

February 28, 2023

Good afternoon,

My name is Nancy Jorgenson, and I am here to speak on my support for HF 979 and SF 1022. My husband, James Jorgenson and I lived in Fridley, Minnesota where we raised our family for 43 years. James was diagnosed with Parkinson's Disease in 2004. He worked at Onan, Cummins Power Generation, as a Purchasing Manager. In 2009, Jim had to take disability retirement due his Parkinson Disease. We continued to live in our home until November of 2019. I was his caregiver.

We moved into Orono Woods, a Senior Independent Community, to be closer to our daughter, Sarah Magnuson and her family. Orono Woods, a three-story building, provided us a one-level apartment with an elevator, community room, activities, exercise room and underground garage. During the COVID-19 period Orono Woods did not raise our rent but instead added a per occupant water and sewer fee to our rent. We also paid electric, cable television, indoor parking and home telephone service.

During the 18 months we lived at Orono Woods, my husband had two spinal surgeries for spinal stenosis. After his last surgery he needed to wear compression stockings to keep the swelling down in his legs. We were able to get him physical therapy, occupational therapy and speech therapy for a short period of time. Jim was unable to walk more than a short distance and started using a Golden Jazzy Scooter. The older apartment complex was not built for use of motorized assisted living devices. He had a very difficult time maneuvering in the apartment and using the small elevator. This resulted in some damage to sheetrock and trim.

I had tried to hire a personal care attendant to assist Jim with his activities and exercises. Unfortunately, none were available in the area. I started doing research into independent and assisted living facilities closer to our daughter. We were interested in a community that could provide ongoing care for Jim as his disease progressed. Independent living first, assisted living and finally memory care. We also wanted a dining room and exercise area.

Newer facilities were being built all over the Twin Cities and suburbs. I was in contact with The Struthers Parkinson's Center, A Place for Mom, AARP, Minnesota Ombudsman, and many other agencies that provided information on Senior Housing. I visited several of the facilities recommended. James and I needed a two bedroom, two bath handicapped apartment. These were hard to come by unless the community was new. We also wanted a community that had a good understanding of Parkinson's Disease and its progression. We were looking for a home for us until our death.

At my visit to Havenwood of Buffalo, also a Struthers Parkinson Center, I was told that a new community was being built in Maple Grove. I contacted the Marketing Department, and we made an appointment to visit their location with Elizabeth Meyer. We were so impressed that we put down a deposit and selected an apartment on the first floor. This apartment had almost direct access to the backyard, pond, gazebo and walking paths. Havenwood of Maple Grove, managed by Walker Methodist, opened on April 13 of 2021. We moved in on April 15 as independent residents. Since our move in we have had one other management company, Grace Management. A third management company will begin on April 1, 2023.

Moving into a new community was a challenge. Staff needed to be hired and trained and work was still being done on the yard. We had new neighbors to meet almost every day. Staff knew our names right from the start and helped us in anyway they could. The dinning room where we had our evening meal was excellent. Jim liked the exercise room and trainer. Membership was provided by our insurance company's Silver Sneaker Program.

During our move I had twisted my left knee and found that I required knee replacement surgery. After my visit to the surgeon's office, I contacted Havenwood Director of Nursing, Carol Shields. I wanted to see if James could be in assisted living care, from our apartment, during my recovery. Unfortunately, she was

unable to accommodate us. She did a Resident Agreement Assisted Living with Dementia Care assessment on August 1, 2021. My surgery was on August 4, 2021.

They were having trouble hiring and training staff as Residential Aides RA's. Instead, my daughter's took turns staying with me until I could walk on my own. I did physical therapy at home until I was able to drive a car. Jim was finally admitted to assisted living care with dementia on August 27, 2021. Then I went to the Northwest Orthopedics Building in Maple Grove for physical therapy.

My surgery and recovery time was difficult for James, we noticed his cognitive decline and balance issues. We then moved more towards assisted living for him. His Parkinson's Disease affected his balance, speech, swallowing and memory. He was having more bladder difficulty as well. We were able to attain assisted living for him in the morning with waking, bathroom assistance, dressing and breakfast. I would put out his medications, cereal, fruit and utensils. The Residential Aides RA's would help to get him started in the morning. They bathed him once a week and got him ready for bed at night.

In November 2021 James developed aspiration pneumonia shortly after eating his dinner. He was transported by ambulance to North Memorial Hospital. He was kept overnight, giving antibiotics and steroids to reduce the swelling in his throat and lungs. His heart and legs were enlarged and was put on a diuretic. Jim had a difficult time in the hospital, he was confused and wanted to go home. We followed up with his Pulmonologist, Dr. J Hovda and General Practitioner Dr. Patel. Again, we found more cognitive changes in his behavior. Soon after we had to park his scooter and use a wheelchair for mobility. He was placed on thickened liquids and a mechanical soft diet to try and prevent further aspiration. With each episode of aspiration pneumonia James had difficulty with balance and started falling several times a week. He didn't understand that he couldn't walk and was determined to try. His Neurologist Dr. E Oreck saw Jim and made some corrections to his Deep Brain Stimulation Treatment (DBS). We had a slight reduction in falls with the DBS changes.

