Testimony in support of SB 228

My name is Jewel Nelson and I am the co-founder with my friend Judith Smith, of the Rawlin Independent Family Council in Springfield.

I am seeking your support for Senate bill #228, which provides that families in Memory Care and other RCFs have the **right to form Independent Family Councils.**

In 2008, my mom Eve who had lived on the east coast for 80 years, was diagnosed with vascular dementia.

For a year, I tried to manage her personal affairs and medical appointments from 3 time zones away. Fortunately, she agreed to move to a retirement community near me in Eugene.

I set things up to simplify her life as much as possible and we had a pretty good run for 10 years.

But the unpredictable demands and mercurial nature of dementia prevented me from being able to keep her engaged, independent and safe.

So despite all my post it notes and the patchwork of caregivers we hired, it wasn't enough.

In **2019** I moved my mom into a memory care facility in Springfield.

After 10 years of such intimate and frequent connection to every facet of my mother's life, the reality of her now living in a group facility behind locked doors being cared for by strangers, was quite a shock - to both of us.

The pandemic started 5 months later. There was no shortage of fear for oneself and one's family at that time.

For our loved ones in care, with each new wave of lockdowns, each painful and confusing window visit, the isolation and despair that all of us felt only added a whole cruel layer to every family's experience.

Management eventually held Zoom "town hall meetings" in order to address the questions and concerns we all had. Families expressed very mixed reviews regarding what we were hearing.

Judith and I asked families if there was interest in meeting with our Ombudsman by Zoom, so that we all might more openly discuss experiences, concerns and resources. The "room" was packed and our Family Council began meeting monthly.

Management graciously forwarded our monthly invites to all families.

They responded to concerns we raised and allowed us to hang a board in the lobby for our Council and contact information.

For part of each meeting we invited professionals from the community to discuss relevant resources and answer our questions.

The value of their expertise that directly affects families in this situation, was immeasurable.

Our Ombudsmen spoke on resident rights and care plans

A scientist on the most up to date research on Alzheimer's

A podiatrist on the importance of good foot care in communal living

An attorney on wills and trusts

A Hospice nurse

An investigator from Adult Protective Services

A Policy analyst from Licensing

Our facility director, nurses, care and kitchen staff

Our meetings offered education, support, community and tools to facilitate advocacy.

We took minutes, wrote bylaws and became "official" in August of 2021.

Our Council's relationship with management worked, until it didn't.

In June of 2023, Judith's mother Virginia died. That September, my mother passed.

At this point, most people typically: say heartfelt goodbyes to wonderful care staff, grieve, then gradually return to whatever in their lives, had been put on hold.

But two weeks after my mom died, a new leadership joined the facility.

They shut down all engagement with our Family Council,

removed our contact information from the lobby,

refused to forward links to our meetings and

informed us they were starting a **management run** support group

and that our Council was no longer needed.

We were pretty devastated that new families, **who don't know what they don't know -** would be denied this rich resource of a Family Council.

Without this right, every new family would have to re-invent the wheel.

This was a pivotal moment for us.

I wrote to the State Long-term care Ombudsman, Fred Steele for advice.

He **called** me back and said,

"I know it's not typical for a civil servant to return calls after 5 o clock.

But in all my time as an Ombudsman, I have never seen such a transparent attempt by a facility, at a hostile takeover of a Family Council, I'm in."

In 1987 President Reagan signed into law the Nursing Home Reform Act.

Part of that act, says that long term care facilities were to provide services so that:

"each resident can attain and maintain their highest practicable, physical, mental and pyscho-social well-being."

Another component of this Act includes:

"the right to organize and participate in a resident OR Family Council."

This Federal legislation was written **38 years ago.**

Since then, there has been an **explosion** in the numbers of long term care facilities being built across the country.

But, in contrast to Nursing Homes - there are no statutory requirements that Memory Care and other RCFs inform families of their right to form Independent Family Councils.

There are 8,293 endorsed memory care beds in locked units for residents suffering with memory related diseases across Oregon.

These family members are some of our most fragile, dependent and vulnerable Oregonians.

Both, **their quality of life** and the **righ**t of their daughters, sons and spouses to participate in Independent Councils, should never again be reliant on the whims of a director or which LLC has bought their facility.

As a daughter, I felt that it was my privilege to try to provide my mother with the best quality of life that I could in that last chapter of her life.

Being involved with Family Council made me feel less helpless and alone in the face of this terrible disease.

No family should have to fight both the grinding toll of this disease **and**

indifference or active resistance by facilities **to Family Councils.**

Since there is no cure, I can only cross my fingers that I don't develop Alzheimer's.

But if I do, I want my daughters to have this life changing resource of an Independent Family Council to help us all through that painful time.

Please pass this bill so that all Oregon families and their loved ones have that opportunity as well.

Thank you.

Jewel Nelson