

Testimony for HB770-Essential Caregiver's Act
By Bonnie Arnold

Some nine years ago it became apparent that my husband was suffering from 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. It was decided that the local nursing facility was the best place to keep him safe and comfortable.

I visited him every day at the nursing home. 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. 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.

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. No exemptions. Day after day I would go to the window of the nursing home and look in at Jim. We was just beginning to become immobile the week I was shut out. He was now in a tilt and space wheelchair. Some days when I went to the window, he was still in bed.

On April 5, 2020, I was called to the nursing home. Jim was unresponsive I was allowed to stay with him for 24 hours. I swabbed his mouth with liquid and he seemed better. At that time I discussed his meds and his condition with the doctor. All meds for his dementia were ceased. It was apparent he was not getting enough to drink and his bottom was badly irritated. After dialogue with the nurse on duty, she assured me that this would never happen again.

So I continue the window visits every day until the virus breaks into the nursing home in September 2020. Loved ones are told that window visits were no longer permitted?! I would sometimes go to the window anyway to catch a glimpse of Jim. I was better able to know how Jim was doing if I could see him. Yes. I made numerous phone calls to the floor. Jim was unable to communicate and although facetime was used a few times, it was not a satisfying experience for us. The one outside visit with a mask did not work for us either.

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

During the course of this eight month period Jim's dementia meds were restarted as he was so restless. I had a hands on approach to Jim's care and once I was locked out, he had no one to advocate for him. I called many times to the Ombudsman for Long Term Care. They too were locked out and could only give me lip service.

I have no doubt that Jim's life was shortened because of the restrictions put in place by the governor and/or health officials. There is no one that cares more about their loved one than their loved one. 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. I would shave him and rub his body with lotion. I tried to make him comfortable and love him as we should do for our elderly that are sick.

When I was called to the facility on November 17, 2020, to visit Jim for the last time, Speret Hall seemed like a morgue. No one but the caregivers and nurse were in the sunny dining area where the residents spent their time together. The hallway that contained the 20 plus rooms was a sea of closed doors with zippered tarp over the doors. 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. 8 months of isolation agony that continues for the remaining residents today. This is the most inhumane treatment of the elderly I have ever witnessed. 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.

I support HB770, Essential 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 family. This is not meant to take away or demean the wonderful caregivers that work in the nursing homes. These lovely people are underpaid, overworked and can only do so much for our loved ones.