

To: Chair Timothy Ginter, Vice Chair D. J. Swearingen, Ranking Member Stephaine Howse, and Members of the House Committee on Aging and Long-term Care

WRITTEN TESTIMONY of JILL CESARATTO

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Many Ohio families find themselves in the position of having a parent or grandparent with physical infirmities which make it unsafe or impossible for them to be cared for at home. These families make the heartrending yet necessary decision to place their loved ones into the hands of caregivers in a nursing facility. Unfortunately, insurance and personal finances dictate which facility a person may enter so it is within these circumstances that families make their best choice, and they hope that good quality care will ensue. My family had to make such a choice, and the experience became unbelievably difficult due to our state's Covid-19 policies. I am submitting to you my assessment of the current eldercare situation in Ohio and sharing my family's personal story. I ask you to consider not only the contrast between "what was then" and "what is now", but also take into account the irreparable damage that has been done and which continues to be done to senior citizens and their families.

What was then: Nursing homes used to be thought of as an ancillary to the family in the mission of caring for elders who suffer physical and/or mental infirmities. Nursing staff, with permission from a patient's family, rendered necessary care in ways which the family could not. The nursing home was an open place where family could stop in almost anytime, even in the evening, to verify conditions of both the facility and their loved one. Family presence, be it spending time in the resident's room, sharing a meal in the dining room, taking a walk down the hall, or attending enrichment activities, also assured the nursing home resident that they were still cared for and loved by their family. The nursing home was supposed to be like a home-away-from-home where real living could take place. Caution was always exercised during the flu season; Nursing homes would post signs asking visitors with any cold or flu symptoms to refrain from entering the facility. While this policy worked well, everyone understood that some transmission of communicable viruses was an inevitability.

What is now: Families are denied access to loved ones who reside in eldercare institutions, whether nursing, memory care, or assisted living homes. There is no longer any possibility of dropping in unexpectedly during reasonable hours to check on a loved one's physical and/or mental status. When nursing staff does grant visitations, they are very limited and constrained by strict guidelines which prevent residents and their families from experiencing the type of interaction as described in "what was then". In other words, real living is not taking place!! Nursing homes are now prisons and the residents are being treated as though they are the property of the state. The mental, spiritual, and emotional health of nursing home residents as well as the satisfaction and happiness of their family members are not considered in any way to be determining factors in decisions concerning visitation policy. Misguided attempts at trying to stop any spread of the Covid-19 virus have replaced the former mission of compassionately addressing *all* of the residents' needs.

My personal story involves my mother who is currently 91 years of age and residing at the memory care unit of The Village of St. Edward in Wadsworth, Ohio. Her name is Jean Lucht and during her life she contributed much to her family and to her community. She overcame many hardships in early life, worked very hard to put herself through college, became a wife, mother, and public school teacher, and made career advances beyond this. Even upon retirement, my mom worked toward the betterment of the communities in which she lived. She boldly faced challenges, was self-sufficient, never expecting to be handed something for nothing, and she taught her children the value of faith in God, love for

family, and devotion to country. I will spare you all of the ugly and frightening details of my family's journey in receiving Mom's diagnosis of Alzheimer's disease and watching the illness rob her of her intellect and nearly everything else in her life. It will suffice to say that at some point it became necessary for my sister and me to be the decision makers in our mother's life. At least we used to see ourselves as the decision makers before control of how we oversee Mom's care was taken from us.

Like every other eldercare home in Ohio, St. Edward's has made decisions in the wake of the Covid-19 virus which have negatively impacted the health and well-being of their residents and the residents' families. In-person visits were completely banned for a time and bans continue to be implemented whenever the home deems it necessary. There are currently two choices for in-person visits and they are not conducive to meaningful interaction. "Window visits" are where the resident inside the building sits at a window where they can see their family members. Depending on what kind of phone is available within the facility at the time and where it is placed, two-way phone communication can be nearly impossible. In my mother's case, she cannot hold a phone to her face, as she has fine motor skill difficulties and also forgets what a phone is for so we run the risk of her accidentally bumping buttons which might end the call. Yet, when the phone is placed on her chair, we cannot hear her voice. Outside noise such as airplanes passing by present another challenge. Still, I opt for this kind of physical visit because it does not require me to wear a mask and I know how important it is for my mother to see and recognize my face. I converse, smile, wave, and blow kisses to her. It's a pathetic substitute for a normal visit. The other method for in-person visitation used to be held outside in warmer weather. My sister participated in this. Our mother was masked and brought outside (why in the world would she have to wear a mask in the open air is beyond my comprehension) where she was seated at least 6 feet away from my sister, who also had to wear a mask. Absolutely no touching of our mother was allowed. An employee of St. Edward's had to remain watchful to be sure the rules were enforced. No physical contact is the most cruel and offensive aspect of St. Edward's policies! I know I could not restrain myself from reaching out and touching my mom in this type of situation! I wonder what the home would do in that case---report me to health officials? Call the police?

