



Maine Hospice Council and Center for End of Life Care  
*Promoting Excellence in End-of-Life Care*

**Testimony in Opposition to LD 1270**  
before  
**Health and Human Services Committee**  
presented by

**Kandyce Powell**  
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**May 15, 2015**

Good morning Senator Brakey, Representative Gattine, members of the Health and Human Services Committee. My name is Kandyce Powell. I have been the Executive Director of the Maine Hospice Council for 22 years and will be speaking this morning in opposition to LD 1270, "An Act Regarding Patient-directed Care at End of Life".

Since 1984, the Maine Hospice Council has worked tirelessly to improve access to quality end of life care for all people. The Council staff, board members, and provider members, along with our many partners have made considerable progress. Utilization of Hospice has grown significantly over the years, including high family satisfaction from individuals receiving services. Maine's ranking for Medicare Hospice utilization increased from 49<sup>th</sup> in the country to 28<sup>th</sup> in a little over twelve years. Sadly, there are still areas of the state with no access to Hospice or Palliative Care services.

During my tenure with the Maine Hospice Council, legislation similar to LD1270 has been introduced several times, precipitating emotional debates with strong feelings on both sides. However, each time a bill is printed and goes to public hearing it provides an opportunity to discuss how we're doing with end of life care, as consumers, providers, policy makers and association members. It also gives us an opportunity to examine social policy priorities.

Frustration, anger, fear and anxiety, especially the perception of suffering, often drive support for aid in dying legislation. Several years ago, an article was published in the British Medical Journal about the correlation of "perceived suffering" to public support for assisted dying. In summary, those who supported assisted dying in greater numbers perceived individuals to be suffering and could never imagine themselves being in a similar situation. The cohort of individuals who were actually living with life limiting illnesses did not generally support assisted dying legislation. This latter group of patients simply wanted someone to listen to them, care for and about them, and assist with the quality of their lives. Certainly this is information that deserves consideration as a vote is taken on this bill.

Existential suffering is part of many lives. This type of suffering can't easily be relieved by medication. This type of pain occurs when the soul itself is wounded. It results in spiritual pain so profound that traditional methods and modes of management simply do not work. This type of pain frequently comes from trauma that defies traditional methods of coping.

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Many of us are interested in story-telling as a way of learning about people. Stories are revealing; however, they require a personal investment of time. Voices endure long after the person has died. When you hear someone say, "It wasn't dying I really wanted to do, it was living I didn't know how to do," that voice has power; it needs to be heard and shared. It also is reality for many in our world today.

Following is a recent email from a friend and colleague whose husband died from lung cancer. "My husband's journey was difficult and sometimes challenging, but the last few weeks were also incredibly healing for both of us."

In summary I offer some additional points to consider.

- Very little consideration has been given to the grieving process for family and extended family after the death of someone from assisted suicide. To my knowledge, there have been no longitudinal studies of grief in this population.
- The United States has the highest preventable mortality rate of any developed country. Many people do not have access to curative treatments because of cost.
- It might be more beneficial to society if policy-makers addressed access to health care before legislating assisted dying.
- LD 1270 talks about ensuring that individuals have access to Hospice Care. However, there are some parts of the state that have NO access to Hospice, Palliative Care or home care.
- In the bill it talks about a "full assessment". What is the standard for a full assessment?
- Persons who are "familiar with the patient's manner of communicating" might not necessarily be individuals who have the best interests of the individual at heart.
- If individuals are in a psychiatric hospital, are they "competent"? Competency as defined by whom? Only 5% of individuals requesting PAS are referred for a mental status evaluation.
- Many people live with the pain of existential suffering. This is NOT routinely assessed or addressed.
- Maine has a very high suicide rate, especially with young people age 17-34.
- For those who contemplate suicide, it's often not dying they want to do; it's living they don't know how to do.
- There are Insurance issues. In regard to paying benefits to survivors; is this suicide acceptable, but other suicides not?
- Disposal of controlled substances presently varies.
- This legislation is asking clinicians (primarily physicians and pharmacists) to consider compromising their professional ethics/roles.

Thank you for considering this important issue. As you deliberate, please consider voting in a manner that contributes positively to the health of our society. Thank you!

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