

Hearing Advance Directive SB494

ISSUES, CONCERNS AND A PROPOSAL

May 30, 2017

William L. Harris

Hearing

- Thank you for the opportunity to address the committee on SB494 and its Minority Report/Amendment
- I would like to articulate three points in my remarks:
 1. Opposition to the Minority Report/Amendment
 2. Purpose of the Advance Directive
 3. My personal experience with Oregon's Advance Directive Statute and the Advance Directive

Opposition to the Minority Report/Amendment

- Minority Report and Amendment Summary⁽¹⁾ states:
 - *Creates a committee to, among other tasks, review and adopt a proposed advance directive **form** and submit the **form** to the interim committee on judiciary.*
 - *Upon receipt, the committee is required to draft legislation amending the statutory **form**.*
 - *Proposed Revisions to the form submitted by the committee do not take effect unless the legislation is ratified by the Legislative Assembly and Governor.*

⁽¹⁾ <https://apps.leg.state.or.us/liz/2017R1/Downloads/MeasureAnalysisDocument/37783>; SB 494 A STAFF MEASURE SUMMARY Carrier: Sen. Thatcher Senate Committee On Judiciary Minority Report

What is different from the original bill?

- *The Minority Report/Amendment "Creates a committee to, among other tasks, review and adopt a proposed advance directive **form** and submit the **form** to the interim committee on judiciary."*
 - The original bill provides details about the number, make up and provides a scope for the committee that creates the form as well as dealing with the section that concerns "...values, beliefs and health care treatment options of the person including both opportunity for narrative and a checklist."
 - The original legislation also limits the scope in that "...the sections of the form relating to appointment of the health care representative, alternates, acceptance, and witnessing remain in statute and may not be modified by the Committee."
- *The Minority Report/Amendment adds an extra step "Upon receipt, the committee is required to draft legislation amending the statutory form."*
 - This is an extra process or step and it is focused on the form.
 - This process puts the contentious discussions about the various components beyond the Advance Directive's form into the Senate committee; whereas the original bill puts these discussions in the Advance Directive Adoptive Committee.
 - And in the original bill "...the Legislative Assembly must adopt the Commission's first form as legislation."
 - Thus the crafting of the updated Advance Directive by the ADAC becomes the legislation, however in the amendment, the form would still have to be crafted as legislation.
- *The Minority Report/Amendment says that "Proposed Revisions to the form submitted by the committee do not take effect unless the legislation is ratified by the Legislative Assembly and Governor."*
 - The original bill allows it to become law: "If the Legislative Assembly does not act in the following legislative session, the new form takes effect."
 - The original bill creates a periodic review of "At least every four years, the measure requires the Committee to review the form and allows it to offer a report and proposed revised form to the Legislative Assembly committees on judiciary and health care in each chamber."
 - The Minority Report/Amendment indicates to me that the committee would be created as needed to update the form which could be another 20 years or more.

What is different from the original bill?

- Other issues not addressed in the Minority Report/Amendment:
 - Additionally, the measure changes the current statutory form.
 - Other changes include changing "physician" to "health care provider" throughout the form,
 - allowing witnessing of the form by employees of a health care facility, and allowing witnessing by notarization.
 - The measure allows a person to execute an older version of an advance directive and retains effectiveness of current advance directives.

What is the purpose of Advance Directive?

- **What Is an Advance Directive?**⁽²⁾
 - An advance directive is a legal document that allows you to share your wishes with your health care team if you can't speak for yourself. An Oregon advance directive allows you to:
 - Identify the person you want the health care team to work with in making decisions about your medical care (known as a "surrogate"); and
 - Generally say what kinds of medical treatment you would or would not want.
 - In layman's terms for me an Advance Directive is a document that tells everyone how I want the process of dying to be handled.
 - For people that have been diagnosed with dementia or Alzheimer's Disease this is a "Right to Die on my terms" document, if you will.
- **Why do I say "Right to Die on my terms"?**

