ACLJ
American Center
for Law & Justice

Jane Marnchianes
1634 N. Scofield Street
Portland, OR 97217

23 February 2017
St. Polycarp

Re: Oregon bills SB 494 & SB 239 (2017)

Dear Jane:

You expressed an interest in having me do an analysis of the above-referenced bills. Let me take them one at a time.

SB 494

Oregon Right to Life has already done a thorough analysis of this bill. I enclose their analysis. Beyond what they address, I would mention the following:

1. The "Temporary Form for Advanced Directive" includes the following definition (p. 7, ll. 40-43):

> The term "as my health care provider recommends" means that you want your health care provider to use life support if your health care provider believes it could be helpful, and that you want your health care provider to discontinue life support if your health care provider believes it is not helping your health condition or symptoms.

This definition essentially gives a "health care provider" total say over treatment. There is no objective standard; instead, what the provider "believes" could be "helpful" governs, with no definition of what "helpful" means. For a provider who thinks patients with dementia, chronic conditions, or disabilities are better off dead, this is a license to proceed on that belief.

Moreover, this definition authorizes a "health care provider" to cut off life support based on a subjective belief that it is "not helping your health condition or symptoms." This language does not say which "condition or symptoms" are relevant. But life support typically is meant to support life, not cure independent conditions or symptoms. Blood pressure medicine will "help" with blood pressure problems but will not "help" with a patient's cancer. BiPAP machines will "help" with apnea but will not "help" with diabetes. Food and water will maintain life but will not "help" with quadriplegia. May a provider ignore the fact that a life support measure helps with one or more conditions or symptoms, and instead focus on the failure to help other conditions or symptoms? The language does not say, creating a serious ambiguity. (This ambiguity could be addressed in part by replacing "your health condition or symptoms" with "any of your health conditions or symptoms". However, this alteration would not change the other concerns identified herein.)

2. The "Temporary Form for Advanced Directive" includes the following definition (p. 7, ll. 44-45):

> The term "life support" means any medical treatment that maintains life by sustaining, restoring or replacing a vital function.

This definition sweeps in virtually all necessary care, while using a term -- "life support" -- that conjures up images of extensive and invasive interventions involving tubes and wires. Consequently, a person who might prefer to receive modest measures like antibiotics or respiratory therapy will unthinkingly be signing off on a broad death warrant.

3. The "Temporary Form for Advanced Directive" includes the following passage (p. 8, ll. 6-12):

> A. Statement Regarding End of Life Care.
>
> You may initial the statement below if you agree with it. If you initial the statement you may, but you do not have to, list one or more conditions for which you do not want to receive life support.
>
> ___ I do not want my life to be prolonged by life support. I also do not want tube feeding as life support. I want my health care provider to allow me to die naturally if my health care provider and another knowledgeable health care provider confirm that I am in any of the medical conditions listed below.

The form does not offer an alternative version. Nor does it state that a person may edit or amend this statement. Thus, the person using the form seems to be put to an all-or-nothing choice: if you wish to refuse any *particular* form of life support (e.g., a ventilator), you have to refuse *all* forms of life support *plus* tube feeding.

4. The "Temporary Form for Advanced Directive" consistently presents three options (pp. 8-9):

INITIAL ONE:

___ I want to receive tube feeding.
___ I want tube feeding only as my health care provider recommends.
___ I DO NOT WANT tube feeding.

INITIAL ONE:

___ I want any other life support that may apply.
___ I want life support only as my health care provider recommends.
___ I DO NOT WANT life support.

There is no flexibility or nuance here. A person using this form cannot say, for example, "I want antibiotics and respiratory therapy but not CPR or a ventilator." Also, the "as my health care provider recommends" language sounds appealing -- relying upon medical authorities -- but as noted above, in fact delegates crucial value judgments to a provider who may or may not actually share the values of the patient. True, a person can take the trouble of attaching a statement of "your values and beliefs related to health care decisions" and describing "what you would like to happen" (p. 9, ll. 13-17). However, "[t]hese attachments" only serve as "guidelines" for health care providers (ll. 14-15) and may or may not be deemed sufficient to override or modify the blanket directives that are checked off.

5. The "Temporary Form for Advanced Directive" employs broad categories -- "close to death," "permanently unconscious," "advanced progressive illness," and "extraordinary suffering" (pp. 8-9) -- as to which persons are to make blanket advanced directives. Again, there is no nuance, no ability to tailor a request to the actual circumstances of the patient's situation. For example, a person deemed "close to death" may want to get through a temporary mental incapacity so as to live long enough to witness an upcoming wedding, birth, or graduation, even though the underlying fatal disease persists.

Furthermore, there is no definition of "close to death". Does that mean within hours? Days? Months? A year or two? Meanwhile, "extraordinary suffering" is apparently defined to mean "permanent and severe pain". But who decides what is "severe"? Are physicians infallible in predicting what is "permanent"? These slippery terms create the real risk of a serious disconnect between what the person signing the advance directive actually intended, and what the representative or provider subsequently interprets that same language to mean.

