Congressional Hearing, September 21, 2022 The Impact of the Coronavirus on Nursing Homes

To: Rep. James Clyburn and the House Select Committee

From: Marla Carter, Daughter-in-law of nursing home resident in Owensboro, KY, POA for two local nursing home residents without family, Consumer Member of the Green River Area Development District Ombudsman Advisory Council, Director of a nursing home volunteer organization

Dear Congressman Clyburn and Members of The Select Subcommittee on the Coronavirus Crisis:

Thank you for the opportunity to share my experiences and concerns as related to the impact of Covid-19 in nursing homes. Because my mother-in-law has lived in a nursing home since 2018, and because of my volunteer time in several local facilities, I feel like I have a lot of "on the ground," "in the trenches" experience to share. While I could share hundreds of stories from the past two years, I will instead list for you each specific concern or suggestion I have, and then offer you real-life examples to demonstrate its necessity.

1. Nursing homes need a specific, research-based federal staffing requirement. We cannot leave this most important issue to the states. Kentucky has introduced staffing legislation year after year and the bill never even makes it out of committee. We have staffing requirements for school classrooms, daycares, and adult daycares; why do we not have staffing requirements for nursing home residents, many of whom are just as vulnerable, frail, and defenseless as children? In 2018, Senator Thomas (D-Lexington), said that "the only time we talk about nursing homes in Frankfort, it's for tort reform, to stop the so-called frivolous lawsuits after someone gets hurt. Maybe we should stop people from getting hurt." If Kentucky can't rise up to enact legislation to protect nursing home residents, then it's time for Washington to take action.

Nurses and CNA's are doing the best they can, but they are weary. Even now they frequently work 7-10 days of 12 hour shifts with no day off. It is physically impossible for them to do their jobs properly. When staff are overworked, the likelihood of mistakes and neglect soon follows.

During the visiting restrictions of the pandemic, we received many calls from our friends within the nursing home. Here are some of their reports to us:

One gentleman told us he had to wear pull-ups because there weren't enough staff to do his laundry and wash his underwear.

We were on the phone with a resident with severe COPD when we heard him ask a staff person for a new oxygen tank because his was empty and they told him they had other people to take care of and he'd have to wait.

One resident told us that he hadn't had a shower in two weeks and he was embarrassed because he could smell himself.

A resident called us and asked us to call the front desk because he had pushed his call light hours before and no one had come to help him.

A resident told us she had had an accident (she had defecated) and the staff told her she'd have to wait for them to clean her up because they were getting ready to pass out meal trays. She waited two hours.

We were on the phone with a resident one evening when we heard a CNA tell her she needed to stop pushing her call button because she was not the only patient on the floor and she (the CNA) was the only person on the floor that night taking care of 40 people.

A resident called us to say that she could hear another resident, a lady who is normally ambulatory and happy, crying all day and calling out for help over and over and no one was coming to help her.

Residents told us they often did not get their meals in a timely manner. It was often 7:00 at night before many received their dinner.

When outdoor visits were finally allowed, we could only schedule them within a small window of time, Monday-Friday, because there were not enough staff to accommodate visits The same was true of scheduling FaceTime visits; there were never enough staff to assist the residents with those.

From the above comments it might seem like many residents have phones. This is not our experience. Fewer than 25% of residents own cell phones in my mother-in-law's facility, and the resident rooms do not have landline phones. If

residents do not have a cell phone, or if they lose it, break it, forget to charge it, etc....they must use the phone at the nurses station, or family must call the facility and ask to speak to the resident. Many times we would call the main line for the nursing home and it would ring and ring with no answer. If someone did pick up, they would transfer us back to the unit where my mother-in-law is, and no one would ever pick up the phone. If someone actually picked up that phone, we were often told my mother-in-law was sleeping and they didn't want to get her out of bed. That is entirely a staffing issue.

These issues have not been resolved just because covid has slowed down. These problems existed before the pandemic and continue to be so. Last week I walked past a resident who was sitting in the front lobby looking out the window. He told me he wanted to go outside and sit on the porch but the staff were too busy to take him. I asked the staff if I could sit with him on the porch and they told me no, because I was not staff. That same day, when I arrived, there was no one at the front desk to let me in the building. I rang the doorbell repeatedly. A resident saw me there and rolled himself down to the nurses station to ask someone to come let me in. It was a Sunday—a prime visiting day—and there was no one there to let visitors in. There were also no activities staffers present that day, and since I was there for my weekly Sunday school class with residents, I had to go room to room to gather residents and take them to the dining room. The residents who had to be dressed or needed more assistance than I could give did not get to come because there weren't enough staff to assist.

