

Your Invitation to Age Well, Die Well and Be Remembered Well.

Regarding: Senate Bill 193: Amends Advance Directive Law Written Testimony for Senate Committee on Judiciary - April 7, 2015

To Whom It May Concern:

As someone who has experience with the Oregon Advance Directive Law personally and professionally, please accept this testimony as expressed interest in FAVOR of changing the existing law.

At age 21 I never really knew the importance of the Advance Directive until I was faced with making the end of life decisions for my father, who at age 55 had bladder cancer. Unfortunately the cancer had taken over many parts of his body, including his brain. Cancer left him unable to share his medical wishes with family or his doctor and it forced my mother and I to make his end of life decisions for him. I do not wish this on anyone, it was a day I will never forget.

After his death, I advocated for those around me to complete the Advance Directive, but truthfully I didn't even have the form completed myself. It was complicated to understand and hard for even me to confidently know that what I was completed would accurately reflect my wishes and values.

Fast forward 8 years, I experienced two more deaths in my family - I witnessed my Grandfather in cardiac arrest in ICU and then watched my Grandmother slowly deteriorate with Dementia. These life experiences around death and the personal experience with the Advance Directive prompted me to make it my life's work to advocate for people to plan ahead and understand their options in the midst of illness, aging and death.

I am now the publisher of a magazine/workbook called Departing Decisions - with distribution 20,000 guides/year in over 100 locations throughout Multnomah, Washington and Clackamas Counties. Available free of charge, the mission of the guide is to educate the public, practitioners and professionals about the importance of planning ahead and to provide the necessary resources to have these important discussions.

From a professional viewpoint working with individuals and groups, I have seen first hand how complicated the existing Advance Directive is for Oregonians. Many people look at me after I hand them the form, with hopelessness and confusion - even with an understanding that I would be coaching them through completion of the form.

The existing document is cumbersome and confusing. Let me ask you a few questions to exemplify this:

- 1. Without the ability to ask any questions about the existing form, could you confidently complete the form knowing that what you are signing will in fact reflect what you want for medical and end of life care? And would it accurately reflect your values?
- 2. Could you confidently hand this form to your mother/father or grandparents and know that they could complete the form easily without questions or the need for a practitioners guidance?
- 3. Many patients who are going into surgery are asked to complete the Advance Directive. In these situations, most do not have the luxury of having someone explain the legal structure of the form. Can we design a form that is easier for them to understand and does not require guidance to complete?

Food for thought:

- Only about one-third of adults have an advance directive expressing their wishes for end-of-life care (Pew 2006, AARP 2008).
- Only 28 percent of home health care patients, 65 percent of nursing home residents and 88 percent of hospice care patients have an advance directive on record (Jones 2011).
- Even among severely or terminally ill patients, fewer than 50 percent had an advance directive in their medical record (Kass-Bartelmes 2003).

Let's make it EASIER for people to share their wishes on a document that does not require detailed instructions. The public needs to confidently know that whatever they sign will accurately reflect their wishes - otherwise, my belief (and experience) is that the likelihood of the form not being completed becomes very high.

Senate Bill 193 would allow the Advance Directive to be removed from statute, allowing for a user friendly document that all Oregonians could use to easily document and share their values and wishes for medical and end of life care.

The time is now! My request is to have this bill move forward in a timely manor. I, along with many others who support this bill are committed to bringing members of various organizations, religions and cultures together to create a document that meets the needs of ALL Oregonians. Let's get started!

Thank you,

Angela Kienholz President & Founder, Departing Decisions