

United States Senate Special Committee on Aging
Assisted Living Facilities: Understanding Long-Term Care Options for Older Adults
January 25, 2024
Testimony of Patricia (Patty) Vessenmeyer
Gainesville, VA

Good morning, Chairman Casey, Ranking Member Braun, and members of the Senate Special Committee on Aging. My name is Patricia (Patty) Vessenmeyer. Thank you for allowing me to share this testimony of my experience with assisted living for my husband, John Whitney, during his journey through middle-stage dementia. I will focus on my experiences and observations that I believe are most relevant to your national focus.

In 2013, my husband was diagnosed with Dementia with Lewy Body. Although this dementia is like Alzheimer's, it manifests itself a bit differently and it is important that caregivers be informed and trained appropriately to ensure the comfort, safety, and security of their patients. Some key symptoms are loss of sense of smell; REM sleep behavior disorder (RBD) which causes individuals to violently act out dreams, often falling out of bed, visual hallucinations, marked fluctuations in attention and alertness; and gastrointestinal issues including severe constipation, all of which my husband experienced. Loss of memory occurs much later in the disease process.

I took several free courses on caregiving for individuals with dementia, including a "virtual reality dementia experience" which helped me to understand the challenges that people with this disorder face, and most importantly, why they become so fearful and combative. I mention this to provide a basis for my ability to recognize problems with care. These same courses are offered for professionals at a reasonable cost.

In June of 2017, when John's disease was progressing more rapidly, I moved to Virginia to be near family. I cared for him at home until January 26, 2018, when he attempted to strangle me in my bed. The State determined that John should be placed in a long-term care facility. I found him a room in an assisted living facility in Warrenton, VA that specialized in memory care. He moved in the first week of March 2018. I provided the management team with John's history, his diagnosis, and disease progression.

The following is a list of issues I observed in the memory care unit during my daily visits with John.

Poor facility design. There were blocks of rooms built around a large central room for group activities and TV. The central room was extremely loud and high levels of noise can easily

agitate dementia patients. Activity stations were set up for residents. One of these had various lengths of PVC pipe (not kidding), some longer than a baseball bat. These are weapons in waiting and you can guess what happened. There was no quiet area for the residents other than their rooms. The hallways in the room blocks were isolated, making it difficult for staff to monitor. There were many incidents that I witnessed when there was no staff around. I will share the one I feel is the most significant. A woman fell by tripping on a raised area where the rug abutted hard flooring and nobody saw her fall. I found her bloody and staggering down the hall. A company knowledgeable about dementia would not design a facility this way. They would certainly understand that people with dementia have problems with gait and balance. There were video cameras in place, but these were used to review incidents after-the-fact.

Understaffed. Too many patients were assigned to each caregiver. In the mornings, each caregiver needed to get their assigned residents up and dressed for breakfast. Everyone ate at the same time, putting more pressure on the staff. They only gave residents a shower when necessary, as they were always pressed for time. Caregivers needed extra time to spend on residents in more advanced stages of dementia, as they required help to move from their bed to a wheelchair, be hand fed, etc.

After lunch, the caregivers would place most of the residents in chairs in the main room while they worked getting the advanced-stage patients back into their beds. Every day after lunch, my husband urgently needed to empty his bowels. Several times while I was there, I tried to find help as it was difficult for me to help him alone, since I had a fractured arm at the time. I could not find anyone, so I did the best I could. When I was not there, he often soiled himself while waiting for help.

I once saved a man's life. I was with my husband in a room off the main activity area. I heard someone crying for help. I ran into the hallway and found the old man on the floor, trying to prevent himself from being beaten with his own cane by another resident. I called for help and quickly moved closer and redirected the attacker's attention. I kept him busy while calmly calling for assistance, trying not to further agitate him. It took several minutes before a staff member finally heard me and came to help.

Night was no better, as staff levels were even lower, as allowed by state regulations. They placed residents who had trouble sleeping in front of the TV while they dealt with other residents.

Inadequate staff training – Most of their caregiver staff were trained as nurse aides, but nothing specific to memory care that I could see. I witnessed them providing some new hires dementia care training in a conference room. This consisted of a member of the management team showing them parts of Glenn Cambell's "I'll be Me" movie and pointing out behaviors that demonstrated his dementia problems. I saw the movie and it was not appropriate for training purposes. I observed several instances where caregivers and nurses displayed limited knowledge

of working with dementia patients, particularly those in mid-stage of the disease who become more fearful and combative. Examples:

- * Nurse running toward resident, causing resident to become combative

- * Quick, erratic hand movements, frightening individual

- * TV on at 9:30 PM, with extremely high volume. Several residents were seated in chairs and wheelchairs in front of the TV. Anyone who understands dementia and “sundowning” would never do this. They were over-stimulating their residents instead of allowing them to relax and quiet their minds for sleep.

At one point, the Director of the facility told me to spend less time there and let them do their jobs. I could not abide, because they weren't doing their jobs.

In closing, unless things change, I would never recommend using this type of facility for a loved one. I am hopeful that you found my testimony helpful and that the committee will find a way to set national standards for appropriate levels of staffing and training for that staff. This would be a huge step in improving assisted living.

Thank you for your time.