

Testimony for HB120-Compassionate Caregiver's Act

By Bonnie Arnold

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Nine years ago it became apparent that my husband Jim was suffering from the dreaded disease of dementia. We learned all we could about the disease and used many alternative therapies to keep the disease livable. Two years ago the dementia went full blown with a bout of kidney infection that Jim never recovered from. It was decided that the local nursing facility was the best place to keep him safe, comfortable and close for me to visit him. (I am within five minutes of the facility.)

I visited Jim every day at the nursing home and as he continued to decline, I was there early for breakfast and mid afternoon through evening for dinner. Although the staffing there met the state regulations, I was told, there was always something I could do to make Jim's life more comfortable. I would go to the nursing home every morning for breakfast and feed Jim. In the afternoon I would arrive early for dinner and stay 3-4 hours making sure he got enough to eat and drink. Since Jim was not the normal dementia patient, I never knew what I would find when I arrived at the nursing home. He may be working on the floor, walking into walls or sleeping. Various drugs were used to calm his restlessness but nothing seemed to help. It became apparent that Jim's condition did not meet the normal (whatever that might be) dementia patient.

On the afternoon of March 11, 2020, I was met at the door by the nursing home administrator. She told me that the nursing home was now closed to visitors because of the virus. We chatted and I asked her to pursue an exemption for me as Jim needed me to feed him and look after him. She did pursue my request and called me later that night. There were No exemptions. Day after day I would go to the window of the nursing home and look in the window at Jim. Some times our children and grandchildren would accompany me. Jim was just beginning to become immobile the week I was refused entry to the nursing home. Jim finally ended up in a tilt and space wheelchair. The chair's sharp parts tore at his legs. Because of Jim's continued restlessness, he had rips and tears plus blood visible through the leggings used for padded protection. Some days when I went to the window, he was still in bed thus I missed checking on his condition and wellbeing. His bedroom was on the backside of the nursing home behind a fence thus I was never able to look in his bedroom window. I had to depend on the dining room window for my visits.

On April 5, 2020, I was called to the nursing home. Jim was unresponsive. I was allowed to stay with him for 24 hours before I was herded out the door. I swabbed Jim's mouth with liquid every few minutes and he got better. At that time I discussed his meds and his condition with the doctor. All meds for his dementia were discontinued. It was apparent he

was not getting enough to drink and his bottom was badly irritated from improper changing. After dialogue with the nurse on duty, she assured me that this would never happen again.

So as time continued past the two week curve to stop the spread of the virus, I continued the window visits every day. The virus then breaks out in the nursing home in September 2020 in spite of the isolation and safety precautions administered. On Tuesday, October 6, 2020, the nurse told me at the dining room window that window visits were no longer permitted?! I would sometimes go to the window anyway to catch a glimpse of Jim in the dining area. He was never brought to the window. I was better able to know how Jim was doing if I could see him through the window. Yes, I made numerous phone calls to the floor personnel at the nursing home. Sometimes the phone would ring and ring and I could not reach anyone. The staff was simply understaffed to handle all the needs of the patients and families. Jim was unable to communicate and although face time was used by the staff a few times, it was not a satisfying experience for us. I did schedule an outside visit before the September outbreak. The visit proved confusing for Jim as he did not recognize me and was several feet away. I continued the daily window visits thereafter until that was deemed a risk!?

I could see over this period of time that Jim was losing weight. In April he weighted 161 pounds. Because of the virus, the weighing of the patients ceased because the residents had to be taken to another area of the nursing facility. Jim was skin and bones when my daughter and I saw him the last time before his passing in the nursing home on November 17, 2020. The funeral director was shocked at his emancipated condition...skin and bones.

During the course of this eight month period that I was locked out, Jim's dementia meds were restarted as he became more restless. I had a hands on approach to Jim's care and once I was restricted, Jim had no one to advocate for him. I called many times to the Ombudsman for Long Term Care plus the governor's liaison. They too were blocked from entry of the nursing home and could only give me feckless lip service.

I have no doubt that Jim's life was shortened plus horrifying in the end days because of the restrictions put in place by the governor and/or health officials and others. There is **NO ONE** that cares more about their loved one than their family. I put Jim in a facility within 5 minutes of my home so I could visit him regularly and keep an eye on his care. I would encourage Jim to eat and make sure he had enough to drink. I always supplied fruit and other foods from home for him. Sometimes I would take extra treats for the other residents. I would shave Jim, rub his body with lotion and soak his feet. I tried to make him comfortable and love him as we should do for our elderly loved ones that are sick.

I was called to the facility on November 17, 2020, to visit Jim before his passing. I was thankful for that last visit. Speret Hall at Summit Acres Nursing Home resembled a morgue that night. No one but the caregivers and nurse were in the sunny dining area where the residents spent their time together in normal times. The hallway that contained the 20 plus rooms was a sea of darkness with closed doors and zippered tarp over the door openings. The patients were isolated in there rooms. It was apparent that the required staffing for normal patient care would need to be increased to care for patients locked in their rooms.

So after 8 months of keeping loved ones from visiting the nursing home residents, some 13 plus residents died of the virus on Speret Hall where my beloved Jim resided. 8 months of isolation agony that continues for the remaining residents today. Yes today, March 9, 2021, the nursing home is in lockdown still because of a positive virus test of a worker or resident. This is the most inhumane treatment of the elderly I have ever witnessed. History will hopefully define it as it is....genocide of our elderly! I will never know the loneliness and suffering my Jim experienced. 252 days I could not touch or hug my husband and now he is gone. What would a dementia patient like Jim... when 5 minutes of sanity overtook him, think of the horror he must have witnessed in that environment!?

I support HB120, Compassionate Caregiver's Act. Family caregivers are an essential must for nursing home patients....**no one** and I mean **no one** cares more about their loved ones than their willing family members. This is not meant to take away or demean some of the wonderful caregivers that work in the nursing homes. These lovely people are underpaid, overworked and can only do as they are instructed by their employer. Loving family members can enhance the lives of their loved ones in a facility and thus support the structure in place to care for these residents despite the rules of the nursing facility. The Compassionate Caregivers Act must be top priority and passed as an emergency.