

The Devastating Effect of Lockdowns on Residents of Long-Term Care Facilities During COVID-19



A Survey of Residents' Families

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A SURVEY OF RESIDENTS' FAMILIES

OVERVIEW

On March 13, 2020, the Centers for Medicare & Medicaid Services (CMS) issued a lockdown order, banning everyone but essential personnel from entering nursing homes. As a result, nursing home residents began a months long period of isolation - cut off from their families. Those who could, took advantage of electronic visitation, but because of a lack of resources or due to a resident's medical condition this was not always possible. The lack of family presence severely restricted the ability of families to monitor their loved one's care. Further compounding isolation was CMS barring state survey agencies and long-term care ombudsmen from entering homes.

From the start, Consumer Voice has been extremely concerned that nursing homes would not have sufficient staff to provide needed care to residents. For years, understaffing has been a problem in facilities. COVID-19 exacerbated these shortages. In addition, facilities have benefited from families providing care to residents-care the facilities themselves should have been providing. We feared that these factors, when combined with little or no oversight, would result in residents suffering and dying from neglect and isolation.

In September 2020, CMS eased the visitation restrictions and permitted visits under limited circumstances. This was the first time that residents and families could see each other in-person. Very quickly, Consumer Voice began hearing from family members that their loved ones were almost unrecognizable because of physical and mental decline. Families shared stories about residents who had lost extreme amounts of weight, not been washed, developed pressure ulcers, and suffered significant cognitive decline. To better understand the effects lockdowns were having on residents, we created a survey¹ asking families who had in-person visits to answer questions about their loved ones' appearance and functionality.

The results confirmed our concerns. Of the 191 respondents from across the United States, an overwhelming majority indicated that they had seen decline in both physical and mental conditions. Additionally, families reported that their loved ones were missing possessions ranging from glasses and hearing aids to wedding rings and clothes. Family members repeatedly noted the same issues - residents were unkempt, clearly had not been bathed or groomed in months, had lost significant weight, and were significantly depressed-even suicidal.

To prevent further suffering during this pandemic and in the future, Consumer Voice calls on Congress and federal agencies to address staffing; visitation; training and equipment; and oversight.

Key Findings

Of the family members who responded:

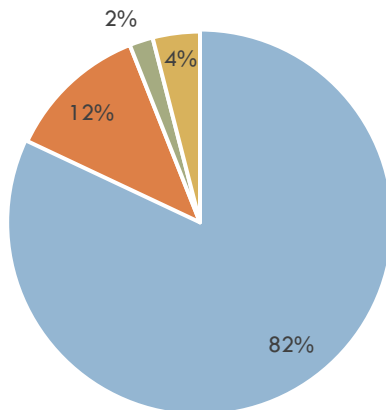
- **85% noted a decline in physical abilities.**
- **87% indicated their loved one's physical appearance had declined.**
- **91% of reported that their loved one's demeanor (mental status) had declined.**
- **40% indicated their loved ones were missing personal belongings.**
- **69% indicated the facility did not appear to have sufficient staff to care for residents.**
- **10% observed facility staff not wearing or properly using personal protective equipment (PPE).**

¹<https://theconsumervoice.org/issues/other-issues-and-resources/visitation/reentry-survey>

Physical Decline

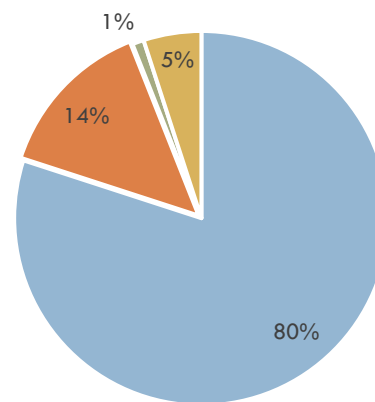
8 of 10 respondents indicated their loved ones had experienced physical decline. Among the problems family members reported were significant weight loss, bloating, weakness, and difficulty lifting objects and ambulating. Respondents also reported their loved ones suffered from pressure ulcers as a result of lying in bed for long periods of time without being repositioned.

Was there a change in your loved one's physical appearance?



- Yes, my loved one's physical appearance had declined.
- No.
- Yes, my loved one's physical condition had improved.
- No response

Was there a change in your loved one's physical abilities?