A week later another episode of aspirational pneumonia. This time they kept him in the Emergency Room until he could be transported to North Memorial Hospital in Robbinsdale, some 12 hours later. Following Jim's discharged he was sent to the Good Samaritan Specialty Care Community Robbinsdale for 10 days to regain his strength with physical therapy, occupational therapy and speech therapy.

Later in November James didn't seem to be getting better even with medications, nebulizer treatments. This time I took him to Health West. His legs were very swollen and red, breathing raspy. They conducted tests, x-rays, and CT and determined he still had pneumonia. He was transported by ambulance to Abbott Northwestern Hospital in Minneapolis. James spent a week there and was discharged to Marathana Care Center in Brooklyn Center. Prior to his discharge Director of Nursing, Carol Shields did an assessment of Jim at the Marathana Care Center to see if he could return home after discharge. Our daughter Beth and I met with her and Jim for this assessment. We spoke to Carol about placing James in the Memory Care Unit in January.

The family decided to keep him in our apartment until after the holidays. I contacted the Director of Nursing, Carol Shields and started making arrangement for James to be placed in Memory Care here at Havenwood. James and I met with Trevor Tohey and signed a resident agreement in late December. We were told that Jim could be moved in on January 5, 2022.

We saw Dr. Honda's Physician Assistant. Tests were taking to see how Jim's was breathing and a short test of his walking ability and balance. At this time, we were told that his condition would not get any better. They recommended putting him on a preventative treatment of steroids to keep the swelling down. It was also suggested that he be put in hospice or palliative care. His General Practitioner Dr. Patel agreed with the assessment. At the request of Director of Nursing, Carol Shields we place James in Hospice care on February 28, 2022.

Unfortunately, the Director of Nursing did not complete the necessary paperwork and give it to the Director of Financial Services. So, the move in couldn't be completed until January 17, 2022. We were told that this was delayed due to Residential Aide shortages in the building. I had asked about the staffing ratio of RA's to patients in Memory Care and was told 3 RA's in the morning shift, 2 RA's in the afternoon shift and one overnight RA.

We found that after James transferred into the memory care unit his Parkinson's medications were seldom delivered on time. Even though his Physicians stressed the importance of on-time delivery in order to keep a steady stream of Carbidopa-Levodopa in his system. When asked about the late or early delivery of his medications we were told that they had a period of one hour to deliver medications. They were unaware of the problem this caused James. More cognitive changes and falls were reported. On at least three occasions James ran out of medications because no one was auditing the medication carts. I received phone calls from Dr Patel asking me to have the Director of Nursing, Carol Shields to stop calling him for refills after hospice care started. The hospice nurses were here every week and after every fall. They could not understand why Havenwood wouldn't contact them for medications. On three separate occasions I was asked to provide 1 on 1 care for James or move him to a nursing home. Our hospice team and I met with Havenwood Nursing staff the Wednesday before James died. They had told hospice they could no longer care for James. We were told that James could live out his natural life here when we moved in. I refused to remove him. James died on Sunday, October 16, 2022.

In August of 2021 Havenwood started charging a fee of \$200 per fall. If multiple falls occurred in 48 hours they were one fee collected. It was not unusual to have \$600 to \$1,000 of fall charges each month. I had requested fall reports and calls to me with each fall. I seldom received a call for a fall and never received a fall report. It just showed up on my monthly charges. From the time James started assisted living care with dementia the costs went from \$2,000 in our apartment to \$5,800 a month in Memory care. We also had a fee for his apartment of \$3,100 to start in January 2022 to \$4,057 effective November 1, 2022. This cost did not include his prescription drug costs nor the Collaboration of Care for his Hospice services.

I would also encourage you to remove the Minnesota State Income Tax on Senior Citizen's. For many of us the cost of keeping loved ones safe is eating up our personal savings, social security benefits, pensions and/or IRA's. The Stock Market and economy has not been kind to us as well.

There needs to be some Statewide Financial Oversight into the way rents are raised and the financial management of these assisted living facilities. They are bleeding us dry and will eventually cost the state of Minnesota through Medicaid services.

There needs to be staffing ratios and adequate training for the RA's. When asked about the training requirements we are told they received 48 hours of training and follow a seasoned RA for a week. Also, many RA's have worked in previous senior communities and bring their training with them.

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