February 20, 2018

Good morning, Chairman Prozansk.
My name is Jane Marnchianes, and I live in Portland, Oregon.
I am in opposition to HB 4135. In addition to my objection, I have submitted a legal analysis by Walter Weber, Senior Counsel for the American Center for Law and justice, Washington, DC.
Allow me to discuss a collection of my objections in some detail.
To begin, it needs to be stressed that this bill encases substantially negative elements in implicit language and, consequently, is gravely misleading, first and foremost because those very elements involve taking advantage of the elderly and confused.
More specifically, let us consider a first element of the bill, the directive as regards the wording of "life support." In this bill, the options for expressing desire for or against future" life support" in difficult conditions are basically for only extremes, that is, no middle ground. This means that, effectively, one either elects to receive ALL further life support measures, or none. Now, life support by this bill's standards includes not only CPR, ventilators, and tube feeding, but also necessary treatment such as antibiotics and medications used to control blood pressure, diabetes, epilepsy, heart conditions, and more. Hence, if, in your directive, you refuse any particular form of life support, you have to refuse all forms of life support.
As a second element, if you want life support "as your health provider recommends"—your health care provider being, amongst other possibilities, a nursing home, a foster home, or a hospital—then that same health care provider has complete jurisdiction over what treatment you will receive. Hence, if a patient has dementia or chronic conditions or disabilities, and the provider deems them better off dead, then this bill would effectively be a license to proceed on that belief.
Thirdly, if a patient has a change of heart from their directive and wants treatment, they can revoke the directive at any time and in any manner, even if there is no showing that the person is "capable of making medical decisions;" however, and this is a serious consideration, if the health care provider is *not aware that it can be revoked in this manner, the written directive has priority over the patient's resistance.*
Finally, regarding the wording of "close to death," there is no definition; it is unclear—days, weeks, months, years.
May I conclude by saying that we are all vulnerable—not only the elderly and confused—but all of us. This bill is disastrous and could become mandatory to the misinformed.

Respectfully,
Jane Marnchianes

Analysis of Oregon HB 4135

To Whom It May Concern -- The current text of HB 4135 is available at https://olis.leg.state.or.us/liz/2018R1/Downloads/MeasureDocument/HB4135. I have prepared an analysis of the bill, addressing the current text. Page references refer to the text. -- Walter Weber, Senior Counsel, American Center for Law & Justice

HB 4135

Oregon Right to Life did a thorough analysis of SB 494, a predecessor of this bill. https://www.ortl.org/wp-content/uploads/2017/02/SB-494-Fact-Sheet-1.pdf. Beyond what ORTL addresses, I would mention the following regarding the current bill, HB 4135:

1. The "Temporary Form for Advanced Directive" includes the following language (p. 7, ll. 12-16):

> • If your advance directive includes directions regarding the withdrawal of life support or tube feeding, you may revoke your advance directive at any time and in any manner that expresses your desire to revoke it.
> • In all other cases, you may revoke your advance directive at any time and in any manner as long as you are capable of making medical decisions.

This language appears to enable a person to revoke a directive by any word or action that expresses disagreement with the directive, whenever the directive authorizes withdrawal of "life support or tube feeding," even if there is no showing that the person is "capable of making medical decisions." This is therefore a life-protective provision: it makes it easier for a person to convey a change of heart in favor of life. The effectiveness of this provision will depend, however, on making sure that health care providers are aware that advanced directives can be revoked in this way; otherwise, a provider may believe that the written directive takes priority over a person's subsequent resistance, expressed by word or action, to the removal of life support or tube feeding.

2. The amended "Temporary Form for Advanced Directive" includes the following definition (p. 8, ll. 7-10):

> 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.)

3. The "Temporary Form for Advanced Directive" includes the following definition (p. 8, ll. 11-12):

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

This definition sweep in virtually all necessary medical care, while using a term -- "life support" -- that conjures up images of extensive and invasive interventions involving tubes, machines, and wires. Consequently, a person who might prefer to receive modest measures like antibiotics or respiratory therapy could easily make the mistake of unthinkingly signing off on a broad death warrant. The likelihood of such an error -- reflecting a lack of properly informed consent -- will presumably be higher if the person is beginning to suffer the loss of mental faculties, whether from the beginnings of dementia, confusion resulting from medication, or from some other cause. In short, this use of language may be setting a trap for vulnerable elderly persons.

4. The "Temporary Form for Advanced Directive" includes the following passage (p. 8, ll. 18-24):

> 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 statement to choose from. 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.

5. 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 this language delegates crucial value judgments to a provider who may or may not actually share the values of the patient. True, a person

> may attach supplementary material to an advance directive. In addition to the form of an advance directive adopted under this section, supplementary material attached to an advance directive under this subsection is a part of the advance directive.

(p. 4, ll. 14-16). Many people will not take the trouble of this extra step. Moreover, it will be difficult, if not impossible, to make such instructions comprehensive, as one cannot know with accuracy what future conditions and circumstances will be, much less how one will actually react to them when that time arrives. Further, instructions to a health care representative may be specified as mandatory or as simple guidelines (p. 7, l. 45 to p. 8, l. 3). Even when mandatory ("must follow"), the instructions only apply "[t]o the extent appropriate" (p. 7, l. 45). Hence, the supplemental instructions may or may not be deemed sufficient to override or modify the blanket directives that are checked off on the form itself. Indeed, the temporary form specifies that "[a]dditional [i]nstruction" that the person attaches only "will serve as guidelines" (p. 9, ll. 25-27), a weak assurance at best.

6. The amended "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, and (aside from any supplemental instructions of dubious force that the person may draft) 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.

Walter M. Weber received his A.B. degree from Princeton University in 1981 and his J.D. from the Yale Law School in 1984. He has specialized in constitutional law for over 33 years and has written over 130 briefs for U.S. Supreme Court cases. When in law school, Weber worked as a summer intern with Americans United for Life (1982) and the U.S. Department of Health and Human Services (1983). After law school, Weber worked for the Catholic League for Religious and Civil Rights (then headquartered in Milwaukee, Wis.) and Free Speech Advocates (based in New Hope, Ky.) prior to joining the American

Center for Law & Justice (ACLJ). In addition to his work at the ACLJ, Weber taught First Amendment Law from 2004 to 2011 as an adjunct law professor in the Washington, D.C. program of the Regent University Law School.