

Monday March 3 Camera Testimony

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

My name is Jewel Nelson and I am seeking your support of SB 134, which provides the right to have a camera in a loved one's room in a long-term care facility.

In 2019, I moved my mother Eve who was suffering with vascular dementia, into a memory care facility in Springfield.

I had a camera in her room until she died at 95, in September of 2023.

Sometimes what I saw was really hard - but more often it was a blessing.

Because of the camera, I was able to feel closer, more connected to my mom.

My sister who lives thousands of miles away, felt tremendous comfort in being able to look in on her any time of day or night. Sharing these moments with my sister, offered me invaluable support

At the height of the pandemic when I was unable to visit, I didn't have to wonder or guess how she was doing. I could check the camera and see that she was ok, **or**, that she wasn't.

One particularly rough night, I called the caregiver and asked her to play my mom's Sinatra CD. She soon calmed down and I saw her singing along!

Another night, I saw my mom adamantly refusing her meds.

I called the med tech and suggested he give her a Snickers bar from a bag of chocolate which I had stashed in her nightstand.

From then on, he never had a problem getting my mom to take her meds.

One morning before breakfast, a caregiver found my mom crying in her bed. She sat beside her, holding her hands and rubbing her back.

Pretty soon she was brushing mom's hair and they were both laughing - while I was holding back tears.

Yes, I saw plenty of pain, confusion and suffering.

But this gift of a camera also allowed me to bear witness to so many, instances of incredible patience, joy, compassion and kindness from these hard-working, dedicated care staff.

When a family brings their loved one to live in a long-term care facility, they **really don't** know what that care looks like in the middle of the night, or when the facility is under a pandemic shut down, or even when you just don't have time to visit..

Every family deserves the right to know, and a camera is the instrument to offer that. It can assist families, staff and management to work collaboratively, providing the best care possible for our loved ones.

The combination of visits, an Independent Family Council, communications with caregivers and having a camera, enabled me to make my mom's life as comfortable and bearable as I could, even while this disease was stealing her from me.

**Senate Bill 134 provides this right.** It contains excellent guardrails and clear provisions that address concerns of privacy, choice, transparency and dignity.

In 2021 there were 10 states with camera laws on the books. As of today that number has nearly doubled. Another 10 states are currently considering laws and policies regarding cameras.

This nationwide momentum behind cameras, is unmistakable.

Since there is no cure, the best I can do is to cross my fingers and hope that I never develop dementia.

But if I do, because of the unrelenting nature of this disease, I want **my** daughters to have the right to choose a camera so that they can have this incredible gift that helped me, to help my mom.

Please pass SB 134 to improve life for all families with loved ones in Long-Term Care in our State.

Thank you.