

## Testimony for SB 228

Good morning Chair Gelser Blouin, Vice-Chair Linthicum, and members of the Committee,

My name is Judith Smith and I am co-founder of The Rawlin Independent Family Council together with Jewel Nelson in Eugene, Oregon.

I'm here to ask for your support in favor of SB228 which gives the right to a resident or their legal representative to organize and participate in an independent Family Council in a Memory Care Facility without willful interference from the facility.

My mother, Virginia Baker, was diagnosed with Dementia while she was in her 80's. I knew I could not provide the level of care she required at my home so I placed her into memory care at The Rawlin in Springfield in April of 2019 after my father passed away due to complications of a fall in their home in California.

This was one of, if not the most heart wrenching decisions I've ever made.

My mom became depressed, confused and was unable to remember that dad had passed away.

My parents were married for 72 years.

Jewel Nelson and I had been friends before she placed her mom, Eve, into care at The Rawlin not long after my mom arrived.

Then Covid hit.

This was a difficult and frightening time for everyone. Window visits and FaceTime were available but no physical access to my mom left us both without human touch from each other, adding to the torment of being behind locked doors.

At that time, the facility held Town Hall meetings, trying to calm worries of concerned family members, but trust began to deteriorate. We received letters assuring us that our loved ones "will continue to receive the utmost attention and care".

Jewel and I wanted to know how other family members felt so we reached out with a few emails and phone calls to set up a Zoom meeting of our own to let others voice their concerns. We found out we were not alone with our questions and concerns about Covid and staffing.

We felt strongly that our loved ones needed a voice, our voice. That's when we made the commitment to officially form and grow a Family Council, with the help of our Ombudsman.

New management embraced and supported our efforts. They began to promote the Council by forwarding announcements to all resident families regarding meeting times and dates, allowing the Council access to a bulletin board to pin fliers, business cards and information, even allowing Council information to be included in new resident admission packets.

Management worked with families for 2 years in good faith to resolve systemic issues by addressing and responding to families' concerns and proposed solutions. Our group continued to meet monthly via Zoom.

We invited guest speakers to educate family members about Hospice, Medicaid, the different types of Alzheimer's and how to redirect and comfort loved ones with the power of music. We invited Doctors, Lawyers, SOQ policy analysts, APS, and a brain pathologist. We learned how to be prepared for a care plan meeting, and about the peace of mind of having pre-paid funeral arrangements. We also have invited Directors, RCC's, the facility nurse and the chef that runs the kitchen in the facility.

Until a new corporate Director of Operations cut all ties with the Family Council.

Jewel and I were devastated, our moms had passed away within 9 weeks of each other in the summer of 2023 and now the Family Council is being dismissed by a Corporate person stating that the facility would be starting their own "Family Support group", run by management, to engage with families and answer their concerns.

She, the new Director of Operations, threw out the bulletin board in the lobby and all Family Council information.

We carried on with nothing to lose.

We invited State Ombudsman, Fred Steele, to be a guest at our next meeting. He stated it was his opinion that this was "an attempt at a Hostile Takeover of a Family Council".

This is why:

- We wrote By Laws and changed our official name to The Rawlin Independent Family Council. We thought it was important to differentiate between a resident Family run Council and a Management sponsored Council or group.
- Through some research we found information from The National Consumer Voice, a resource for Nursing Homes which mentions Independent Family Councils, which contains Family Council rights under the 1987 Nursing Home Reform Act.
- I thought we had Family Council rights in Memory Care Facilities, but it is a Federal Law for Nursing Homes, not a State Law for Memory Care Facilities here in Oregon.

SB228 is built on the foundation of this 1987 Federal Law, The Consumer Voice, and some current California State Statutes allowing the resident or resident's legal representative the right to organize and participate in an Independent Family Council.

Most of the residents in the approximately 230 Memory Care Facilities in Oregon have lost their ability to effectively communicate or advocate for themselves due to a cruel and debilitating brain disease. They live behind closed doors, cared for by strangers, typically until they die.

Currently, in Oregon, there are no statutory requirements that Memory Care Facilities inform Families of their right to form Independent Family Councils.

We can change that.

My mother, Virginia Baker is gone but she never forgot that I was her daughter.

In memory of my mom and Eve Nelson, I want future residents of Memory Care Facilities to have a voice, the collective voice of advocacy for quality care. Voices of sons, daughters, POA's and Guardians through Independent Family Councils and may they never be silenced.

Please use your voice to allow and protect Independent Family Council rights by voting Yes on SB228.

Thank you,  
Judith Smith