

The Pandemic's Hidden Victims

Nursing homes and other assisted-living communities have become COVID-19 hot spots, garnering headlines across the country. But many don't know that people with Alzheimer's and other dementias in those communities are especially vulnerable—and they need more support.

BY NADRA KAREEM NITTLE



When Don Petersen last visited his wife, Judi, they binge-watched classic TV shows. He didn't realize at the time that those episodes of *I Love Lucy* and *The Andy Griffith Show* would mark the beginning of a months-long forced separation from his spouse of 55 years.

Before the COVID-19 pandemic, Petersen visited his wife five days a week at the Portland, Oregon, assisted-living community where she receives care for Alzheimer's disease. Now, those visits have stopped entirely, and life apart has been a difficult adjustment. Alzheimer's, a type of dementia that causes a progressive loss of memory and other cognitive skills, makes phone conversations frustrating for Judi. But two weeks into lockdown, the couple's daughter helped them find a new way to communicate: singing on FaceTime.

"My daughter just started singing 'You Are My Sunshine,'" Petersen recalls. "My gosh, Judi lit up. And when that one was done, I sang 'I've Grown Accustomed to Her Face.' It was magical."

While singing together has helped the couple connect during quarantine, Petersen fears that his 76-year-old wife could rapidly decline if her loved ones continue to keep their distance. She's not the only one at risk. People with dementia, including Alzheimer's, make up 48 percent of the population in nursing homes and 42 percent of the population in long-term care communities. For this group, isolation during the pandemic is a serious health issue.



claim. The association recently issued a set of policy recommendations that calls on state and federal lawmakers to provide more support for nursing homes and assisted-living communities during the pandemic. Given the resources to accelerate COVID-19 testing, immediately report cases to public health officials, and deploy “strike teams” to virus hot spots, these communities could allow families to reunite sooner than later.

“If we had testing, then family members could come visit,” says Beth Kallmyer, vice president of the Alzheimer’s Association’s care and support division. “That would be significant, not only for the families, but really for the people living with dementia and other residents living in long-term care who have been so isolated from their loved ones.”



Laura Edelbacher

Instead, nursing homes and assisted-living communities remain in crisis due to inaccurate reporting of coronavirus cases, a lack of institutional transparency, and insufficient access to testing equipment and personal protective equipment (PPE). More than 50,000 residents and workers have reportedly died from coronavirus in long-term care communities, and the numbers continue to rise.

“They tend to live in very close conditions, and those are the circumstances where we know spread is most likely to happen,” says Robert Egge, chief public policy officer of the Alzheimer’s Association. “Although controlling infectious disease has always been a theme in these settings, it’s never been as acute a need as it



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Individuals with Alzheimer's in such communities are particularly vulnerable. More than 95 percent of people with Alzheimer's and other forms of dementia have an additional chronic health condition—such as diabetes, heart disease, or hypertension—which increases the likelihood of complications from COVID-19. Dementia, meanwhile, makes it more challenging for these individuals to protect themselves from the disease because it renders them unable to discuss their needs or symptoms. Their discomfort might be mistaken for cognitive decline rather than a coronavirus symptom.

