## For the attention of the: Joint Interim Committee on the First Special Session of 2020

June 24, 2020 Delivered by electronic mail to: J1ss.exhibits@oregonlegislature.gov

## Testimony Recommending Changes to Senate Bill 1606, as Amended

Dear Co-Chair Senators and Representatives, and members of the joint interim committee:

I write to express several concerns about SB 1606-1, as written. The bill seems to unnecessarily limit a hospital's ability to offer and provide a range of alternatives for end-of-life care and treatment planning, interferes with the privacy of a patient-physician relationship, and therefore may lead to unnecessary pain and suffering for patients who may never learn about portable orders for life-sustaining treatment (POLST) options.

I respectfully ask that you do not pass SB 1606 without considering the below suggestions to improve the bill and resultant outcomes for patients wanting to receive compassionate and person-centered care at the end of life. Alternately, the issues and concerns that brought forward the need for a considered response to reports of individual abuses of well-established advance care-planning practices can be discussed among a variety of interested stakeholders before potential and perhaps similar legislation may be introduced in a future session.

My concerns regarding the **-1 amendment** include:

- Page 2, line 10: in addition to information about advance directives, care planning for persons with disabilities might reasonably include information about the appointment of a health care representative and alternates, POLST discussion and counseling, and information about health care advocates available for persons with disabilities under Oregon Administrative Rules.
- Page 2, lines 24-25: the definition of support person could include an appointed health care advocate.

- Page 2, line 29: having 3 different designated support persons per patient may lead to inconsistencies in helping a patient to communicate his/her care preferences and treatment wishes.
- Page 3, section 4: I suggest that confidentiality of a patient's discussions with a physician should be the default arrangement, with a possible requirement for a provider to ask the patient if he/she wants a supporter present, rather than the other way around. Privacy of an individual's medical information and treatment records should be upheld unless specific consent to share information is given by the patient.
- Page 7, line 6: I suggest removing "(2) or" after the word "subsection." As a matter of practicality, many (lay) guardians, family members, relatives and friends of a patient are not going to know how to promptly contact the Department of Human Services to be able to speak with a case manager in a reasonable amount of time. As well as simply not being advised of the (proposed) new Oregon law, many persons appointed under ORS 127.635 may live out of state, not be English-proficient, or may simply be too occupied with providing comfort and companionship to a loved one to properly notify a case manager if there is one.

Thank you for your kind consideration and for the work you are all undertaking to make difficult decisions in these uncertain times.

## Christian Hale,

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