 Examine the private-equity firms who are buying up nursing homes and hold them to a higher standard of transparency and patient care. "When morality comes up against profit, it is seldom that profit loses." -Shirley Chisholm, US Representative.

"The only reason for choosing to understaff a nursing home is to save money and increase the bottom line. Not surprisingly, then, for-profit corporate owners are more inclined to understaff than the non-profits. The problem for patients is that low staffing levels are widely considered to be the strongest predictor of poor-quality care." -Abuses and Excuses: How to Hold Bad Nursing Homes Accountable, by Jeffrey Powless

My mother-in-law's facility was owned by Genesis Healthcare and is now owned by the Portopiccolo Group, a private-equity firm based in New Jersey (though

you have to DIG through records to discover that). We are very often told that "corporate" is the reason for the decisions that are made. Some examples include:

At one point during the pandemic when the phones at the nursing home had not been answered for days, the administrator told me that they were having trouble with the phone lines, but she couldn't simply call the phone company because "corporate" had to do that. It was weeks before that was fixed.

My mother-in-law had a mild case of covid and was sent to the "covid wing." She was kept in her room there for 30 days, though she tested negative for covid within a few days and had little to no symptoms. Each time we called to inquire about when she would be moved back to her regular room, we were told things like, "oh, she has an upset stomach now," or "she's still not feeling well," and finally, "we can't move her back until corporate approves it."

"Among the 75 facilities for which Hyman (CEO of Portopiccolo) is listed as an owner in federal regulatory data, 43% have one star, the lowest overall quality rating, whereas only about 17% of nursing homes nationwide have one star. The ratings are based on quality measures, staffing, and three years' worth of health inspections."

https://www.barrons.com/articles/as-the-pandemic-struck-a-private-equity-firm-went-on-a-nursing-home-buying-spree-51596723053

My mother-in-law's facility is a one-star facility now. In fact, the facility was recently fined nearly \$100,000 for a variety of violations, including abuse and infection control. As documented in the inspection: "Based on observations, interviews, record reviews, and the review of a facility policy, it was determined that the facility failed to keep the indwelling catheter drainage bag off the floor for one (1) of four (4) sampled residents (Resident #67); and, failed to maintain social distancing in the main hallway and wear the face mask properly in three (3) locations within the building. The deficient practice occurred during the COVID-19 pandemic and had the potential to affect all residents....On 08/24/2021 at 10:51 AM, six (6) members of housekeeping staff were seen in the hall outside of the laboratory door. The staff members, in some cases, were almost shoulder to shoulder. Housekeeper #1 stated someone in housekeeping had tested positive and the six (6) standing in front of the lab were waiting to be tested since they had close contact with the positive member of their team."

Mills Nursing and Rehabilitation in Mayfield, Ky., a 98-bed facility that Portopiccolo's ClearView Healthcare Management (same management group

which manages my mother-in-law's facility now) took over in late 2019, had 107 cases among residents and staff and 23 deaths, one of Kentucky's largest long-term care outbreaks.

3. Include loved ones and volunteers as critical partners, essential members of the team providing care to nursing home residents. In every nursing home I've been in, family and volunteers are not given a warm welcome. There is a definite feeling of "us versus them" that exists between staff and anyone else who comes in to provide assistance. This was especially true during the pandemic. I'm confused and saddened by this attitude. Family members and loved ones know residents so much better than the staff. Loved ones see who the person was before they declined so much they need skilled nursing care. Staff members tend to only see the resident as a "patient" and a list of diagnoses and inabilities. Loved ones are the first to notice when a resident is experiencing a change.

