

Good Morning, I'm Beckie and I live in Hermiston,

I'm asking that Legislative Concept 52 (or "LC 52") be introduced and passed this Special Session so that **Oregonians experiencing disability can access healthcare, use support from people they trust while they are hospitalized and have support when making end of life decisions.** Everyone deserves access to healthcare and support from people they trust to help them understand their care and communicate with doctors. Today, too many people experiencing disability are not able to access healthcare, are denied support from people they trust while they are hospitalized or having end of life discussions."

We know this first hand, our son has refractory epilepsy with intellectual disabilities. He has been air-lifted just about every 2 years to Portland since the age of 6 months, he is now 27 years old. We have dealt with all kinds of doctors and their opinions of how we should allow them to treat him. Some understood our quest for a quality of life for our son vs. a quick fix in the hospital and sent home, while others tried to intimidate us into thinking their solution was the only way, by dragging in the whole medical team to intimidate us and others where bold enough to make the comment, "Well do you think we should be treating him when he is in this condition?" which, my replay back to them was, "Are you saying by us choosing quality of life for our son is determining the quality of care that he will get.? We have a list of 27 years... The only thing that has kept him a live this far is our faith, and our determination to be by his bedside day/night while in the hospital to advocate for him. We are his legal guardians and he has a POLST and I pray that in the event that he should every make it to the hospital without us next to him, the doctors will honor it until we get there and not just make their own decisions, due to the fact that our son is cognitively 3-4 years old and will not be able to make decisions for himself. He has behaviors, which are his words, and in order to know why he is having certain behaviors you need to know him. He says NO a lot and his NO has lots of meanings. It can mean no, yes, a seizure, (he may be feeling a seizure coming on), it means frustration, (He's frustrated with trying to put a puzzle together or something he's working on). No can mean, he's teasing you. So for somebody to just make the assumption that "He said NO so I didn't do it would be incorrect, because they do not know our son.

I want to say thank you for taking the time to read this and ask that you PLEASE introduce and pass "LC 52" so our love ones have the support that they need while they are in the hospital.

*Have a great day,
Beckie*



Everyone you meet is fighting a battle you know nothing about..Be Kind. ☺
Anonymous



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