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SPEAKING IN FAVOR OF SB 494 AND SB ⁷⁶⁸786~~0~~

I am a Registered Nurse with over 35 years of practical and professional experience related to Advance Directives and health care decision making. I am not a lawyer and do not provide legal advice. From a practical perspective, I have had to develop expertise to meet the basic requirements of my position. I have worked with Palliative Care physicians and the interdisciplinary team as well as health care lawyers to better understand the concepts of Advance Directives and Health Care decision making. I have had the privilege of working as a nurse leader to help clients, staff and physicians make the most effective use of Advance Directive documents including the assignment of a Health Care Representative. The desired outcome of this work is to provide guidance for health care decisions when a client can no longer speak for himself. Currently, I am a community educator working with clients to help them understand and complete Advance Directives.

In reference to SB 786: Although not covered in either of these bills, the use of the POLST (Physician Order for Life Sustaining Treatment) has had unintended impact. As originally conceived the POLST was a physician order sheet that was completed in order to assure a client (likely at end-of-life) in the community could communicate their wishes in a legally framed format that would allow the EMS to alter their protocols in accordance written physician orders. A central registry allows the physician to register the POLST and the client is then provided with a wallet card with a number that corresponds to the POLST in the registry. In the event of an emergency, if the card is located on the person the Emergency responder can call into the registry and access the information on the POLST. Many of the patients with whom I work see this as a safety net to assure their wishes are respected.

The unintended effect is that providers are choosing to complete the POLST for a population outside of the medically fragile clients for whom it was initially intended. On more than one occasion, I have heard that the reason they are completing a POLST is that the patient can have this placed on the registry. Additional unintended impact might also to be narrowly emergency treatment options that could limit medically appropriate treatment.

Having a registry for Advance Directives could provide an additional safety net in having this important document available to medical providers in a timely fashion. As we move into the digital age, there are opportunities to make sure that Advance Directive documents are in the medical system clinical information system. I support the development of a State Registry

of Advance Directive documents to create a more robust safety net for the retrieval and effectuation of these documents when it is needed.

I support HB 494 to create a committee that will revise the standard Oregon Advance Directive documents and review the document periodically. I worked for almost 30 years in a community hospital in Western Washington county in a variety of roles. As a staff Nurse, on admission, we had a process and policy and we asked all patients if they had Advance Directives, did our best to get the “paperwork” to the hospital and provided them with information. We knew that patients could not be required to complete Advance Directives, but they often had questions about how to complete them.

Eventually as I moved into leadership roles I provided coaching to the nurses on this process as well as working to improve the hospital policy and process. On occasion, Physicians would ask that I meet with patients to help them complete the “form”. It was clear to me that this was a very important conversation and more than just filling out a form. Probably the most frustrating barrier seemed to be the fact that even though patients would say they had an Advance Directive, they often did not bring them to the hospital on admission. We developed a paper process with Medical Records to help us store and retrieve Advance Directives.

From 2009-2014 I worked as an Administrative Director of the Inpatient Medicine Units at a University Medical Center in the Southeast. I was asked to address issues related to health care decision making, Advance Directives and end-of-life care. The work started with revising the “Code Status” policy including helping to develop an informatics solution to communicate a patient’s resuscitation status within the hospital. I helped lead work to revise the organizational policy on Health Care Decision making clarifying the Advance Directive forms, and language.

The concept of when a client or patient can no longer make their own decisions is a challenge particularly when a patient in the hospital is sedated or their cognition is altered in some way. In some situations, the patient’s decisional capacity may wax and wane based on these factors. There are many decisions that may need to be made throughout a patient’s illness and having someone assigned to speak for them when they cannot express their wishes can facilitate effective and timely medical decision making. A patient may improve and be able to speak for himself and at that point the Health Care representative steps back from the decision making role. The issue of capacity and decision-making capacity can be complex.

