

House Children and Seniors Committee Testimony 2-14-17

Good Morning Chairman Alford and members of the Children and Seniors Committee,

My name is Janie Carney. I am a resident of Wichita, Kansas and I am testifying on behalf of EM Bill – HB2232

I am here representing some of those that are rendered silent by maladies such as Alzheimer's and the world of dementias. One such person, my husband Frank Carney, has spent the majority of his life optimizing the opportunities of success for others and nurturing his fellow man. Sadly, he is now a small part of the muted voices unable to protect others, let alone themselves. I am here doing exactly what he would expect me to do and speak with the intention of helping others.

Our story is just a sampling of the thousands that experience similar situations. We are in year eight of this journey and in our third year of having to entrust care to a source outside of the home. The choice is not easy, but often a necessary one as Frank's brothers and sisters became increasingly concerned that I was to become part of the 62% of caretakers that predecease the victims of Alzheimer's.

For a year and a half, Frank was a resident of a memory care in Wichita Kansas. Beautifully appointed complete with friendly faces, the immediate impression of the facility represents attention to detail and the aura of a country club like atmosphere. I viewed them as obviously successful as this home was owned by a company that had many just like it across the state of Kansas. But, like my grandmother said "Never judge a book by its cover."

Myself, as others that have gone before and are sure to come, are down-trodden and defeated upon admission. We are drawn to a circumstance that we have never dreamed of. In fatigue with our self-imposed sense of failure, we acquiesce to accepting the duty of primary care of our loved ones to another.

I should have heeded my instincts that rang "caveat emptor – or let the buyer beware" at the time I was signing admission papers. I was asked to please sign the permission for the facility to use photos for marketing and promotion, but when I asked about the monitoring system they used for the protection of residents – Oh, no, due to privacy laws, we do not allow anyone including us to use any form of photography or videography." Throughout the building signs stating this language are on display.

In time, I would come to realize those protections were for the ownership and not for the residents. Quickly it became apparent that the privacy they wish to protect is the singular advantage of their own personal interest.

We have all heard and watched some of the accounts of actual physical abuse discovered by cameras placed both with and without permission. When a felony is committed, of course, it takes precedence in any given situation. Regretfully, the most prevalent exploitation of the elderly lies in guise of mental abuse and neglect. Mistreatment of this sort leaves the disenfranchised in a state of fear and abandonment.

I was fortunate to be able to be with Frank for many hours a day. Others are not. Yet their worry and concern is the same. They have families to care for and commitments of employment to sustain the exorbitant cost of twenty-four seven care.

In the particular memory care that Frank resided, doors to the resident rooms lock upon closing so that others will not wander in. That makes sense. Doors do not lock from the inside so Residents are able to exit, but that only works if they know how to operate a door handle, as most do not. Staff are in possession of pass keys to access the room for the wellness and assistance checks that are a part of the contractual care plan. These checks are supposed to occur at a minimum every two hours. As time goes on, fees are increased substantially with promises of additional care.

Frank was suffering from an undiagnosed prostate blockage and it had been arranged to check him hourly for toileting assistance – for a price to which I agreed. Doubts began to grow. On many occasions I would walk into Frank's room in the morning, only to see how it had been methodically disassembled through the night. Sometimes I would find items such as lamps broken and window shades torn down. Pictures taken from the walls and hidden in drawers and bed linens stripped from the bed tucked into a corner. So carefully taken apart, one would know that it took hours to be undone. Heartbroken each time, my mind could only imagine how long he had been left unattended in a state of frightful confusion. Oh, how I wish I could have had a camera in there to verify what I suspected.

Others, who are not able to be here to represent themselves today, have had horrific experiences. One especially wishes to tell the story of her father-in-law. Joe, a stroke victim confined to a wheelchair and incontinent, was assured that he was attended to on an hourly basis. Yet, so many times when they arrived for their daily visit, he was found to be sitting in his own urine and feces without any acknowledgement from the staff. Management continued to reassure them that he was getting the care as promised. But then the inevitable occurred. One night, alone for an undocumented amount of time, Joe fell. He was found in a pool of blood about three feet in circumference. The ambulance was called and the daughter-in-law had arrived in a flash. I asked her if the blood appeared to be dry. "Why yes, I believe so", I shook my head as she continued. "I have such doubts about how long he really laid there. They promised that they check him hourly, but I don't think that they are." Luckily he survived.

You see, I knew to ask about the blood because of another incident in which a former employee arrived for her shift at 7:00 a.m. to find a woman resident on the floor of her bathroom. She survived, but the dried blood on the sink and the floor were an indication to this employee that she had not been checked for many hours. When she brought her concerns to the management, her hours were cut severely forcing her to accept employment elsewhere. This was a good and caring employee, but it became obvious that the main character asset sought after, was the ability to keep secrets about insufficient patient care.

The majority of us, respect the protocol of facilities and do not place electronic monitoring devices in rooms, even when care is questioned. We are law-abiding citizens of the state of Kansas and unfortunately we are part of only a very small handful of states that do not have the right to do so.

Frank was receiving an experimental treatment from John Hopkins Rockefeller Blanchette Neuroscience Department. My request for electronic monitoring for observation was denied. Red flags, too numerous to count, began to fly and my physical presence within the facility was revealing that I knew that they were not following contractual obligations, not only for us, but for others. I began to feel that there was a private protocol of the management, ownership and staff, that went something like this "Out of Sight, Out of Mind." I made an off the cuff remark that maybe I should go ahead and hide a camera in Frank's room. Shortly thereafter, on the first of May 2015, we were evicted.

Without the benefit of electronic monitoring, we fall not into a crevice, but a ravine of the unprotected consumer where the burden of proof is unaccountable by the voiceless. The evidence of services rendered is entirely substantiated by the so-called provider. It is their word only versus our inconsequential suspicions. These so called suppliers of health care prefer to keep things as they are because without proof, there are no consequences. And with that, they are still allowed to find a place of trust under the umbrella considered as 'care'.

Fortunately, Frank and I are now in a whole new world. We a part of a care facility that actually uses electronic monitoring throughout all common areas of the facility. Individual monitoring is not discouraged. I visited with the director about his open use of cameras. "It's absolutely great. It actually protects us in many ways. If there is ever a fall or an incident, I want to know why." He went on to explain that there is no way supervisors can be with employees constantly, but with the use of cameras it enables them to better identify potential negative behaviors that need retraining or on rare occasions, termination. The greater benefit is that we can recognize the hard working and caring employees. You know, the ones who don't walk by residents without acknowledging them. In this place there is very little turnover. Employees are happier and residents are more satisfied.

Under the Kansas Resident Rights Act, each resident is afforded the right to a dignified existence. Dementias and Alzheimer's Disease render them voiceless, therefore their 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 the players in the adult care home industry, seek to take advantage of the protection we are without, and operate as they choose within the secrecy of their walls.

We live in a world of monitoring. Our schools, our street corners, day cares, stores and eating establishments and even doggy day cares choose to accurately depict the truth with surveillance. Our law enforcement elect the use of body cams for not only their protection, but the necessity to defend the innocent. All this, and still, the most vulnerable of us all have been denied the very right to this shield of safety under our current state statutes.

When attempts have been made to change the law, attachments to legislation have previously halted our ability to pass such rights, rendering us one of the last states in the country to do so. I am here to urge you that it is finally time to stand up for those that have no voice. It is time for you to act on behalf of those, that in the past, have protected and nurtured you and your loved ones. As you contemplate your actions, remember, look around today – one in eight of us will suffer some sort of dementia in our lifetime. Love thy neighbor as thyself. Where do you stand?