



June 23, 2020

Joint Committee on the First Special Session  
900 Court St. NE  
Salem, Oregon 97301

Subject: LC 52

Office of Government Relations

tel 503 494-6629

[hannaju@ohsu.edu](mailto:hannaju@ohsu.edu)  
[www.ohsu.edu](http://www.ohsu.edu)

Mail code: L101  
3181 S.W. Sam Jackson Park Rd.  
Portland, OR 97239

Chair Courtney, Chair Kotek, and members of the Committee,

Thank you for the opportunity to provide input on LC draft 52 which provides protections for people with disabilities seeking care at the hospital. My name is Dr. Susan Tolle and I am the Director of the Center for Ethics in Health Care at Oregon Health & Science University (OHSU). I have spent my career advocating for compassionate end-of-life health care.

Important aspects to this bill that I want to provide comment on.

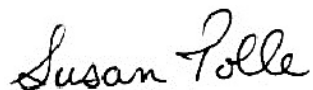
1. Treatment should never be contingent upon completion of a POLST or advance directive. Doing so violates the Federal Patient Self-Determination Act, and the founding principles of the POLST program as illustrated in this document, [Guidelines on POLST Use for Persons with Significant Disabilities who are Now Near the End of Life](#).
2. With regard to the bill's direction on visitation policies - OHSU supports the guiding principle set forth in this bill. Patients that require support workers must be contemplated in the visitation guidance the state gives to hospitals. The experience of this pandemic has drawn a light to the need for the state to recognize this need going forward. We may discover a need to fine-tune how the state issues this guidance going forward, but the language in LC 52 should be adopted to ensure access is not denied in the immediate future should the state require strict visitation policies again in the near future.
3. The bill also makes changes to existing statute on how end-of-life care is delivered. This is an area that I have spent my academic career studying and educating others. I am acutely aware of the difficulty and complexity surrounding it. It is on this portion of the bill that I offer specific recommendations
  - a. Under sections 5 and 6, a patient or their health care representative who has made the decision to have a POLST or advanced directive that articulates their wishes could have those wishes delayed or denied. These sections add a requirement for notification "to the system described in ORS 192.517" but it is not clear what the process for the notification would be or what would happen after the notification. It is also unclear what the role of this system is in end of life decisions for patients and their health care representatives.
  - b. If passed without further clarification, these sections could result in a patient receiving care against their wishes or the wishes of their health care

designee. This could lead to trauma for the patient and their support persons when their wishes ultimately are not honored because of a delay as a result of an undefined reporting process.

- c. This language could also result in the investigation of a family member that has honored the wishes of their family member or support person. We are very concerned that the family members and support persons of our patients who have made a thoughtful and extremely difficult decision to withdraw life-sustaining care will be subject to an investigation into their decision and further traumatized.
- d. I work closely with these patients and their families and these decisions are difficult for our healthcare professionals, patients and their caregivers. Section 5 and Section 6 of LC 52 insert a new complication, delay and possibly investigative process into an end-of-life decision making process that is already challenging and highly regulated. Without further clarification or removal, these sections could have very detrimental impacts on our patients with intellectual and developmental disabilities who are at the end of their life, and the family members and support persons who care for them.
- e. We ask that you consider removing Section 5 and Section 6 or further develop the language so that it does not result in unintended, detrimental consequences for our patients and their families.
- f. We are happy to work with the proponents of the bill to further refine the language in LC 52 to ensure the wishes of our patients and their families are honored.

Thank you again for the opportunity to share this testimony with you. If you have any questions please do not hesitate to contact me or Julie Hanna at 503-860-2662.

Sincerely,



Susan W. Tolle MD  
Cornelia Hayes Stevens Chair  
Director, Center for Ethics in Health Care  
Professor of Medicine  
Oregon Health & Science University  
3181 SW Sam Jackson Park Road, UHN-86  
Portland, Oregon 97239  
[tolles@ohsu.edu](mailto:tolles@ohsu.edu)  
503 494-4466