

Limitations on Visitation Continue to Harm Nursing Home Residents

A SURVEY OF RESIDENTS' FAMILIES

JUNE 2021



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OVERVIEW

In January 2021, the Consumer Voice released a [report](#) detailing the devastating effects on nursing home residents of visitation bans that had been imposed starting in March 2020 by the Centers for Medicare & Medicaid Services (CMS). Effects included significant physical and mental decline, with residents suffering and dying from neglect and isolation. Since then, CMS has gradually eased its [guidance](#) on visitation restrictions, with major changes in March 2021. However, despite the revised guidance, the proven efficacy of the vaccines, and the accompanying decline in COVID-19 cases and deaths, families and residents continue to face significant barriers to visitation, and residents continue to suffer from isolation and neglect.

The primary reason for continued limitations on visits is the almost complete discretion afforded facilities by the CMS guidance. Facilities persist in imposing their own visitation policies that restrict the length, frequency, and location of visits. These restrictions are commonplace even though the guidance states that facilities should allow indoor visitation at all times and for all residents, except in certain limited circumstances. Even when in-person visitation is allowed, visits are too short and infrequent to meet the significant needs of residents.

In May 2021, Consumer Voice began surveying families regarding their recent visitation experiences. Our survey found that families continue to face arbitrary barriers to visitation, such as time and frequency limits, and where the visits take place. Families also indicated that their loved ones were still significantly declining, both physically and mentally.

This report documents the responses of 392 family members, and contains Consumer Voice's recommendations, which include the full restoration of the resident's right to receive visitors.

KEY FINDINGS

- 77% of respondents indicated they were able to visit inside the facility with their loved ones.
- 88% of respondents indicated they were required to schedule a visit with their loved ones.
- 73% of respondents stated the facility did not require they be tested for COVID-19 before visiting with their loved ones.
- Only 62% of respondents stated that the facility allowed them to touch their loved ones.
- 76% of respondents indicated that the facility limited the length of their visits, while 63% stated the frequency of their visits was limited. On average, visits were 40 minutes and occurred only twice a week.
- 78% of respondents indicated that their loved ones had experienced physical decline.
- 79% of respondents indicated that their loved ones had experienced mental decline.
- 56% of respondents stated that visitation had been shut down temporarily at least once since March 2021, the date of CMS's most recent visitation guidance.
- 69% of respondents indicated the facility did not appear to have sufficient staff to care for residents.

FAMILY EXPERIENCE WITH VISITATION

While infrequent and short, 77% of respondents indicated that they were able to visit inside with their loved ones. 88% of respondents reported that they were required to schedule a visit to be with their loved ones. Many families complained that visitation only occurred during the week and when they were working, making it impossible for them to visit. Families faced other significant barriers as well, such as being prevented from touching their loved ones or being unable to visit in their rooms. Almost 8 in 10 respondents found that residents had experienced significant physical and mental decline, which they attribute to over a year of isolation and insufficient care.

Vaccination and Testing

CMS guidance states that facilities may not require visitors to be vaccinated. Nevertheless, 8% of respondents indicated the facility required them to be vaccinated before visiting their loved ones. Although this is contrary to the CMS guidance, family members obtained the vaccine so they could be with their loved ones.

Only 25% of families stated that facilities required them to be tested prior to visiting inside with their loved one, with 68% of those families indicating the facility provided the testing. The CMS guidance does not require testing, but many families agreed to be tested out of desperation to see their loved ones.

Visit Length and Frequency

76% of family respondents replied that facilities placed a time limit on the length of their visits, with those visits averaging roughly 40 minutes. 63% of families revealed that facilities were placing limits on the frequency of their visits, with visits averaging 2 times per week. Families expressed extreme frustration with these limitations, believing that more frequent visitation could help prevent further physical or mental decline, and help improve residents' well-being and functioning.

Location

Only half of respondents were able to meet with their loved ones in their rooms, with only 63% indicating the visits were private. Most respondents were frustrated at being barred from visiting in their loved one's rooms for several reasons. First, families wanted to be able to see the room to ensure their loved ones were in a clean and safe environment. Second, families expressed concern that their loved ones were missing items, such as glasses, dentures, clothes, and valuables, and they wanted to search for them. Finally, prior to the pandemic, many families provided significant assistance with activities of daily living, such as feeding, bathing, and dressing. Such assistance cannot be given if the resident is not in their own room.

