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April 1, 2017

Health and Human Services Committee ATTN: LD 347 and LD 1066 c/o Legislative Information Office 100 State House Station Augusta, ME 04333

Email: Jill Laplante jill.laplante@legislature.maine.gov

Senator Brakey, Representative Hymanson, and other members of the Health and Human Services Committee:

My name is Ann Jackson. I live in Portland, Oregon. I am an expert about end-of-life issues and options, including Oregon's Death with Dignity Act (ODDA). I was the Executive Director and Chief Executive Officer of the Oregon Hospice Association (OHA) between 1988 and 2008. I was OHA's voice during the public debates over the voter initiative, the legislative repeal effort, and the ODDA's implementation. In Oregon's "laboratory of the states", I was a co-investigator of published research about the experience and attitudes of hospice workers with aid-in-dying.

Since my retirement nine years ago, I have made my expertise available—and gained much more—as a consultant about end of life policymaking.

I have accepted an invitation to go to Maine to help clarify misrepresentations of Oregon's experience. The ODDA has served as a model for those states considering end-of-life options. I will attend the April 5 hearing to talk with you about what really happens in Oregon.

There are people who know more about hospice than I, and people who know more about aid-in-dying. I would submit, however, that I am among the few who know more about both.

As the CEO of the Oregon Hospice Association in 1994, on Election Day, I was an informed voter when I marked "no" for Ballot Measure 16, the citizen's initiative to allow Death with Dignity.

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I was a more informed voter in 1997 when I voted "yes" on Ballot Measure 51, a legislature initiated measure, for the repeal of Oregon's Death with Dignity Act.

Today, 23 years later, I would vote "yes", and if I were in your shoes, I would vote in favor of Senate Bill LD 347 or House Bill LD 1066. Contrary to what you hear, just a simple request about aid in dying virtually guarantees that a person will be referred to hospice, the gold standard of end-of-life care, if—or when—he or she enters the 6 month window of life expectancy. Those who assume the responsibility for their care at the end of life are far more likely to get it.

More than 90% of Oregonians who used the ODDA in the past 19 years were enrolled in hospice. Their median length of stay was closer to 50 days than the typical 20 days of those patients who waited for their doctors to think they were ready. Not only did those who considered prescriptions get better care, they—and their loved ones—had it in a timely manner.

OHA also subsequently dropped its opposition—whether aid in dying is right or wrong no longer matters in Oregon. It is the law. Dying Oregonians can choose both aid in dying and hospice, as well as other respected end-of-life options.

When I voted against the ODDA, I did so because I believed physician-aid-in-dying was unnecessary if dying Oregonians had access to high quality hospice and palliative care. In 1997, 99% of Oregonians had access to hospice in their communities.

However, it did not take me long, once the law went into effect, that I came to realize I was arrogant to believe that hospice and palliative care professionals can indeed meet all the needs of people who are dying. Worse, I am ashamed to have believed some needs, such as the need to control one's own life and death, are somehow unworthy needs.

Oregon was then, and is now—contrary to what you hear—consistently rated among the best states in the USA for the provision of hospice and palliative care. Yet some persons still suffer and wish to end their own lives.

Many opponents of aid-in-dying claim that palliative sedation is an effective way to ease the suffering of those whose symptoms are not adequately controlled. I agree. However, 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

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define dignity. Furthermore, palliative sedation is an underused and under-offered end-of-life option.

In Oregon, the outcomes of legislating for physician-aid-in-dying have been very different from those direly predicted before the law's implementation. Yet opponents of aid in dying continue to make pronouncements of doom, here in Maine, and in other jurisdictions of the world.

Contrary to what you hear, there have been no abuses of Oregon's law. There are many reasons to oppose assisted dying, but no reason to fabricate evidence when data is readily available. I am appalled that so much of what we hear—and wrongly believe—is told us by people who speak from positions of authority.

Until I retired from the Oregon Hospice Association, I met with front-line hospice workers regularly to discuss their experiences. Whether they supported or opposed assisted dying or the ODDA, there was unanimous agreement that conversations about death and dying improved significantly following the Death with Dignity Act, which literally put the topic on the table.

In September 2014, I was able to reprise those meetings. Hospice workers reported that the improvement in conversations about death and dying has endured.

Evidence shows that these conversations are far more likely to reassure a dying person rather than coerce from them a request for physician assisted dying. The vast majority of people who raise the possibility of physician-assisted dying with their doctor will not go on to make a formal request. 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 than when a law deters patients from expressing their concerns and wishes.

Those Oregonians who do not use the Act may be those who gain the most: Hospice workers describe patients as asking for a prescription on day 1, qualifying for a prescription on day 15, and then, finding comfort in the knowledge that they have an out, should suffering become unbearable, they get on with living.

I repeat, today I would vote in favor of physician-assisted dying and "yes" if the ODDA were again on the ballot. I am convinced that physician-assisted dying can be, and is, practiced responsibly in Oregon, and that the ODDA is a very well crafted law.

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I am more than happy to address questions about what really happens in Oregon. Please refer to www.ann-jackson.com for the most recent supplementary materials documenting facts and data. This information now reflects 2016 data about utilization of the ODDA as reported by the Oregon Health Authority.

Thank you very much for the opportunity to speak, as an Oregonian, on behalf of Oregon.

Yours sincerely,

Ann Jackson, M.B.A.

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