

To the Legislature:

I am writing to let you know of my opposition to this bill as written as the daughter, sister, and grandmother of disabled persons, and a healthcare professional (Clinical Bioethicist). This is my professional and personal opinion and I am not representing PeaceHealth.

1. I work with disabled individuals and their families and caregivers as part of my clinical bioethics work. My focus has always been to uphold the autonomy of patients and to include them in decision-making to the best of their abilities. I have worked diligently to make sure that our physicians, staff and nursing home staff know that no patient has to complete a POLST or advance directive to receive care.
2. I am the decision-maker for my brother with Fragile X; making these decisions are not easy and even as a healthcare professional, ones that are emotionally difficult. I do not make any of these decisions lightly and work in concert with his beloved physician. We just changed his POLST after a recent hospitalization during COVID- he did not have COVID, but other complications from diabetes and chronic kidney disease. I do not want someone assuming that I don't have my brothers best interests at heart when we have carefully made this decision, including him to the best of his abilities to do so. If this passes as written, I or other loving family members could be investigated for following the wishes of our loved ones.
3. Requirements for reporting and gaining approval for withdrawal are not entirely new, but more stringent in this language. This could result in delayed care for a patient and potential suffering. I have been involved in cases with disabled Oregon citizens; requiring obtaining permission when someone is clearly at the end of life to change their code status or other orders is already cumbersome, often takes days, and these issues never occur M-F during business hours. The emergency numbers you call rarely respond. Thus, patients must wait, often prolonging not only their dying process, but their suffering as well. The understandable fear that a patient will be unable to advocate for themselves may contradict support for autonomy in the disabilities community. I would hate to see a competent patient caught in a system which takes away their rights, rather than protecting their rights as intended.

I appreciate the care, concern and support intended to honor the autonomy of those with physical and intellectual disabilities, but feel that this legislation as written will cause more harm than good. I respectfully ask that you reconsider this and work with those of us in the medical and advocacy community to ensure protection for patient rights without causing harm to our patients and family members.

Sincerely,

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