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The Crisis Inside America's Nursing Homes

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For several days in April, Susan Cady didn't know where her mother was. A resident at Hornell Gardens Nursing & Rehabilitation, a nursing home in Hornell, N.Y., her mother had recently tested negative for Covid-19, Cady says. So when Cady saw a news report saying that the facility, the site of a cluster of Covid infections, planned to transfer its Covid-negative residents to another facility about 70 miles away, she assumed that her mother might be among them.

She called her 89-year-old father, who hadn't heard anything about the move, and the facility, which wouldn't give her any information, she says. A few days later, she called her father again, and he was in tears: He had just learned from the facility, she says, that her mother had subsequently tested positive for Covid and remained at Hornell Gardens. "It's heartbreaking," says Cady, 57. Her mother, who suffers from Alzheimer's disease, "doesn't know who I am," she says. "But she's still my mom."

Hornell Gardens and Hurlbut Care Communities, which operates the facility, didn't respond to requests for comment. In a statement on Hurlbut's website, CEO Bob Hurlbut said the company is regularly updating residents and families by phone and in writing, "in order to ensure transparency in affected facilities."

The coronavirus has caused long-term-care facilities serving older and disabled people, who are among the most vulnerable to the pandemic, to draw the curtains. Following regulators' guidance, family members, volunteers, and long-term-care ombudsmen—whose job it is to advocate for residents' rights and help them resolve complaints—have generally been barred from facilities since mid-March. Visits from state surveyors, who check that nursing homes are complying with federal regulations, have been curtailed. Regulators have also waived a host of nursing-home rules, including, under certain circumstances, the requirement that facilities give residents and family members advance notice before transferring residents from one facility to another.

"What's going on behind closed doors? We have no clue," says Brian Lee, executive director of resident advocacy group Families for Better Care. More than 10,000 long-term care facility deaths have been linked to the coronavirus, according to an analysis by The Wall Street Journal. Over two million people live in roughly 45,000 nursing homes and assisted-living or other residential-care communities, which employ over 1.2 million nursing and social workers, according to a 2019 report based on 2016 data from the National Center for Health Statistics. Private equity and other forms of for-profit ownership dominate the industry, and most facilities are chain-affiliated. Oversight varies among facility types: Nursing homes participating in Medicare and Medicaid must comply with a raft of federal rules, while assisted-living facilities are largely regulated by states. But in all types of facilities, advocates say, family members, volunteers, and other outside visitors play a critical role in spotting problems and ensuring residents' well-being.

While many in the industry "are doing an incredible job," the rule waivers, diminished inspections, reduced oversight, and chronic understaffing in long-term care facilities may be a toxic combination, says Toby Edelman, senior policy attorney at the Center for Medicare Advocacy. "There's a lot of neglect in nursing homes in the best of times," she says, "and these are not the best of times."

The American Health Care Association/National Center for Assisted Living, an industry group, disagrees. "This type of criticism is a disservice to the brave heroes of this fight, who leave their families every day to care for others," AHCA/NCAL said in a statement. Such concerns "don't recognize the gravity of the situation that this virus is having on our population and only further distracts from the more important issue" of inadequate protective gear, testing, and staffing, the group said. Facilities recognize that communication is key, it said, and "families need to work together and with facilities to identify a single point of contact who can be responsible for information dissemination within families."

For many families and resident advocates, fears about residents' basic welfare and safety weigh just as heavily as the coronavirus. One in five high-risk emergency-room visits by nursing-home residents result from potential abuse or neglect, according to a 2019 report based on 2016 data by the Department of Health and Human Services inspector general. Nursing homes failed to report many of these incidents to survey agencies as required by federal rules, the inspector general found.

Angela Chavous, a representative with the Georgia long-term care ombudsman program, found herself peeking through the windows of a Richmond County, Ga., board and care home in early April. At the start of the month, she had received a disturbing report from a local hospital that had admitted a resident of the facility. The resident, an older woman, had lost significant weight, Chavous says, and the hospital suspected neglect. Chavous had previously had concerns about the facility, including the adequacy of the meals, cleanliness, and the quality of patient care. Given the Covid-19 restrictions, she couldn't visit, and when she called the facility, the number was disconnected, she says. So after consulting with the state ombudsman, she went and knocked on the door.

The awkward scene that followed underscores resident advocates' concerns about the Covid-induced separation between long-term care facilities and the outside world. Chavous talked with the residents, some of whom have dementia or physical disabilities, out on the front porch while maintaining her distance, she says. They didn't raise any serious complaints, which is "not surprising," she says, in part because a staff member hovered nearby. Chavous peered through the windows, but she could not see residents' bedrooms or bathrooms. She did however, note a strong odor of urine wafting through the door, she says.