Various terms have been used over the years and there is variation from state to state. Since 1993, the term Health Care Representative has been used in Oregon to refer to the person who will speak from the patient if the patient cannot speak for himself. The term Health Care agent or surrogate decision maker is sometimes used. When Advance Directives were first developed the term “Health Care Power of Attorney” was used to refer to the surrogate decision maker. From a practical perspective, this created some confusion related to power of attorney role that was more legal in focus but had not been designated for surrogate medical decision making. When teaching, I use the term Health Care Representative consistently. My understanding is that the terms Health

Care Representative and Power of Attorney for Health Care have essentially the same meaning.

I have been asked by two friends to act as their Health Care Representative. In the process of helping them complete their document, we had questions about Section 7 on page 5 of Advance Directive. **This is a very confusing statement and I noted that it has been eliminated from the newer form presented in HB 494. I support the elimination of section 7 on page 5 of the AD form.**

In 2014, I completed a training program with Oregon Health Decisions in the use of "Key Conversations Planning Guide". Oregon Health Decisions provides a discussion guide that includes the official Oregon Advance Directive. This guide focuses on the importance of a conversation, and includes an individual worksheet specific to the clients choices. The terms included in the AD form are integrated into this conversation guide. There is also an expanded discussion of the role of the Health Care Representative and emphasizes selecting someone who can be trusted to represent the client's wishes when the client cannot express their own. There is an emphasis that the Health Care Representative "represents" the client and their wishes **not** the personal wishes of the Health Care Representative.

Although, I may be stating the obvious, the following must be in constant consideration.

Clients cannot be required to complete Advance Directives and cannot be discriminated against for not completing them.

A client who is capable/competent/able to make their own decisions can change their Advance Directive including their Health Care Representative at any time.

A client who is capable/competent/able to make their own decisions may consent or not consent to treatment.

These concepts are relevant and important to make sure that Advance Directives including Directions to Physician and the assignment of a Health Care Representative are documents that can and should be updated periodically, as long as the client has decision making ability. Although Health Care Representatives are to assure that the client's wishes are respected, they cannot request care that is illegal, immoral or unethical. A patient who is end of life still should be kept clean and comfortable. "Comfort care" includes offering food and fluid by mouth if the patient requests and is physically able to swallow. In my experience if someone does not want to eat, they will clamp their lips shut or say no. Offering does not mean forcing someone's mouth open to accept a spoon or syringe. Comfort care involves medicating with a goal of managing pain and anxiety. I recall an experience years ago, after a patient care conference where the daughter assigned as Health Care Representative made the decision to transition her mother to comfort care. After the conference, the daughter came to the desk and told us that her mother was ready. She had the idea that after the decision was made that we would give her mother a "shot" so that she would die more

quickly. We explained that we would medicate to maintain comfort but that our goal was not to hasten her mother's death.

I do support having a distinct form that allows for the assignment of a health care representative without having to complete the directive to the physician. Some suggest that the it is most appropriate to encourage anyone 18 or older to assign a Health Care Representative. The stand alone form is a very clean way to make this assignment. In my experience one of the more common reasons for an invalid Advance Directive and assignment of Health Care Representative is failure to properly witness the document. Oregon Advanced Directives are very specific in the requirements of witnesses and if this is not done properly the directive can be invalid. In addition, the Health Care Representative must sign to accept their assignment. Not all states require this.

I support the concept of a committee to make changes in the standard Advance Directive document. In order to teach clients how to complete the form, as well as for Health Care providers to understand and engage with the client based on their preferences my preference would be to minimize change in the form itself. I support the concept of a standardized state format with the understanding that there can be accompanying documents that provide more instruction and/or explanations. Several of the health care systems have their documents and processes on-line. As an additional comment, the ideal place for completion of Advance Directives is in the client's regular living situation and when they are in a stable state of health. Moving these documents in the Health Record and creating a registry from Advance Directives are important steps in the future.

Issues around death, dying and medically appropriate care can be emotionally laden. Oregon is a leader in these areas. There is ongoing need for education for staff and the community. Conversations about wishes at end-of-life can provide surrogate decision makers the information they need to make difficult situations and decisions just a little easier. Thank you for taking the steps to help make needed improvement in our Advance Directives process. and considering this testimony.