Testimony

My name is Janie Carney. I am a resident of Wichita, Kansas. I am testifying on behalf of Senate Bill 456.

My story. I am here, not only with accounts of personal experience, I additionally speak on behalf of those who cannot be here. And my voice is raised for those that have been squelched in silence.

I am Frank's voice. I am here, as he would want me, to help the many voiceless in an attempt to improve care and protect the innocent. Spending as much time as I do within a care facility, I have become that voice of the many. But I am just one person with my own limitations. How do you protect the indefensible? I am here to attempt to illuminate a need and provide a right for people to exercise a simple solution that has benefits for not only the patient but ultimately the very facilities that wish to be providing care as promised.

Our story of personal experience lies within a memory care facility in Wichita Kansas. Beautifully appointed, friendly faces in the front of the building, only revealing truth to the saying 'never judge a book by it's cover.'

Myself, as others that have gone before, are down-trodden and defeated upon admission. It is blindly understood and assumed that these attractive homes and their staff are there to care for our loved ones.

The price is high. $4410. per month plus add-ons. Additional services came with a cost. Additional $350. For level two, $650. for level 3, $950. for level 4 and $1250. for level 5. Although continent, one by one, as expected, services were added to Frank's care plan.

The room itself was an empty room with a bath. As a resident, we are responsible for our own furnishings, television and anything that pertain to upgrade of services from Cox Communications. Those services are paid separately to Cox. In addition to art and furniture, I provided curtains, a dementia friendly shower head and toilet seat as that was not included in this memory care facility. Other than care, all other stipulations are those as if we have a tenant/landlord agreement.

After I signed the agreement, I inquired about camera systems within the building. I myself have sixteen cameras within our home to make sure that Frank was okay since I had been caring for him by myself. This allowed me to do laundry, office work, ironing or anything within close proximity, such as gardening while always keeping an eye on Frank. The answer was "Oh no, we don't allow or do we have any cameras. For everyone's privacy, we don't allow any camera or video systems.

This is a memory care. The commitment made to protect these individuals is, at a very minimum, to do welfare checks in their rooms. Some are told that they do this hourly, some are told every two hours through the night. They are there to redirect. They are there to protect. Yet we have no proof of their actions.

Even though the staff had increased the promises, because of my physical presence, they knew I had figured out that these services that they wished to charge for were not being provided. Promises and care plan instructions were to toilet Frank hourly as he was suffering from an undiagnosed prostrate blockage. Yes, we too, were paying for service not rendered. Soon, we were evicted.

I was fortunate to be able to be with Frank many hours a day. Others are not. Yet their worry and concern is the same. They have families to care for. They have employment to help sustain the exorbitant cost of twenty-four seven care. But even I wished I was allowed the right to monitor his room with a video device. When I would walk into Frank's room in the morning and see how it had been methodically disassembled throughout the night, sometimes with things broken, my mind could only imagine how long he had been left all alone, in a state of frightful confusion.

The management urges consent at admission for blanket permission for residents photos to be use in advertising. This permission is solely for the benefit of the facility. Contradictory to the transparency they want to portray, you will find in the front lobby, a well placed, brashly displayed sign that states "In keeping with our promise to support and protect the privacy and dignity of those we serve: (then in bold large print) "It is company policy to prohibit the unauthorized use of photography or videography devices on these premises." They do these things while ringing their bells of patient discretion. How quickly did it become apparent that the privacy they wish to protect is to the singular advantage of their own personal interest.

Without the right to have videography in these facilities denies us the very right to question the type or timing of the care provided. It also prevents us from having the proof that our loved ones are exhibiting behaviors such as paranoia or anxiety that could be dealt with if observed. We reference abuse as physical, but indeed, the mental abuse of the voiceless is heart rendering. Un monitored isolation for hours at a time without welfare checks is nothing less than abandonment.

Over ninety percent of all individuals with dementia experience some type of psychosis, causing behaviors exhibiting sadness, depression, paranoia, anxiety, anger, grief and other conditions too numerous to list. They are voiceless. Oh, the many times I had wished I just knew what Frank was doing in the night. That knowledge would have helped create a teamwork relationship, providing the best care possible.

Others, who were not able to represent themselves today, have had horrific experiences. One especially of which was not available to be here today to tell of the experience of her father-in-law. A stroke victim with serious short-term memory loss, incontinent and confined to a wheel-chair. The family, whom almost daily visit him, was told that he was attended to hourly at minimum. Yet, many incidences would find him sitting in his own urine and feces upon their arrival. Yes, there are the continual verbal guarantees of services rendered, but under no condition is videography allowed in order to prove the performance.

One night, alone for an undocumented amount of time, Joe fell. Found later, in a pool of blood after hitting his head, ambulance and family were called. His daughter-in-law arrived in a flash. She told me by demonstrating with her hands the magnitude of the size of pooled blood. Her motions indicated a circumference of about three feet. I asked if any of it was dry by the time she arrived, as this had been described in another incidence within the facility. “Yes, I believe so,” she replied and continued. “I have such doubts about how long he had laid there. They are supposed to check on them, but I don’t think that they are.” I had to agree.

Other incidents happened around us that were similar. This just happened to be the only one I had reached out to with short notice, particularly, since Joe, amazingly is still alive. Others have passed.

Under the Kansas Resident Rights Act each resident is afforded the right to a dignified existence. If they are voiceless, the legal representative has the right to full disclosure. Yet when the doors are closed and the representative is no longer on the premises, some of these adult care homes are allowed to conduct themselves as they choose, within the secrecy of the walls.

We need to be able to facilitate all possibilities of this technology age to better care for these individuals. To let the management of these facilities continue to be allowed to restrict our access to these tools only encourages the ongoing mystery of the very services we, the customers, are paying for. Without this additional legislation, we are saying, “Go ahead and operate in the secrecy of darkness.”

Thank you for allowing me to come before you and listen to my opinions.