Chavous reminded residents they could call her and discussed her concerns with the facility's owner, and she plans to check up on the facility at least every two weeks. But she's very concerned that serious issues may be overlooked while ombudsmen are barred from facilities. The residents, she says, "need us now more than ever."

Regulators are tackling at least one key aspect of nursing-home transparency: the reporting of Covid-19 outbreaks. On April 19, seven weeks after the world learned of the nursing-home Covid outbreak at a Seattle-area facility, the Centers for Medicare and Medicaid Services, or CMS, said it would require nursing homes to inform residents and their families of Covid cases in the facilities and report those cases directly to the Centers for Disease Control and Prevention. CMS plans to make the data publicly available.

The fact that many long-term care residents can't speak for themselves leaves advocates and family members uneasy with some of the recent nursing-home rule waivers. CMS, for example, has said that facilities don't need to provide advance notification before transferring residents in certain situations, such as when the transfers are made to separate Covid-positive from Covid-negative residents. Some families are discovering that their loved one has been moved only after the fact,

says Laurie Facciarossa Brewer, the New Jersey long-term care ombudsman. "People's rights are being temporarily suspended," she says.

Suspension of regular nursing-home inspections means that many other serious threats to residents' welfare may be overlooked, advocates say. In March, CMS said that nursing-home inspections would temporarily focus on just infection control and incidents cited as "immediate jeopardy"—the most severe level of violations. (Even in these cases, inspectors should enter facilities only if they have appropriate personal protective equipment, CMS said.) But the vast majority of nursing-home health-inspection violations are cited at less-severe levels, and many involve serious harm to residents, including broken bones and medication errors, advocates say.

CMS did not respond to requests for comment for this article. In a previous statement to Barron's, CMS said it "is using every tool at our disposal to keep nursing homes free from infection." Rule waivers, it said, provide facilities with necessary flexibility and help them prepare for Covid-19. The streamlined inspections, said AHCA/NCAL, help "ensure our caregivers and staff can keep their focus and every resource dedicated to residents during this outbreak."

In normal times, ombudsman representatives help identify problems before they get too serious by visiting facilities and chatting with residents. In March, Melanie McNeil, the Georgia state long-term care ombudsman who, at the time, was also president of the National Association of State Ombudsman Programs, urged CMS to reinstate ombudsman representatives' ability to enter nursing homes when necessary to respond to situations that could threaten residents' health, safety, and rights. It isn't clear, she wrote in a letter to CMS administrator Seema Verma, that ombudsman representatives "pose any greater risk to residents than do the health-care workers at the facility." McNeil says she received no response from CMS. Facilities can review ombudsmen's access on a case-by-case basis, CMS said in its guidance.

That generally leaves ombudsman representatives on the outside looking in, trying to accomplish most of their advocacy work remotely. When they try to reach facility staff and residents by phone, it's "becoming increasingly difficult to even get through, because the facilities are very stressed," says Brewer, the New Jersey ombudsman. Although she has 11 full-time advocates and 200 volunteers, Brewer says she had no early warning of the crisis building at the Andover Subacute and Rehabilitation Center, the Andover, N.J., facility where police said there were 17 bodies in mid-April. The facility had 112 cases and 31 confirmed Covid-19 deaths as of April 22, according to the state. Facility owner Chaim Scheinbaum said in a

statement that "current staffing is solid" and that no more than 15 bodies were kept in a room with a normal capacity of four.

Such scenarios aren't the end of ombudsmen's worries. A 2019 report by the U.S. Government Accountability Office found that incidents of abuse cited by nursing-home inspectors more than doubled from 2013 to 2017. In New Jersey, Brewer has found a nearly 40% increase in long-term care facility abuse and neglect cases from 2015 to 2019, and she's "extremely concerned" that such incidents will be overlooked while facilities are on lockdown.

As the crisis grinds on, some families are being denied the window visits that provide the only possible face-to-face interaction with their loved ones. Bayside of Poquoson Health and Rehab in Poquoson, Va., recently halted window visits to "eliminate potential for disease spread by individuals congregating and also given the fact that there is a Stay-at-Home Order in effect in the state of Virginia," the facility said in a statement. Bayside said it is connecting residents and families by phone, email, text, and video chat.

That's not much help to the family member of a Bayside resident who was recently denied permission for a window visit. The resident "gets so confused by Zoom or FaceTime" and has trouble hearing phone calls, the family member says, adding that for many older people, electronic communication "is not the same as seeing a face through the window."

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