- Yes, my loved one's physical abilities had declined.
- No.
- Yes, my loved one's physical abilities had improved.
- No response.

What Family Members Said

"Horrible, so skinny and weak near death. Deprived of food, drink, activities and access to loves ones"

"Extreme weight loss...bedsores, extreme back pain. Kept in bed March 13 until October."

"My mom doesn't stand or try to walk as she used to before. She also had a bedsore."

"Declining cognitively due to severe weight loss."

"Not getting physical therapy or range of motion exercises. They keep his hands covered but once the sheet slipped and I was horrified at how contracted his hands are."

Resident Hygiene

In addition to physical problems, respondents reported significant and disturbing problems with their loved ones' hygiene. Residents were often unkempt, wearing dirty clothes, and disheveled. Some reported that teeth had not been brushed in months and that finger and toenails were long and dirty. Respondents noted how the failure to perform basic hygiene for residents contributed to despondency and cognitive decline.

"Mom's hair and nails haven't been cut in 7 months."

"Nails huge digging into her skin. No oral care. Room filthy and dusty. Cards we had sent were unopened and shoved in a drawer."

"Two of her regular teeth have turned brown. Her dentures were so beyond disgusting. I found out they had not brushed her teeth or cleaned her dentures since March 11."

"She has long dirty nails. Her hair was a greasy mess most days, causing mom to lose dignity. Mom asks why she is in prison."

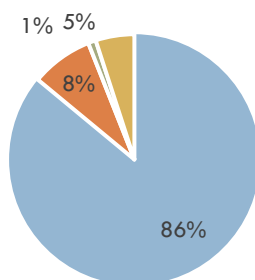
"Besides looking depressed, he's unkempt – his hair, facial hair, hands and toes."



Demeanor (Mental Status)

Only one respondent of all the persons surveyed indicated that their loved one had not experienced a decline in demeanor. Residents who, prior to the pandemic, were suffering from cognitive impairments, such as dementia, invariably declined. Families reported despondent residents who felt abandoned and did not understand why they had no visitors. Some residents expressed a desire to die rather than to continue living in isolation. Residents with cognitive impairments often rely on family, friends, and staff to help them cope with their declining mental health. Stripped of these supports, families reported precipitous declines, noting their loved one no longer recognized them or were completely unresponsive.

Was there a change in your loved one's demeanor (mental status)?



■ Yes, my loved one's demeanor had declined ■ No ■ Yes, my loved one's demeanor had improved ■ No response

What Family Members Said

"Long term memory declined, started to believe that her stuffed animals could talk...Begging to be taken home."

"He was a very optimistic person. Now he frequently states 'this is not a way to live,' and cried."

"My mother doesn't understand why we can't be together. She is angry and upset most days and it is heartbreaking."

"Repeating same things over and over again. Can't remember names and information. Lack of stimulation."

"I just moved my dad home. He is screaming and crying now at night and when I leave to do errands. He says they just left him in a wheelchair all day long."

"Appears to be drugged, head hanging down, no or very little response when spoken to."

"Completely disengaged, disoriented, despair, left in same clothing and diaper days in a row...crying to be taken home."

"She said she has felt like she is in prison. She has been locked in her room for over a month never leaving and only having contact with people when they brought or picked up her meal trays."

Missing Possessions

43 % of respondents indicated residents were missing personal effects, such as eyeglasses, hearing aids, dentures, clothes, and jewelry. Adding to the isolation of being locked down in their rooms, some residents could not hear or read for weeks or months on end. Residents whose dentures were lost were forced onto mechanical diets of chopped, ground and pureed food because they could not chew their food. Some families were forced to pay thousands of dollars to replace hearing aids, clothes, and glasses. Many respondents noted that their loved one had been constantly moved between rooms because of COVID and that during these moves belongings often went missing.

What Family Members Said

"The facility lost hearing aids twice, making the isolation worse."

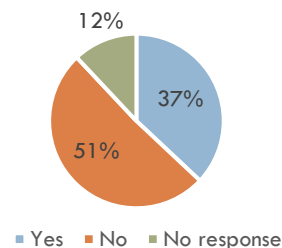
"Her wedding band disappeared the last week she was there."

