"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.<sup>1</sup> 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.<sup>2</sup> 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. 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. Bill's attorney specifically cited VSED as justification for this order. 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. 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."
- 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.<sup>8</sup> The nursing facility, Fern Gardens, stated that they do not pressure her to eat when she refuses.<sup>9</sup> 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.<sup>10</sup>
- 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.<sup>11</sup>
- 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. 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 <u>completely unaccountable</u> 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)
  - $\circ\quad$  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, <u>does not use the term</u> "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 <u>DOES remove the definition</u> 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.

<sup>&</sup>lt;sup>1</sup> 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.

<sup>&</sup>lt;sup>2</sup> 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).

<sup>&</sup>lt;sup>3</sup> 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-shemust-be-spoon-fed (she was eating a sandwich while other patients ate a hot prepared meal).

<sup>&</sup>lt;sup>4</sup> Hearing Memorandum at 8, In re Nora Harris, No. 13017G6 (Jackson County filed April 27, 2016).

<sup>&</sup>lt;sup>5</sup> Id at 5

<sup>&</sup>lt;sup>6</sup> 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).

<sup>&</sup>lt;sup>7</sup> 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.

<sup>&</sup>lt;sup>8</sup>Memorandum in Opposition at 5, In re Nora Harris, No. 13017G6 (Jackson County filed April 27, 2016).

<sup>&</sup>lt;sup>9</sup> Tribune News Services, Supra note 7.

<sup>&</sup>lt;sup>10</sup> OR. REV. STAT. §ORS 125.135(1)(c)(2015); REV. STAT. §127.580 (2015).

<sup>&</sup>lt;sup>11</sup> Hearing Memorandum at 7, In re Nora Harris, No. 13017G6 (Jackson County filed April 27, 2016).

<sup>&</sup>lt;sup>12</sup> Ho v. Presbyterian Church of Laurelhurst, 116 Or App 115, 840 P2d 1340 (1992).