Submitter: Melissa Fisher

On Behalf Of:

Committee: Senate Committee On Human Services

Measure, Appointment or Topic: SB228

This time last year I was the caregiver of two family members with dementia in long term care in Oregon, my dad and aunt. Sadly, my dad passed this time last year. I continue to support the care of my aunt, and my mom, who is in the independent side of an LTC. In due time my mom with Parkinson's and dementia will require more care than I can provide her, and I will need to make the excruciatingly difficult decision to move her to a higher level of care.

I am an active participant in the care of my family. I am also very concerned that if my mom is moved how much I will be allowed to continue to contribute to her day-to-day life, entrusting a facility to provide the care my loved ones needs. I have learned a great deal about what matters in their care over the years, and what happens when we are not seen as a core part of the residential facility team. I want to participate actively in making not only her experience better, and that of her community.

My reasons are many as to why this inclusion matters so much to me. I am haunted, no, TRAUMATIZED - by what has happened to my family in the past.

My mom's mom had Alzheimer's and died in a geriatric psych ward out in Forest Grove in 2015 after being transferred from her memory care with hours notice and not with her family's permission. She died on the floor by her bed a week after transfer, having suffered a massive heart attack.

During the pandemic, my role as caregiver to my dad was impossible due to the lockdowns - I was not only not allowed to be with my dad for 18 months, I was completely dependent on what limited communications were provided to me by the administrator of my dad's skilled nursing facility and the short :15 calls with his "team" held monthly via phone.

Most recently, my aunt, a former resident of Mt Hood Senior Living closed abruptly by DHS in January of 2024 with hours notice, with no notice to families of any investigation.

My primary role for my loved ones is advocating for their needs since they cannot for themselves, and I know that my inclusion in the day-to-day in the residential facility setting is essential. Being the sole person responsible for an adult loved one with dementia is a daunting task, consuming a great deal of my time, but without a means to assemble with others with loved ones in long term care, we are shut out. Families and representatives should be provided a means to assemble, contribute ideas, ask questions and give feedback in an organized, constructive and beneficial way that improves the quality of life for all residents.

Independent family councils are the means to achieving this and I sincerely hope that you pass SB 228 for the betterment of our community and the lives of all Oregonians in residential facilities.

Thank you.