(2) From - <http://oregonpolst.org/advance-directives/>

Advance Directive And Oregon Law

- In July, 2016 I went to court to have Fern Gardens, a memory care facility, stop spoon feeding Nora Harris, my wife, in accordance to her Advance Directive. (5)
 - Nora's current state (and at the time of the hearing) was/is:
 - Does not know any friends or family members. She neither remembers them, nor does she understand her current circumstances.
 - Can not communicate in meaningful language or gestures;
 - She does not know how to eat, use a utensil, or when to eat or drink; everything must be done by another person.
 - She weighs plus or minus 95 lbs and is fed by the staff at meals; when she was placed in 2013, she weighed over 160 lbs.
- I lost the hearing with the judge who cited Oregon Administrative rules (based on Advance Directive statute) that over-rode the advance directive.
 - The judge also indicated that she did not doubt that Nora would just hate the position she was in.
 - Nora's daughter testified that this (no spoon feeding) was absolutely what Nora wanted and that "she did not want to be treated like a baby."
 - Nora's court appointed attorney talked with her friends, who testified in the hearing, and reiterated that she did not want spoon feeding. Still, he testified that **Nora changed her mind**, because she accepted food when presented to her mouth.
 - The ombudsmen law/rules state that Nora must be assisted in feeding when she cannot feed herself and according to the ombudsman that she could only refuse food by turning her head, spitting it out or not open her mouth when a spoon was presented.
- I thought this took away Nora's right to die on her terms, to have state law overrule an Advance Directive.
 - I talked with an attorney who specialized in appeals and he told me that I had a good case as it was based on law and not a dispute over facts.
 - He also informed me that the appeal would take about 10,000 dollars and 18 to 36 months; if Nora passed during this appeal, it would stop immediately.
 - I was also informed that precedent is only created from an appeal and not from the local ruling.
 - I choose not to appeal as I did not think that Nora would live beyond 18 to 36 months.

(5) The write up of the court hearing by Medford Tribune, dated 9/17/2016, is a good recap of the proceedings. I have attached to the end of this ppt.

Advance Directive And Oregon Law

- The ruling by the judge did the following:
 - Condemned Nora to experience the full gamut of Alzheimer's disease to the bitter end.
 - There is "no exit" for Nora, even though her Advance Directive gave her one.
 - The judge and Oregon Statute took Nora's right to die on her terms away.
 - Nora's passing now could be pneumonia from food going into her lungs, a broken hip from a fall, or an inability to swallow (ironically), etc..
 - Because I had a well paying job, I was and am paying the expenses out of pocket for her care at Fern Gardens.
 - The rate is 6,000 dollars a month or 72,000 per year.
 - \$4700 for Fern Gardens, \$200 for doctor coverage, \$250 for medicines and materials (diapers), and \$50 miscellaneous; and
 - Nora being under 65 years of age, does not qualify for Medicare, so I have to pay for private health insurance for her which is about \$800 a month.
 - So since July of 2016, I have paid 60,000 dollars cash from my retirement assets to continue her care and
 - Over the course of these four years (2013-2017) I have paid about 288,000 dollars cash.
 - My assets will be depleted within the next 12 to 18 months to the point where Nora would qualify for Medicaid assistance under the *Preservation of Spousal Assets* statute.
 - However with the new health care initiative from the Republican House, Medicaid may not be available in the near future.

Evidence of Not Understanding Dementia or Alzheimer's Disease

- We were informed that we could just ask Oregon's Health Services to change the Administrative Rules to allow for "no assisted feeding"
- Bruce Van Zee, MD, a member of the Providence Hospital Ethics Committee, requested such a rule change:
 - "After a delay of 5 months, this is the official response to our request to alter the administrative rule for LTC facilities to allow a specific exception to assisted/spoon feeding if so requested by an addendum to a person's AD...." (3)
- Here is the essence of the response:
 - This email is in response to your request for clarification from the Department of Human Services (hereinafter Department) regarding whether the Department could require a facility to honor a request made by someone who does not want spoon or assistance eating if they are unable to do so on their own. An Advance Directive for Health Care is governed by statute. Oregon Revised Statute (ORS) 127.505 defines "advance directive," "artificially administered nutrition and hydration" and "health care" as:
 - (2) "Advance directive" means a document that contains a health care instruction or a power of attorney for health care.
 - (4) "Artificially administered nutrition and hydration" means a medical intervention to provide food and water by tube, mechanical device or other medically assisted method. "Artificially administered nutrition and hydration" does not include the usual and typical provision of nutrition and hydration, such as the provision of nutrition and hydration by cup, hand, bottle, drinking straw or eating utensil. [emphasis added]
 - (8) "Health care" means diagnosis, treatment or care of disease, injury and congenital or degenerative conditions, including the use, maintenance, withdrawal or withholding of life-sustaining procedures and the use, maintenance, withdrawal or withholding of artificially administered nutrition and hydration.

(3)[From: Bruce Van Zee [\[mailto:bvz@charter.net\]](mailto:bvz@charter.net); Sent: Friday, May 05, 2017 4:44 PM; To: Goldberg, Adrienne; Bill Harris; Joanne Kliejunas; efoster@fosterdenman.com; Gell, Jonathan; Grebosky, James; John & Lynn Forsyth; Angela Warren; Subject: Fwd: Spoon or Assisted Feeding

