) form. I am

an author of letters and articles related to research findings and professional observations that have been published in respected print and online media.

Many people are surprised to learn that I am not a health care clinician. I have an MBA in Not-for-Profit Management from Willamette University's Atkinson Graduate School of Management in Salem, Oregon. I bring a layman's perspective to this difficult issue, an advantage in many respects.

I believe strongly, as did the Oregon Hospice Association (OHA), that people must be well-informed about end-of-life choices and options, if they are to make good end-of-life decisions—"good" as they define good, not as I might define it. I respond openly and honestly to all questions, including those about physician-assisted dying and hastening death, and about all concerns. I make sure that people know where they can get more information or help, if they wish.

The Oregon Health Authority's annual reportsⁱ about the ODDA reveal that people with conditions that are likely to cause the most distressing symptoms, as their illnesses progress, are more likely to ask for a prescription. Patients with ALS (Lou Gehrig's disease), lung cancer, pulmonary arterial hypertension, for instance, are disproportionately represented among those who use the ODDA. The reports reveal, too, that people who ingest medication under provisions of the ODDA highly value autonomy.

Many—patients and their loved ones—worry about choking to death, because they cannot swallow, or suffocating, because they cannot breathe. I've talked with those who have waited too long to use Oregon's Death With Dignity Act because they can no longer swallow, or believe they have waited too long, because they do not know that self-administrated ingestion through a feeding tube may be possible within the law.

Palliative sedation, which would make these individuals unaware of their distressing symptoms, is an underutilized end of life option and accepted throughout the world as good pain management. As hospice and palliative care physicians frequently tell their patients, "I can promise to manage your

pain and symptoms, but I can't promise to keep you awake." Being sedated to the point of coma is not an acceptable option for most persons whose primary concerns are about losing autonomy, their quality of life, and dignity—as they define dignity.

Interestingly, palliative sedation is very rarely offered to people experiencing distressing symptoms. A study by Joanne Lynn published in 2003, revealed that 98 percent of hospitalists, hospital specialists, would want to have palliative sedation for themselves, if they had chronic obstructive pulmonary disease. But that only 2 percent had ever offered it to a patient.ⁱⁱ

Palliative sedation is subject to the “double think”. A request for palliative sedation from a patient, or his or her family, or an offer of palliative sedation from a physician, may be misconstrued. Is the intent of palliative sedation to kill the pain or to kill the patient?

I do not often reveal my personal position related to Oregon's Death With Dignity Act. My goal, as I consult, is to present data, to provide open and honest information about Oregon's experience as the first place in the world to offer physician-assisted dying as a legal end-of-life option, to allow the facts to speak for themselves. To allow my audiences to draw their own conclusions.

I'm not going to do that at this time. I will instead share with you the conclusions I've drawn in the past 14 years. Oregon took seriously its role as a "laboratory of the states" and its responsibility to close a data void. Physician-assisted dying had never before been practiced in a legal environment.

As the Oregon Hospice Association's executive—no one knows more about dying than the hospice community—I have been very much involved with this issue. I am now, and I was well before 1994 and 1997, very well informed. I voted against ballot measure 16, the public initiative that adopted the Death With Dignity Act in 1994. And I voted for its repeal in 1997. At that time, I agreed with those who believed physician-assisted

dying was unnecessary, if dying Oregonians had access to high quality hospice and palliative care.

I now believe that it was cavalier of me to even consider that hospice and palliative care professionals could indeed meet all the needs of people who were dying—or that some needs, such as the need to control one's own life and death, were unworthy needs.

Today I would vote in favor of physician-assisted dying and "yes" if Oregon's Death With Dignity Act were on the ballot. I am convinced that physician-assisted dying can be, and is, practiced responsibly in Oregon, and that the Death With Dignity Act was very well crafted. The bar is high enough that people who are clinically depressed, for instance, and whose judgment is questionable are not likely to seek it. The bar is low enough, however, that motivated terminally-ill Oregonians are not unduly restricted from participation. The safeguards in place are not merely meaningless obstacles.

