

January 25, 2023

To: Chairman Prozanski & Members of the Senate Committee on Judiciary

From: Mary & Paul Oldshue
Portland, Oregon

Re: **Senate Bill 528**

We are the parents and guardians of our 36-year-old son, who is quadriplegic, blind, non-verbal and Developmentally Delayed since birth. Over time he has developed several serious health conditions. He is totally helpless in terms of Activities of Daily Living. We care for him at home.

We recognize that there are situations in which guardians abuse their power and we particularly agree that protected people who recover their capacity for self-care and decision making should be free to make their own decisions.

However, some of the proposed provisions in SB 528 seem to limit the decision making of the guardian with significant negative consequences to the protected person. Specifically, proposed amendments c and d to Section 20 will effectively prolong dying in situations where medical professionals agree it is futile to expect recovery because the protected person *never* had the capacity to execute an Advance Directive reflecting their own thoughtful health care decisions. That is a cruelty that non-disabled persons do not have to endure.

We have been actively involved in our son's medical care and have made the effort to cultivate solid on-going working relationships with the many competent, well respected and caring healthcare professionals involved throughout his life. These connections have included in-depth discussions of end-of-life issues. Reason, reflection and maturity dictate that we accept that our son's situation is fragile. We have worked hard to make each day a good day for him and we also know that we may face a time when 'allowing natural death' with the best possible 'comfort care' is more loving than insisting on extreme measures that amount to extending the dying process in painful and frightening ways. Allowing the POLST that documents this philosophy to govern his care is important to us.

In closing, we would like to express our serious concern that this proposed bill came as a surprise to us and several organizations less 24 hours before the opportunity for testimony was scheduled. There are many people with deep and relevant experience who have not been given reasonable time to form and submit their thoughts on a bill that, if enacted, will have wide-reaching consequences including many that may not be intended.