SB 239

This bill addresses residents of residential care facilities and of adult foster homes.
The bill defines "Individually based limitation" to include "a limitation on the resident's right to

. . . (B) Access food, freely and with support, at any time" and "(C) Have visitors of the resident's choosing at any time" (p. 3, ll. 35, 38-39; p. 6, ll. 15, 18-19). The bulk of the bill involves authorizing third parties to consent to such an "individually based limitation," i.e., to refuse (among other things) food and visitors to the resident, when the resident is personally incapable of giving or refusing consent. The only limitation on such third party's decision is that party's "good faith understanding of the resident's best interest and of what the resident would have wanted if the resident were capable of making the determination" (p. 1, ll. 24-25; p. 4, ll. 20-21). The bill also would broadly immunize any such third party (p. 3, ll. 4-6; p. 5, ll. 29-31):

> (8)(a) A legal representative is not subject to civil or criminal liability or in violation of any professional oath, affirmation or standard of care for any determination the legal representative made in good faith under subsection (2) of this section.

Hence, liability would only attach if it could be proven that the third party acted in bad faith. This, in turn, could only happen if someone raised an objection, pursued it with the relevant authorities, and found someone willing to follow up with the matter.

Finally, it bears mention that the third party decisionmaker need not be a spouse or family member or even someone designated by a spouse or family member. If no such person is "available or can reasonably be located" (p. 1, ll. 26-27; p. 4, ll. 22-23), the facility can create a committee to make the decision.

***

I hope these analyses are helpful to you.

For life, in Christ,

Walter M. Weber
Senior Counsel

Enclosure

"Several states, including Wisconsin and New York, forbid health care surrogates to stop food and fluids. (Oregon legislators, on the other hand, are considering drafting a bill to allow surrogates to withhold nutrition [from patients with dementia or mental illness])." – ***NY Times, October 21, 2016***

SB 494

SB 494 removes the current safeguards which prohibit surrogates from withholding ordinary food and water from conscious patients with dementia or mental illness.

- Suicide advocates are currently championing Voluntarily Stopping Eating and Drinking (VSED) as a way to hasten death.[1] VSED involves a person who is capable of eating normally but chooses not to in order to cause his or her death. In the United States a competent adult has the right to decide what will happen to his or her own body.[2] Therefore VSED, if not affirmatively sanctioned by law, is still available to competent adults. However advocates now want to extend VSED to incompetent adults with dementia or mental illness who have not indicated that they want to starve to death.

- The forefront of this push is taking place in Oregon. In 2016 Bill Harris, of Ashland, filed a lawsuit as guardian of Nora Harris, his wife who suffers from Alzheimer's disease, asking the court to issue an order to her nursing facility to stop providing Nora with spoon feeding assistance when eating. The nursing facility had begun to spoon feed Nora because she could no longer use utensils to eat, but could only eat with her hands.[3] Bill argued that because Nora indicated in her advanced directive that she did not want artificial nutrition and hydration, this meant she also did not want assistance with ordinary eating and drinking.[4] Bill's attorney specifically cited VSED as justification for this order.[5] The court denied the order in part because all advanced directives followed in the state are subject to Oregon law, and Oregon law requires nursing facilities to provide help with ordinary eating and drinking.[6] At trial the judge suggested that she would have liked to rule in favor of Bill and suggested that Nora is being forced to eat. She said, "It's not a happy decision for me."[7]

- However, Nora's attorney in his brief pointed out that it was Nora herself who was choosing to eat. Sometimes Nora chooses to eat and sometimes she doesn't.[8] The nursing facility, Fern Gardens, stated that they do not pressure her to eat when she refuses.[9] Thus, although Nora has Alzheimer's disease, she is choosing to eat and her will to eat should be respected.

- **SB 494 removes the statutory safeguards that currently prevent the representative of a patient with Alzheimer's disease or mental illness from ordering facilities to withhold food and water from the patient even if the patient did not indicate this desire in an advance directive and shows a desire to eat.**

- Oregon law currently allows guardians and health care representatives to remove feeding tubes, IV's, and other forms of artificially nutrition and hydration. This bill does not concern feeding tubes, IV's, ventilators or other forms of extraordinary care.[10]

- SB 494 removes the provision in Oregon law which requires all advance directives executed in other states are subject to Oregon law. (Page 12, line 21-25). Bill Harris argued that California law provided a guardian with the authority to prevent a nursing facility from assisting a person with ordinary eating and drinking.[11]

- SB 494 removes the statutory definition of "tube feeding" from Oregon law which currently defines it only to mean <u>artificial</u> nutrition and hydration. (Page 14, line 34). This creates ambiguity about the intent of a person who states in an advance directive, "I do not want tube feeding." (Pages 8-9). This could allow a court to determine that the incompetent person intended this statement to mean that he or she did not want ordinary assistance with eating or drinking.

- SB 494 removes the statutory definition of "life support." (Page 14, line 7). This creates ambiguity about the intent of a person who states in an advance directive, "I do not want life support." (Pages 7-8). This could allow a court to determine that the incompetent person intended this statement to mean that he or she did not want ordinary assistance with eating or drinking.