Touch

Despite explicit language from CMS and the CDC that allowed families and residents to touch each other, only 62% of respondents indicated that they were allowed to touch their loved ones, with 33% of families stating that the facility did not allow them to touch. Numerous families were required to remain six feet away from their loved ones, which impeded communication and frustrated residents. Many residents have not been hugged by family for more than a year.

Personal Protective Equipment

48% of families indicated that facilities required PPE and provided it to visitors, such as masks and gowns. 39% of families stated the facility required them to provide their own PPE. 7% of families indicated there was no PPE requirement.

Visitation Continues to be Shut Down

56% percent of respondents reported that visitation in their loved one's facility had been shut down during an outbreak at least once in the previous two months. Many families attributed the shutdowns to unvaccinated staff members.

Significant Problems with Compassionate Care Visitation

CMS guidance explicitly states that compassionate care visits must be allowed at all times, even when there is an outbreak. Further, the guidance is clear that compassionate care visitation is not just for residents who may be approaching death, but for residents who undergoing a variety of experiences, including grief, loneliness, or depression. Despite this guidance, many families stated that the only reason they were allowed to visit with their loved ones was because the facility considered them compassionate care visits. Yet, even then, facilities were limiting the frequency and length of visits, often to only twice a week and for short periods of time.

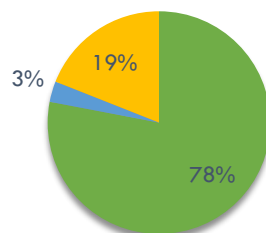
Quotes from family members:

- *"The facility makes you feel like she's in prison and they're the wardens and not like they want you to be there with your family member at all."*
 - *"Married 57 years and watching his decline thru a window. The saddest time in both our lives. Visiting at a table 6 feet apart in masks, I can't hear a word he says. Cruel!"*
 - *"Visitation is only M-F from 1 to 3 pm. This means that most working family members cannot visit at all."*
 - *"I usually stay about 10-15 minutes because it's uncomfortable to have a staff member sitting in the room while I'm trying to talk to my mom. My mom is in an advanced stage of disease, but I would still prefer to have a private visit with her."*
 - *"We have been vaccinated, my loved one and her roommate have both been vaccinated, and yet we still cannot go in their room."*
 - *"We are still told no compassionate care visits. We have read the facility guidelines on visits but the facility claims they follow the state guidelines."*
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IMPACT ON RESIDENTS

Physical Decline

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



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

Like Consumer Voice's earlier family survey, 78% of respondents indicated their loved ones had experienced a decline in their physical appearance, with many of those reporting significant declines in physical ability. Families complained that loved ones had lost significant weight and the ability to lift and carry objects. Respondents continued to report that their loved ones suffered from pressure ulcers from lying in bed for so long. One family member reported that her mother developed a pressure sore on her toe that became gangrenous. As a result, her mother had to undergo a partial leg amputation.

Quotes from family members:

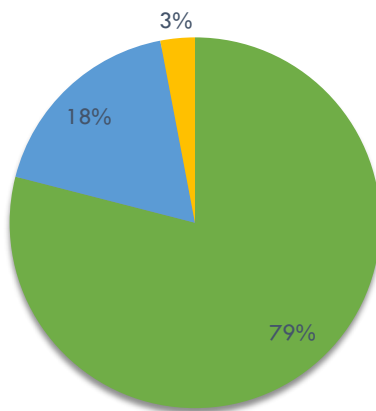
- *“Horrible so skinny and weak near death. Deprived of food drink activities and access to loved ones.”*
 - *“Extreme weight loss...bedsores, extreme back pain. Kept in bed March 13 until October.”*
 - *“My mom doesn’t stand or try to walk as she used to before. She also had a bedsore.*
 - *“Declining cognitively due to severe weight loss.”*
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COGNITIVE AND MENTAL HEALTH DECLINE

For months, most residents spent each day shut in their own rooms with little to no interaction with family or other residents. As a result, loneliness, depression, and cognitive decline took an extreme toll on residents. 79% of families reported that their loved ones felt abandoned, seemed depressed, and in some instances, suicidal. Residents with dementia and other cognitive impairments suffered precipitous declines, often being disengaged or completely unresponsive.