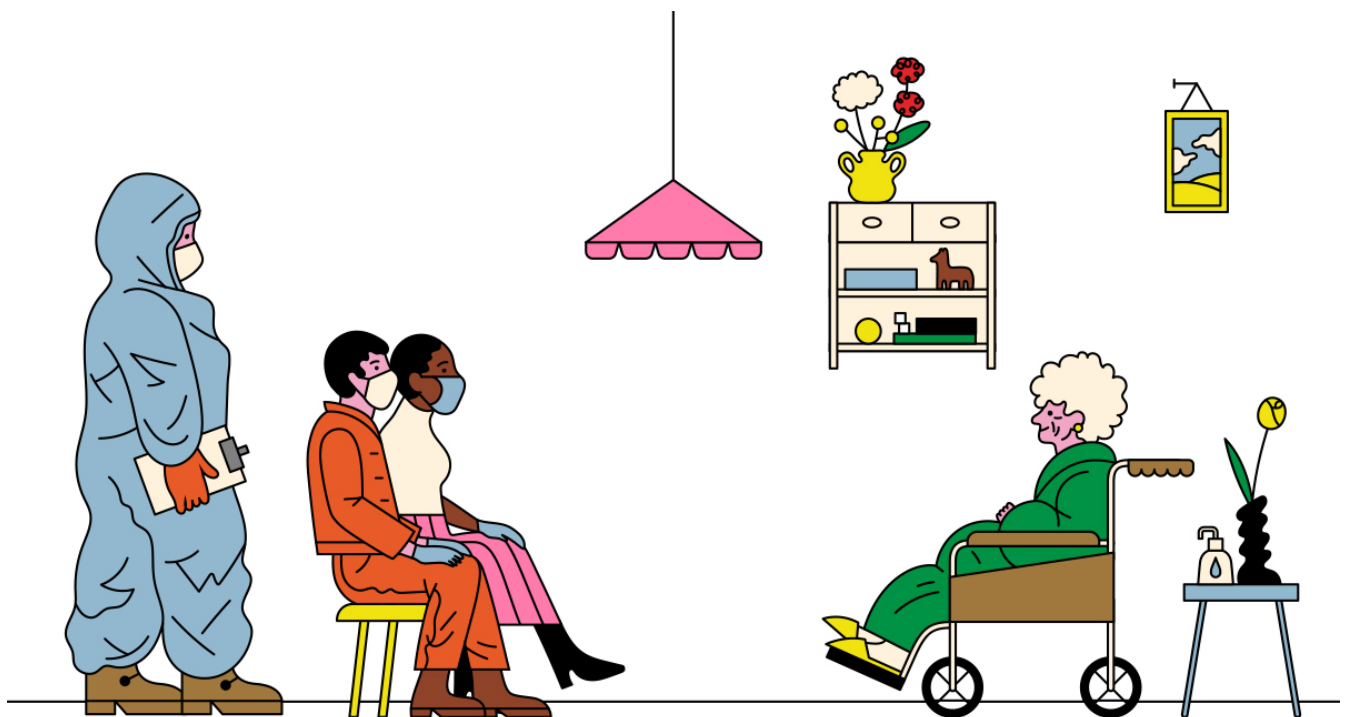
According to Shenell Hinton, the director of clinical services and nursing at Kendal at Oberlin, one of 13 Kendal senior living communities, those increased risks demand that staff members devote even more time and attention than usual to residents with Alzheimer's. "We have strived to go over and beyond for this population to keep them safe," says Hinton.

While many long-term care communities have not been allowing visitors in order to reduce the spread of the disease, they still see plenty of people coming in and leaving on a daily basis. Workers help residents eat, bathe, get dressed, and engage in other activities that require close contact. Experts say, therefore, that the Centers for Medicare & Medicaid Services' recommendation that staff be tested just once a week isn't nearly enough.

"They really need to be tested every time they leave the facility and come back in. And that is not happening now anywhere that I know of," Kallmyer says.

care communities have taken the initiative to protect their residents and workers from coronavirus on their own. Take Senior Star, which operates 15 senior living communities in six states. The staff at those communities have long used PPE to stop viral outbreaks from spreading. To fight the coronavirus, however, the company recently had to ramp up its resources.

“We went from having on hand thousands of dollars worth of PPE to ... over \$3.7 million worth of PPE and other safety supplies,” says Letitia Jackson, Senior Star’s senior vice president. “We know that that [hasn’t been] possible for everyone.”



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There have been signs of progress on this issue at the state and federal level. Maryland has been a leader in using strike teams to respond to COVID-19 clusters at nursing homes, and legislation



Alzheimer's Association continues to field reports about nursing home staff bringing their own PPE to work because employers aren't able to provide it.

As the Alzheimer's Association continues to advocate for long-term care communities, residents and their loved ones are doing their best to get by in trying circumstances. Dan Goerke, for one, uses FaceTime and makes window visits to stay in touch with his wife, Denise, who was diagnosed with Alzheimer's at 56 in 2012 and now resides at an Atlanta-area assisted-living community.

"COVID has absolutely had a downward effect on Denise," Goerke says. "She has just lost a lot of motivation. You see ... the lack of connectedness she has with me. It's just not there like it was before COVID."

While Goerke says Denise's mood has been improving lately, he suspects she won't be back to her old self until they're reunited. He's willing to have his temperature taken, wear as much PPE as possible, and even have timed visits. He just doesn't want his wife to be isolated.

"There is so much to just the physical touch of holding someone's hand that brightens their day," he says. "Denise often doesn't acknowledge the fact that I'm holding her hand or touching her face, but I know it helps."



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