

Losing a family member during the pandemic

My 73 yr old sister, Kathy Moll of Fremont, passed on May 30th with what was believed to be the virus. Nine years ago she displayed unusual health problems. After a number of doctor visits and a trip to Mayo Clinic she received the diagnosis. Corticobasal degeneration, a rare and fatal neurological disease. Round the clock caregivers enabled her staying in her own home until it was no longer possible. She entered Nye Legacy nursing home in Fremont, Nebraska, where she has been for over 4 years. Her health slowly deteriorated resulting in loss of movement and speech.

Two days before Nye Legacy closed their doors for protection against the virus Kathy had a nurse call and ask me to come to her room. I was there often so I knew something immediate was troubling her. I went. She said she wasn't afraid of dying but was afraid to die alone. She asked if I'd promise to hold her hand when she died. Of course, I agreed. The doors closed and all residents went into isolation since early March. She spent 3 months with only visits through a window and a speaker phone.

The call came on Wed morning, May 27th. A nurse reported she was having unusual throat problems and they reported they would be watching her closely. Mid afternoon another call. This one to report that a caregiver in her ward had tested positive for the virus. That same evening another call. This one saying she had a high fever and was unresponsive. They felt she was going. I rushed there and was greeted at a back door where I was temperature tested and gowned in full PPE. I was instructed not to leave her room. After several hours I was asked to leave due to regulations. I asked if she could be tested for the virus as results would help other residents and staff. A doctor said she was too ill to move to the only facility that could do that, the emergency room. I learned it takes special training to do the test. I was told I would know if she had the virus when the results came back from a mass testing by the National Guard of all staff and residents. Should there be other cases it would be probable she did have the virus. The testing was scheduled for Tues, 3 days too late for Kathy.

The nurses knew me from years of tending to my sister. I told them of my promise to my sister. I said I'd be back early in the morning. Upon returning I went through the process again in full PPE and headed for her room. I spent about 16 hrs at her bedside. My respect for the amazing caregivers rose. I was miserable. The nosepiece on my mask was painful and sweat poured in droplets down my fogged over face shield. The gown was so hot I felt sick. Our amazing doctors and nurses are working in this for hours each day. I talked, read and sang to Kathy through both masks in muffled words. The nurses were very kind. I listened to their fears of getting the virus themselves or taking it home to their families. A nurse on her break came in and asked if I'd like her to pray with me. I'll never forget.

Through the process of going in and out of the facility I observed how they had set up stations to protect everyone. Each staff member had their own paper bag hung on hooks to hold the reused face shields. A lot of thinking has gone into how to keep everyone safe. Others that deserve recognition are the cooks and maintenance people. It became more apparent to me how much work has been put into dealing with so many unknowns.

While sitting at Kathy's bedside I thought of the many other families that were experiencing the same thing. Families unable to hug or sit near each other due to fear of exposure while an isolated family member passed. I can think of little worse.

I was exhausted and went home for a few hours sleep with instructions to call with any changes. I unclothed in my garage and went to the shower without touching anything. Nurses were kind to instruct me on what I needed to do for protection.

The next morning I headed back but was told due to regulations I was limited to only 30 minutes with her. I was very unhappy and couldn't understand what the difference would be of how long I was there if in PPE and staying in her room. However, regulations were carried out and I was sternly told I would have to leave. I blame no one, I realize why but doing so wasn't easy. Thank you to the staff for caring about my sister and me. For 30 minutes I held Kathy's hand, sang to her, played her favorite piano music and stomped out of the building crying so hard I couldn't see. A call came at 4:30 a.m. that she wouldn't be with us much longer.

Its hard to describe the hurt and anger I was feeling to be denied being with her as she lay there dying, alone. The only thing I could think to do is drive to the parking lot. I could see her window in the distance. I called a nurse and told her I was there waiting. She was so kind and turned on a light in the window for me to see. She told Kathy I was there and held the phone to her ear for a few last words. I sat in the parking lot for 7 hrs staring at that light so hurt I have no words to describe it. At least I had that light. Somehow I thought she would know I was there with her even though I was in my car 1/2 block away. A dear friend brought me breakfast, cried and prayed with me for awhile. The call came, she was gone. I felt forced abandonment with my promise to her broken. That's all I could give her and that's all she got.

I was later told due to other residents at the home and Kathy's symptoms that it is fairly certain she had the virus. This virus isn't only a physical health issue. Its brought loneliness and fear to many. I cant think of anything good to say about this virus but in my sister's case it took her out of the prison that her body had become and the room that kept her quarantined.

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