

**Oral Testimony by Nick Kockler
February 21, 2018**

Chair Prozanski and members of the committee,

Good morning! For the record, my name is Nick Kockler and I am the Regional Director of the Providence Center for Health Care Ethics. It is an honor and a privilege to be here with you this morning to share on behalf of Providence our support of HB 4135.

Today, I speak to you from the perspective of a clinical ethicist who practices in Providence's Catholic health care ministries including hospitals, clinics, home health, hospice, and ambulatory care centers across Oregon. Ethicists support patients, families, and health professionals through complex, value-laden decisions in circumstances of ambiguity and disagreement. I am drawing on my experience in such clinical ethics consultations, which occur often in conjunction with our palliative care colleagues.

We believe that well-documented, values-based advance care planning – in the form of a valid advance directive – is an extraordinary gift that a person can share with loved ones. An advance directive helps alleviate the burdens and moral distress of making health care decisions on behalf of an incapacitated person facing life-limiting illness. Entrusting someone by explicitly designating them and granting them authority to make your health care decisions is an awe-inspiring decision. As health care representative or as professional caregiver, having access to a statement of values is tremendous help in ensuring appropriate medical care is delivered in alignment with patient preferences.

This vision for best practices in advance care planning is hindered by the current form that has been locked in statute for more than 25 years.

In our consultation service we encounter many types of issues with the current form. As caregivers, we lament situations wherein a family member must make her best guess about what the patient would want. Does the patient want mechanical ventilation even though it is unlikely that he will be able to breathe on his own again?

In the absence of an advance directive, which are often not completed because of the confusing form, health care professionals may turn to a family member by default, and it may not be the person the patient would trust most to make decisions on her behalf. Countless consults involve navigating these complex decisions and care planning with individuals who have only their own glimpse of what the patient would want. Estranged family members are often called upon after years of separation only to confront a heart-wrenching end-of-life decision.

Even with designating a health care representative, we lament situations wherein family members struggle to discern how to best represent the patient's check-box instructions. Health care representatives of stroke patients are often facing agonizing decisions about life-support in the face of uncertain (and often improbable) recovery. A box checked for 'no life-support' may preclude the possibility of recovery.

Finally, we lament situations wherein patients complete an advance directive in English even though their proficiency is in a native tongue of their country of origin. Having the form locked in statute creates barriers to well-informed and culturally sensitive advance care planning.

Providence strongly supports HB 4135 because it creates a process by which the community can improve the advance directive form in Oregon. Such a process will enable Oregonians to complete more user-friendly advance directives that allow greater opportunities to express the values and reasons behind a stated preference. The new form created under this process holds the promise of greater usefulness for family and loved ones, health care professionals, and the patients themselves. The process will allow the form to be more readily updated in response to language preferences and changing medical technology.

Thank you for your time and support of House Bill 4135.