The outcomes have been very different from those direly predicted during the public debates in Oregon in 1994 and 1997—and in the many states and other jurisdictions, since, that have considered, or are now considering, legalizing physician assisted dying. I have to wonder how those who continue to make such easily discredited predictions maintain their credibility. I am very much afraid that it is because the general public believes that people who speak from a position of authority speak the truth.

752 persons, not thousands each year, ended their lives under the provisions of the Act during the 16 years between 1998 and 2013. 752 persons among 480,000 Oregonians who died in that period of time. Those who are poor, of minority race, who lack insurance, or an education are less likely, not more likely to use the ODDA. People who live in rural areas, presumably because access to hospice and palliative care are compromised—they are not, are less likely, not more likely to hasten their deaths.

Concerns about burdening families and loved ones—common to most people who are dying—are not significant factors in choosing to use

physician-assisted dying. Those concerns are held by most hospice patients, regardless of whether they use, or do not use, physician-aid in dying. Nor is a "duty to die".

Patients are not routinely being murdered or coerced to ingest medication, under a guise of physician-assisted dying, by family members wanting to collect inheritances a few days or weeks earlier. It doesn't make sense to compromise a sure thing.

Doctors aren't very accurate in prognosing life expectancies of six months or less, but are more likely to err by predicting an unrealistically longer life. Research confirms that people want to know the truth, if they have a life-threatening illness, yet it's difficult to be the bearer of bad news, or to take away hope. Yet fifty percent of hospice patients die within 20 days of admission, not long enough for them and their families to have benefited from the array of services hospice offers. People are eligible for hospice under Medicare or Medicaid when they have estimated life expectancies of six months or 182.5 days.

These are important findings, most issued by Oregon's Health Authority annually as part of the Act's reporting requirements. The data collected by the Health Authority, as issued, has been corroborated by IRB-approved independent research, conducted by qualified investigators, and published in respected medical and legal journals.

The more compelling reason for reversing my position on physician-assisted dying is that the major beneficiaries of Oregon's Death With Dignity Act are those who do not use it to hasten their deaths. Of 200 people who consider a request for a prescription, one will ingest medication. Of 25 people who talk to their doctor about a request, one will ingest medication to end his or her life.ⁱⁱⁱ

Hospice workers describe patients as making a request on day 1, qualifying for a prescription on day 15, then tucking their prescription, or their medication, if they fill the prescription at all, into a safe place.

That's when they can get on with living. They have a plan, just in case.

To me, the most important benefit of the ODDA, is that Oregonians can talk about dying.

Until 2008, when I retired from the Oregon Hospice Association, I met with front-line hospice workers twice a year to discuss their experiences. Whether they supported or did not support the concept of physician-assisted dying or the ODDA, there was unanimous agreement that conversations about death and dying had improved significantly once the Death With Dignity Act, literally, put the topic on the table.

When one can respond openly to a request for help in dying, the likelihood of successfully addressing fears or reasons behind the request is much greater.

Lessons learned in Oregon have application, not just in Oregon, Washington, or Montana, but throughout our country—and, without doubt, in Vermont.

Very truly yours,



Ann Jackson, M.B.A.

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<http://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Documents/year16.pdf>

ii Advance Care Planning for Fatal Chronic Illness: Avoiding Commonplace Errors and Unwarranted Suffering

Joanne Lynn, MD, MA, MS; and Nathan E. Goldstein, MD. *Ann Intern Med.* 2003;138(10):812-818.

doi:10.7326/0003-4819-138-10-200305200-00009

iii Tolle S, Tilden V, Drach L, Fromme E, Perrin N, Hedberg K. Characteristics and Proportion of dying Oregonians Who Personally Consider Physician-Assisted Suicide. *J Clin Ethics*, Vol. 15, No. 2, Summer 2004