Our experience with my mother-in-law (Linda) provides a good example of how eliminating family members from care leads to disastrous results. In January 2021, communication with Linda became increasingly difficult. She forgot how to use her cell phone. Even with her roommate assisting her with operating the phone, she stopped talking. She could no longer carry on a conversation. She could only answer yes or no questions. At this point it was too cold for outdoor visits, so the only way we could communicate with her was on the phone. We asked staff about the change in her condition and we were told things like, "She's fine," "She talks to us all the time," or "We just don't know how covid affects the brain. It's just her dementia worsening." It seemed unlikely to us that in November she was playing Jeopardy and painting, and by the end of January she could so longer speak and was completely bed bound. We began scheduling doctor visits for Linda with specialists outside of the nursing home. We thought perhaps she'd had a stroke. Bloodwork revealed her thyroid stimulating hormone (TSH) level was 179. (Normal is 0.5-.5.0 mIU/L.) The nursing home's nurse practitioner had discontinued Linda's thyroid medication in December without telling us and without doing any follow-up labs until May. Linda essentially did not have a working thyroid at that point, and could have died as a result. We now have Linda's medical care managed entirely by physicians outside the nursing home, taking her to specialists to regain some of the skills she lost and to improve her quality of life. Not only is this inconvenient, but she is now costing Medicaid much more money for her care because the nursing home cannot provide the care she needs. If we could have seen her, if the staff had consulted with us, we could have identified her thyroid problem much faster.

This is why it is so important for Congress to pass HR 3733, The Essential Caregivers Act. Loved ones are essential to well-rounded care of nursing home residents. We can identify health needs, provide help with activities of daily living, and provide emotional and spiritual support for our loved ones. We are their voice when they can no longer speak for themselves. We keep them connected to who they are and provide a sense of comfort and familiarity.

I include volunteers in this category because of the staffing crisis and the way volunteers could be utilized. Prior to the pandemic, my volunteers were in the nursing home weekly. In addition to providing spiritual support for residents, we helped look for lost remotes, lost laundry items, changed batteries, put clothes in drawers, helped get residents to the dining room, etc. Obviously the role during the height of the pandemic would have changed due to infection control practices, but there were other ways volunteers could have been used. I offered to sit outside with residents so they could get some fresh air, to help screen visitors at the door, or to sit with residents during their outdoor family visits to free up staff to do other things. I was repeatedly told no-it was too risky. Volunteers could easily have been trained in infection control practices and given jobs that were not medical in nature to help a workforce that was (and is) in crisis. My final point is not coronavirus related, but needs to be said. Congress does not need to pass hundreds of pages of new legislation for nursing home oversight. The Nursing Home Reform Act of 1987 contains very specific regulations for nursing home care. The problem is that the regulations are not enforced. Every week I see things that could be reported because the nursing home is out of compliance. Every week. (I don't mean areas of clear abuse–I'm a mandatory reporter and would not hesitate to report abuse, which I have done.)

The problem is that experience has shown me that nothing ever happens to the nursing homes when you report them. Every time I've made a complaint, it has been deemed "unsubstantiated," even though I provided documentation and specific details, including photos. Not only that, but the last time I filed a complaint the state surveyor told the nursing home it was me who called. My relationship with the staff was destroyed and I'm currently unable to volunteer there in an official capacity.

Enforcement of regulations, including training for and hiring more ombudsmen and surveyors is needed more than ever. The nursing homes have NO incentive to change. They know they have a guaranteed income stream from Medicaid and Medicare and they'll make billions. Genesis Healthcare reported generating

\$5.73 billion in revenues for the year 2016 alone. (Abuses and Excuses:How to Hold Bad Nursing Homes Accountable, by Jeffery Powless)

If we can take the lessons learned from the pandemic and create meaningful change in long-term care, we will be honoring all those who died in nursing homes. COVID-19 deaths in LTCFs make up at least 23% of all COVID-19 deaths in the US.

(https://www.kff.org/policy-watch/over-200000-residents-and-staff-in-long-term-care-facilities-have-died-from-covid-19/)

That number does not include the number of deaths from neglect, isolation, and sheer loss of will to live that happened during the long months that residents were confined to their rooms and kept away from their families.

A final thought from Atul Gawande's book, Being Mortal: Medicine and What Matters in the End: "This is the consequence of a society that faces the final phase of the human life cycle by trying not to think about it. We end up with institutions that address any number of societal goals—from freeing up hospital beds to taking burdens off families' hands to coping with poverty among the elderly—but never the goal that matters to the people who reside in them: how to make life worth living when we're weak and frail and can't fend for ourselves anymore.....Our elderly are left with a controlled and supervised institutional existence, a medically designed answer to unfixable problems, a life designed to be safe but empty of anything they care about."