Now that cold weather is upon us, visits must be conducted inside the building. The masking, physical distancing, and no-touching rules still apply, and my sister has found so many difficulties with St. Edward's handling of this scenario. First of all, the visits have been in a lobby area where people are coming and going continually, and the background noise is amplified by the high ceiling. My mother's voice, already hampered by a mask, is indiscernible under these conditions and she sometimes cannot recognize my sister under the face covering! In addition, the last time my sister visited she found the seats designated for her and our mother to be at least 12 feet apart. Upon receiving complaints, St. Edward's is changing some things, but I wonder why families must first be put through many low quality visits before efforts toward good quality visits materialize.

The only other communication option for residents and their families employs FaceTime technology. I have been engaged in this type of visitation, yet I am only allowed a 20-25 minute session just once per week. During these visits my mother is usually in a common area of the facility which is at times fraught with noise from voices, clanging dishes, and ringing phones. I have asked that my mom be allowed to visit from her room and initially my request was honored. Then St. Edwards reverted back to placing my mom in a common area. In addition, I consistently have to ask that my mother's eyeglasses be placed on her face so she can see my image on the Facetime device, as she suffers vision difficulties due to macular degeneration. I am weary of having to make the same requests again and again in an effort to optimize the quality of my visits. Lastly, I must point out that the FaceTime visits are not at all private. Staff members are close by, sometimes answering questions for my mom when she does not respond to me. I do not think the staff intends to be intrusive. My point is that under these

circumstances, there is no opportunity for a private conversation between my mother and me.

The last time I was able to enjoy a normal visit with my mother was near the end of January. I planned a subsequent trip down to Wadsworth for another visit in early March. It grieves me to no end that my plans were delayed by a week. Little did I know that I would be missing my last chance to go into St. Edward's and sit with my mom and hug her because that very week St. Edward's barred their doors and no visitors were allowed to enter under any circumstances! It was not until July that in-person outdoor visits were started. For four long months my sister and I witnessed our mother's cognitive decline as she was denied visits from her family. As Alzheimer's eats away at Mom's memory and her ability to communicate, it infuriates me to know that we have been robbed of many opportunities to engage meaningfully with her! Our mom was denied birthday and holiday celebrations with her family, and there is no redeeming this. Totally valid needs have been ignored and it seems that no one will pay a price for this. Even if someone were held accountable, it would not restore what has been lost.

The people of Ohio feel that those who sit in the legislature with the authority to make law have shirked a constitutional responsibility to repair what is wrong with our state's Covid-19 response. A faulty ordinance in the Ohio code allows for an un-elected health official to have sole authority in matters of "quarantine and isolation". This could have been fixed many months ago but here we are, still waiting for relief from the draconian public health policies which rob my mother and countless other eldercare patients of their freedom and dignity. I am tired of hearing that the health and safety of Ohioans is our state government's top priority while the mental and social health of our senior citizens is sacrificed. What good, I ask you, is completely limiting a person's contact with a virus if you kill their will to live in the process? Our elders are failing to thrive in the pointless existence to which they have been relegated, and their family members are tormented to no end. I have suffered terrible nightmares in which I receive word that my mother has died with no one by her side. I awaken from those nightmares in tears, experiencing sheer panic as I realize that I never got the chance to hug my mom before she passed away! The ensuing feeling of despair is indescribable. The Covid-19 virus is nowhere near as frightening as the dreadful life of suspended animation which senior citizens have been forced into by the state. Preventing anyone dying from communicable viruses is the only goal driving Ohio health policy and it is killing people in the long run.

I do not know whether my testimony will move anyone's heart, but in honor of my mother I submit it to the members of the entire House Committee on Aging and Long-term Care. I hope the result will be seeing HB770 receive the support it needs to become law as soon as possible. This would be a step in the right direction in restoring the rights of senior citizens and their families. It is a tragedy and moral failure that the help will come too late for some!

Respectfully submitted,

Jill Cesaratto