Evidence of Not Understanding Dementia or Alzheimer's Disease

- *An Advance Directive for Health Care, by statute can only can include directions on health care, which by definition, only includes artificially administered nutrition and hydration. Therefore, an Advance Directive for Health Care in Oregon cannot include "special instructions that fall outside the definition of health care. Just to emphasize this, ORS 127.642 restates the items that should be offered regardless of the withdrawal of artificially administered nutrition and hydration, and includes "reasonable efforts to offer food and fluids orally."* [emphasis added]
- Pursuant to the above information, the Department is not able to change our administrative rules. *A statutory change would need to occur first in order for the Department to explore a change.* [emphasis added](4)
- SB494 does not address this issue (assisted feeding) or the above definitions.
- The statute requires Long Term Care facilities to ignore these instructions (no assisted feeding) even if added to the Advance Directive.
- The workshop I attended on crafting this bill, purposely put into abeyance the issues of Voluntary Stopping Eating and Drinking (VSED) and spoon or assisted feeding

(4) From: Potter Ana M ANA.M.POTTER@dhsosha.state.or.us; Date: May 5, 2017 at 4:27:32 PM PDT; To: Bruce Van Zee bvz@charter.net; Cc: Mcqueen Ann E ANN.E.MCQUEEN@dhsosha.state.or.us; Subject: Spoon or Assisted Feeding

Summary

- Defeat the Minority Report/Amendment as it only relates to the “form” of the Advance Directive and does not appear to allow for changes to the statute outside of the form in the ad hoc committee created.
- Defeat the Minority Report/Amendment as it does not fundamentally change the current process or periodically review the Advance Directive and its corollary supporting rules.
- Defeat the Minority Report/Amendment because it does not provide a reasonable path for confronting the issues of the “right to die on my terms.”

Appendix

- Proposal for Advance Directive
- Background
- Who Am I

Proposal

- This clarification and referenced statutes are a fundamental challenge to the idea and efficacy of the Advance Directive.
 - An Advance Directive is to provide a mechanism for the person to state their wishes/desires on how to end life when they cannot speak for themselves.
 - The state takes the position that the Advance Directive is only for the decision on artificially administered nutrition and hydration and "...cannot include special instructions that fall **outside** [emphasis added] the definition of health care...."
- I am proposing that one of two things happen with the new Advance Directive that is being considered by the legislature:
 - Either there be a separate section of the Advance Directive that is specifically designed for persons who have been formally diagnosed with dementia or Alzheimer's Disease.
 - This section would specifically deal with "assisted feeding" in addition to other specific issues.
 - If the person selected "no assisted feeding"; then this would not be overridden by statute or Administrative Rule relating to Long Term Care facilities, e.g. nursing homes, memory care facilities, foster homes.
 - The main issue in the court hearing was, in my opinion, a lack of knowledge of Alzheimer's Disease by the Ombudsmen and Oregon Health Services.
 - Their view is from a legal and statutory perspective, so an Advance Directive created seven years ago was viewed as "illegal" and no longer the valid.
 - Or we have an Advance Directive specifically for persons formally diagnosed with dementia or Alzheimer's Disease
 - Either way, the statute would allow for the person's wishes for end of life even though 7 to 10 years have passed and acceptance of the "...special instructions that fall **outside** [emphasis added] the definition of health care..."

Background

- Nora was diagnosed in July of 2009 with early onset Alzheimer's Disease at the age of 56.
 - Her Advance Directive which was documented and signed in September, 2009.
 - We moved from California to Ashland in July of 2011 because of Oregon's compassionate assisted suicide law and more affordable quality memory care facilities.
- I placed her in Fern Gardens in January of 2013.
 - She entered Fern Gardens at 160 plus pounds;
 - In January of 2016 she weighed 100 pounds, losing about 20 lbs in the previous two months.
 - She entered Hospice in January of 2016, and continued to lose weight to about 90 pounds and then she started to gain weight again.
 - Hospice was discontinued and I found out that Fern Gardens was spoon feeding her, because she could not understand or mechanically feed herself.
 - She had been eating finger food.
 - An Ombudsman intervened and told Fern Gardens to serve her the same food as everyone else, e.g. meat and potatoes.
 - The Ombudsman indicated that she was enforcing Oregon's Administrative rules regarding nursing homes, memory care facilities, etc..
 - OAR stated that she had to be offered three nutritious meals a day and if not able to eat, the facility must provide assistance, i.e. spoon feed her.
 - In July, I went to court.

Who Am I?

- I am William Harris, 75 years old, who just retired on December 31, 2016 from Wells Fargo Bank.
 - I worked for them for 25 years.
 - I had planned to retire at age 67; however with Nora's diagnosis of Alzheimer's and knowing that I would have to pay out of pocket for her care, I worked an additional 8 years so that I would have the resources to pay for her care.
 - Knowing what she wanted as per her Advance Directive and the usual progression of the disease, I hoped that working until 75 would be sufficient.
 - I graduated from the University of Oregon with a Bachelor's (1964) and a Master's (1965) degree in Political Science, but through a circuitous route wound up in Information Technology in the financial industry.
 - I am also facilitating 3 Alzheimer's Disease Support groups for care-givers under the Alzheimer's Association.
 - There are two groups at the Medford Senior Center and one at Rogue Valley Manor.