- SB 494 removes every reference to a power of attorney for health care or an attorney in fact for healthcare. An attorney in fact for health care is an agent of the principal and the powers of the agent are limited to those expressly given and those necessary essential and proper to carry out the powers expressly given.[12] By removing power of attorney from the statute, SB 494 is creating ambiguity as to the authority of a health care representative to make decisions for the incapable person.

- SB 494 removes the statutory definition of "heath care instruction." (Page 13, line 29). This creates ambiguity about the authority of a health care representative to make decisions for the incapable person.

- SB 494 deletes the use of the word "desires" throughout the statute and changes it to "preferences." (Examples: Pages 3, 17, 19). "Preference" is used throughout Section 3, which sets statute for how an advance directive is to be written. (Pages 2-4).

- SB 494 adds, "To the extent appropriate" in the space on the advance directive form that says "my healthcare representative must follow my instructions." (Page 7, line 33).

- SB 494 removes the conflict of interest section which requires at least one witness to the advance directive to not be a person's heir or devisee under their will. (Page 11, line 27-30).

- SB 494 deletes the statutory definition of "dementia." (Page 13, line 10-14).

- SB 494 creates a completely unaccountable Advance Directive Rules Adoption Committee which is appointed by the Governor and has sole authority to make the only advanced directive that may be used in the state. The members of this committee would have authority to change future advance directives at their will without accountability to anyone:
  - No Senate confirmations of Governor's committee appointees (Page 2)
  - Changes to advance directives need to be submitted to health and judiciary committees. **However:**

    No approval of document is needed
    No hearing or vote required
    Submission to committee may be waived (Page 4, line 24-27)

A note regarding the fact that SB 494 does not change the definition of artificially administered nutrition and hydration:

- Although SB 494 does not change the statutory definition of "artificially administered nutrition and hydration" as currently defined in ORS 127.505(4), this does not address our concern that the bill removes safeguards that protect the mentally ill in our community.

- The reason for this is that SB 494, if enacted, would remove the advance directive form from statute and place it under the authority of a committee appointed by the governor. The advance directive form, as currently in statute, does not use the term "artificially administered nutrition and hydration." Therefore, the fact that SB 494 would not change the statutory definition of this term is irrelevant.

- The relevant term is "tube feeding" which is the term that is used in the advance directive.

- SB 494 DOES remove the definition of "tube feeding" from statute and places that term in the advance directive form itself that would be subject to change by the appointed committee. Thus if SB 494 is enacted the committee would be able to redefine "tube feeding" or remove the definition altogether allowing a court to interpret the ambiguous intent of the person who filled out the advanced directive.

- Since an Oregon judge is on the record stating that she wishes that the law did not prevent her from issuing an order to a care facility to withhold ordinary food and water from a patient suffering from Alzheimer's disease, it is important that we retain all of the statutory safeguards that protect vulnerable people with mental illness in our community.

---

[1] Paula Span, *The VSED Exit: A Way to Speed Up Dying, Without Asking Permission*, THE NEW YORK TIMES, October 21, 2016, http://www.nytimes.com/2016/10/25/health/voluntarily-stopping-eating-drinking.html.

[2] Cruzan v. Director, Missouri Dept. of Health, 497 U.S. 261 (1990); Gaston v. Parsons, 318 Or 247, 259 n 12, 864 P2d 1319 (1994).

[3] Vickie Aldous, *Ashland woman didn't want life prolonged, but state says she must be spoon-fed*, MAIL TRIBUNE, September 18, 2016, http://www.mailtribune.com/news/20160918/ashland-woman-didnt-want-life-prolonged-but-state-says-she-must-be-spoon-fed (she was eating a sandwich while other patients ate a hot prepared meal).

[4] Hearing Memorandum at 8, In re Nora Harris, No. 13017G6 (Jackson County filed April 27, 2016).

[5] *Id.* at 5.

[6] In re Nora Harris, No.13017G6 (Jackson County July 18, 2016) (order denying protective order); OR. REV. STAT. §127.515 (2011); OR. ADMIN. R. 411-054-0030(1)(e)(F) (2016).

[7] Tribune News Services, *Oregon orders spoon-feeding for woman who didn't want life prolonged*, CHICAGO TRIBUNE, September 19, 2016, http://www.chicagotribune.com/news/nationworld/ct-oregon-woman-spoon-feeding-20160919-story.html.

[8] Memorandum in Opposition at 5, In re Nora Harris, No. 13017G6 (Jackson County filed April 27, 2016).

[9] Tribune News Services, Supra note 7.

[10] OR. REV. STAT. §ORS 125.135(1)(c)(2015); REV. STAT. §127.580 (2015).

[11] Hearing Memorandum at 7, In re Nora Harris, No. 13017G6 (Jackson County filed April 27, 2016).

[12] Ho v. Presbyterian Church of Laurelhurst, 116 Or App 115, 840 P2d 1340 (1992).