"Three pairs of prescription glasses lost in six months, new dentures lost, and shoes lost."

"Two pairs of hearing aids. One dental plate."

"She was missing her manual wheelchair for a month."

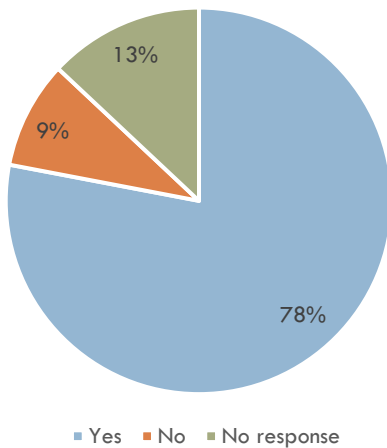
Was your loved one missing any personal belongings?



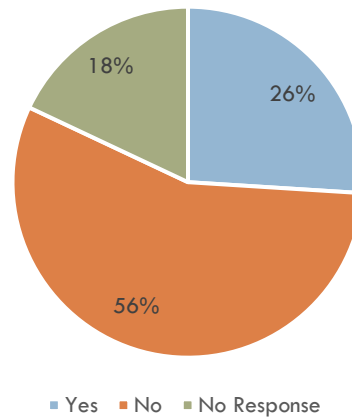
PPE Use and Staffing

We asked family members and loved ones to report whether they believed there was sufficient staff and whether staff were properly using PPE and following infection control procedures. Over half of respondents indicated that there did not appear to be sufficient staff to care for residents. Over 9% of respondents indicated they observed staff not wearing PPE, including masks, nor following appropriate infection control procedures.

Was PPE, such as masks, being worn in the facility?



Did there appear to be sufficient staff to meet resident needs?



"There was one nurse who worked 11 p.m. to 7 a.m. who never wore a mask."

"I have observed several people on camera inside my grandmother's room without masks on."

"Not enough staff, nurses station frequently un-manned, phones not always answered."

"The nurse manager had no mask and he walked from one unit to another."

"CNAs always working doubles. 1 CNA for 15 residents."

"One staff member in particular was not wearing even a mask, and she angrily stalked the hallways glaring at me."

Conclusions and Recommendations

Much of the focus of the impact of COVID-19 on nursing home residents has been on the physical effect of the virus itself on residents. Yet based on family reports, it is clear that the lockdown and resulting isolation have taken an unquantifiable toll on residents. A recent article² by the Associated Press detailing the disastrous effect lockdowns have had on residents estimated that there have been 40,000 excess deaths not attributable to COVID-19 in nursing homes in 2020 as compared to 2019.

Much of the harm is the result of facilities not having sufficient staff to provide required and necessary care and inadequate training of existing staff. Years of short-staffing by facilities and their reliance on family members to provide care proved to be catastrophic when nursing homes' doors shut in March. A significant amount of this suffering could have been prevented with adequate investment in staff and training by nursing homes.

Immediate steps should be taken to help prevent further suffering. The federal government, along with the states, should:

- **Staffing:** Invest in staff of long-term care facilities by increasing wages, providing hazard pay, benefits, and child care for staff. Require that any additional relief funds provided by Congress to nursing homes be used for increasing staff, obtaining PPE, and testing.
- **Visitation and Compassionate Care:** Enforce guidance from CMS requiring all facilities to allow compassionate care visits for residents who are experiencing decline. Ensure that all facilities are following the least restrictive visitation policies possible.
- **Training and equipment:** Ensure all facilities are provided necessary PPE and testing supplies. Hold facilities accountable for training staff in proper infections control procedures.
- **Monitoring and Oversight:** Immediately restart all annual and complaint surveys. Surveys must be comprehensive and assess facility conditions and resident care during all visits. As tens of thousands of nursing home residents died, state and federal regulators were absent from homes, compounding the tragedy.

It is likely we will never know the full extent of the horrors residents experienced or the true number of residents who died as a result of facilities being locked down. But we can take action now to save thousands of lives and stop avoidable and unspeakable suffering; we owe this to residents and their families.



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² <https://apnews.com/article/nursing-homes-neglect-death-surge-3b74a2202140c5a6b5cf05cdf0ea4f32>