

Senators, K. Roers, Mathern, Patten, and Representatives Keiser, Rohr, and Westlind, thank you for introducing Senate Bill 2145. Thank you for letting me share my story.

On a cold March day, it would be the last time I would sit with my mom during her noon meal, encouraging her to eat, and sharing family stories and laughs. Providing this companionship and joy for her was all she had. I did not know it would be the last time to help her brush her teeth, help the CNA take her to the bathroom, wash her hands, give her a big hug, tuck her into bed for an afternoon nap, and tell her how much I love her. I waved goodbye that day as she smiled her beautiful smile back at me and said, "I love you Sharon! I wish you could stay!" I smiled back through tears, "I will see you tomorrow mom, I will be back." The next day, the unexpected call came, that no visits could take place. The doors of the long-term care facility were locked. A sign on the door stated No Visits Allowed. They had a contracted employee test positive for COVID-19.

I always visited my mom, almost daily, because I knew she was not getting the basic care she deserved. Basic care! To be taken to the bathroom throughout the day, to be helped at mealtimes, to be provided with a call light, and to have her teeth brushed, because she would pocket food in her mouth, from not chewing and swallowing so well anymore. No one would wash her hands before meals and after meals, or after being helped in the bathroom. I witnessed this daily when I could visit. So, I would provide as much care as I could. I would brush her teeth, wipe off the narrow dirty metal shelf that was her place in the shared bathroom to keep her toothbrush. I would position the toothbrush in a way that I could tell if someone moved it or took the time to brush her teeth. Every day, the toothbrush was in the same place, dry and stiff, unused. How disappointing. I took my concerns to every care conference for my mom, with nods of heads from managers and care takers, saying it would be taken care of. It was not!

She was in lock down now. I could not physically help her, so I made phone calls to the facility to double check that her plan of care was being followed, that she was taken to the bathroom every 2 hours. I worried about her skin and the breakdown that would occur if she sat in urine all day. Again, I was told, it was taken care of. I was not there to advocate for her, to be with her, and care for her. Who was going to do this? Adequate staffing was needed.

I continue to worry, because on several occasions she had fallen, trying to go to the bathroom herself. More than once she ended up at the emergency room. A deep open cut in her forehead, needing several stitches, and pain medication. A black eye engulfed her face. She has now fallen several times trying to get to the bathroom. I panic every time the phone number comes across my phone. Now what happened? Is my mom okay? Is she safe? I asked the facility director if I could come in and volunteer and help in any way. I am a nurse and educator. I am screening for COVID-19, I have minimized my risks, and would follow policies and protocols. I just want to help and be an extra set of eyes and hands and sit and visit with my mom and any residents that would enjoy a visit. The answer was, "No." The director said, "If you want to be here, then apply for a nursing position. We need nurses."

With the doors locked and new guidelines in place, and no visits allowed, I signed up for Facetime visits with my mom, so I could see her and check in. She would look so lost and bewildered and would wonder why I was not there. She did not understand why I could not be with her. When I would see her on the screen, I would be devastated. Her glasses were crooked, her hair not brushed, food and juice down her face, and food on her shirt. I told her stories and comforting words, I told her I loved her, trying to catch a smile. Her teeth were covered in food. No sweater or light jacket on, as I requested, because she was always cold. Did anyone notice or care? What is happening? My mom cared for her son, my brother with disabilities, for over 50 years, and now it was her time to be cared for. When we moved my mom in to the facility, I was told by the nursing director of the unit that she is in a good place and that they would take good care of her. She told me "don't worry, she is in good hands." Why are they not providing the care they promised? Why is the mission and vision statements of their facility, that are placed on the walls and website, not being followed? Where is the accountability? They are caring for my mother. She is not only a mother, but grandmother, and great grandmother and a beautiful and loving woman. She dedicated her life to care for her son with disabilities. She was a caretaker herself.

In November, she acquired COVID-19. Facility acquired COVID-19! No updates were given except for the initial call, "Your mom has COVID, and has been moved into the COVID unit." Over 30 residents died of COVID-19 there in a few short months. COVID was brought to them. My mom survived. I was told I could visit at her window. Standing again in the cold, I came to her window, she was eating her lunch, alone in the room. She saw me and cried and motioned for me to come in! She continued to motion to come in and all I could do was say, "I'm sorry, I can't." She has been declining these past months, and after finishing her quarantine and getting through COVID-19, she continues to decline. How long do I need to wait to see her? How much does she have to decline before I can be with her? Until she is dying? I am her POA and would love to be her "designated caregiver." She deserves the presence of her family, so does every resident in a long-term care facility in the state of North Dakota. Other states have figured this out, including Minnesota, and recognize the critical role family members and others have in the care and support of their loved one. Efforts that have been made to protect residents have failed to consider the physical and psychological impact of separation from those that matter most. I urge you to help pass SB 2145, so that my mother and all of our community members in long term care facilities, in North Dakota, can have the comfort and support of a "designated caregiver" now, when they need them most.

Thank you for introducing SB 2145.

Respectfully, Sharon Nelson, Ph.D., RN