Notably, these responses mirrored previous responses from Consumer Voice’s earlier survey in January 2021. Almost six months after documenting such significant declines in residents, the problem persists.

Was there a change in your loved ones mental status?



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



CONCLUSIONS AND RECOMMENDATIONS

Much has changed since Consumer Voice issued its previous report on visitation in January 2021. COVID-19 cases and deaths are at an all-time low. Vaccination has proven to be effective and safe. CDC has eased masking and social distancing requirements. Importantly, CMS has loosened its visitation guidance.

Yet while the risk of contracting and dying from COVID-19 has significantly decreased, the risks from isolation, loneliness, and neglect continue. This is because the changes in the guidance have not translated into significant improvements for residents. Connection between residents and their families is negatively affected by arbitrary limits imposed by facilities on the length, frequency, and location of visits.

Prior to COVID-19 families played a crucial role in assisting residents by providing direct personal care, companionship and/or emotional support. This support, often provided daily, was essential to maintaining resident well-being and health. Now, restrictions, such as a 40-minute visit only two times per week, make it impossible for family members to provide the assistance necessary to prevent decline in residents. Further, compassionate care visits, designed to be the way in which residents who were declining or in distress could receive visits from their family members, have not achieved this purpose since these visits are often denied or severely restricted.

Quotations from loved ones and family members:

- *“Very subdued, not alert, sleeping in wheelchair, very short attention span, completely withdrawn.”*
- *“Despondent, depressed, angry. Did not get out of bed whereas before was very physically active, cried a lot. No interest in favorite things.”*
- *“Extreme depression, crying jags, extreme fatigue.”*
- *“My father can no longer hold a conversation. He is depressed, angry, and refers to the facility as a prison. No longer knows me. Flat affect- no smiles or facial expressions.”*
- *“Can’t understand anything she says- no longer speaking in real words.”*
- *“Complete disconnect. From her surroundings and me. Formerly happy and now looks sad, distant. Formerly social butterfly & telling jokes, now appears nonverbal.”*

The guidance fails to address the needs of residents who require regular, ongoing visits the most. The family survey results indicate that very little has changed for far too many residents since our January 2021 report. The physical and cognitive/mental health status of residents continues to decline; residents continue to suffer from isolation and neglect; and residents continue to die.

Further revision of the guidance is not the answer since the wide latitude given to facilities regarding visitation policies and the failure to enforce the guidance would only result in the same problems.

The time has come for the visitation restrictions to be completely lifted. After more than a year of prohibitions and limitations, residents need the ongoing presence and care of family and friends that can only come with unrestricted visitation. Consumer Voice, along with other advocacy groups, is [calling on CMS](#) to restore full visitation rights to nursing home residents without delay.

In addition to the full restoration of visitation, Consumer Voice makes the following recommendations:

Visitation

- Pass federal legislation giving each nursing home resident the right to designate two essential caregivers who can visit the resident to provide care and support during any public health emergency (currently HR 3733; 117th Congress).

Staffing and workforce

- Strengthen the direct care workforce by (a) increasing compensation, including hazard pay; and (b) improving access to affordable health insurance, paid family and medical leave, paid sick leave, and affordable childcare.
- Require a minimum staffing standard of at least 4.1 hours per resident day.
- Require 24-hour registered nurse presence in all nursing homes.
- Increase required nurse aide training to a minimum of 150 hours.
- Establish a robust enforcement mechanism to ensure adequate staffing levels.

Infection Prevention and Control

- Require a full-time qualified Infection Preventionist in all facilities.
- Require enhanced training on infection control.

As we move forward, we must ensure that the tremendous suffering and loss of life residents have experienced for far too long ends, and that residents are never again without supports during a public health emergency. We must also commit to dramatically improving how nursing home care is delivered in our nation. We owe it to the thousands of residents who suffered and died during the pandemic to guarantee that those who survived, as well as future residents, receive the quality of care and quality of life they so deserve.



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