

# Limitations on Visitation and Daily Activities Negatively Impact the Lives of Nursing Home Residents

## **A SURVEY OF RESIDENTS**

**JUNE 2021**



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### OVERVIEW

Throughout the COVID-19 pandemic, it became clear that residents of long-term care facilities were one of the most vulnerable populations in our country. They were at great risk from the virus due to their age and comorbidities, as well as the fact that they lived in congregate settings. According to the Centers for Medicaid and Medicare Services (CMS,) over 132,000 nursing home residents<sup>1</sup> have died of COVID-19.

At the start of the pandemic, CMS issued [guidance](#), banning in-person visitation, activities, and communal dining for nursing home residents, leaving many confined to their rooms. Assisted living and other long-term care facilities followed suit. While initially put in place to protect residents, this guidance led to residents declining, suffering, and dying from isolation, neglect, and poor care.

Fortunately, vaccines have completely changed COVID-19's impact on nursing homes. In the past six months, new cases and deaths have fallen dramatically<sup>2</sup>. However, although CMS has updated their guidance to allow for more visitation and communal activities, facilities continue to have wide discretion in what visitation and activities they allow. As a result, many residents still face considerable barriers to visitation and continue to suffer from isolation and neglect.

In January 2021, Consumer Voice issued a report, based on a survey of family members, detailing how devastating the visitation ban had been for residents. The report shed light on what residents had experienced throughout the pandemic and the extent of their suffering. In May 2021, two months after the updated CMS guidance, Consumer Voice determined it was time to again examine the family experience. The results are documented in the report: [Limitations on Visitation Continue to Harm Nursing Home Residents: A Survey of Residents' Families](#). At the same time, we also felt it was imperative to conduct a survey of residents themselves. With family members, long-term care ombudsmen, and surveyors shut out for a good portion of the pandemic, residents are the only people who can attest to what they have experienced, and they are most suited to explain the current situation they face. Our resident survey included not just questions about visitation, but also about quality of life.

Throughout the pandemic, it has been hard to access residents and hear their voices. The respondents in this survey are the residents who are able to communicate their responses using an online survey. They are not the residents who have experienced the most decline this year, but they are in the best position to articulate the current state of nursing home life and care.

The results of the resident survey are below. Over 100 residents responded to the survey – the majority of whom live in nursing homes. Over 84% of respondents have received the COVID-19 vaccine. Their answers make clear that life has not gone back to normal; visitation is still very restricted; and residents' freedoms within the facility remain limited as well. Many are unable to go outside when they want, dine communally, participate in group activities, and visit friends within their facility. Importantly, a majority of residents report they are not receiving the care that they need.

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<sup>1</sup> <https://data.cms.gov/stories/s/COVID-19-Nursing-Home-Data/bkwz-xpvg/>

<sup>2</sup> COVID-19 Long-Term Care Deaths and Cases Are at an All-Time Low, Though A Rise in LTC Cases in a Few States May Be Cause for Concern. Priya Chidambaram and Rachel Garfield. KFF. April 22, 2021. <https://www.kff.org/coronavirus-covid-19/issue-brief/covid-19-long-term-care-deaths-and-cases-are-at-an-all-time-low-though-a-rise-in-ltc-cases-in-a-few-states-may-be-cause-for-concern/>

## KEY FINDINGS

Of the residents who responded to the survey:

- 85% are able to visit indoors with friends and family.
- 72% report that their visits are limited in length.
- 50% say the frequency of visits is limited.
- 79% report that they're limited in how many visitors they see at one time.
- 69% report that they can touch/hug their visitors.
- 39% report that staff is present during portions or all of their visits.
- 68% are unable to go outside as often as they like.
- 43% have all meals in the dining room, with 40% unable to have any meals in the dining room.
- 23% report that activities are back to normal, with 33% reporting they have no group activities.
- 26% report that they can visit with friends in their facility whenever they like, while 32% report they are not allowed to visit with friends within their facility.
- 60% report they are not receiving the care that they need when they need it.

## VISITATION

While 85% of residents who responded are able to have indoor visits with their friends and family, the majority of those visits are limited in length and frequency. Additionally, because only 55% of respondents stated their facility had explained their visitation policies to them, many residents may be unaware of the rules surrounding visitation.

### Visit Length and Frequency

Most respondents, 72%, reported that the length of their visits is limited by their facility. Some reported visits as short as 15 minutes, though most report anywhere from 30 minutes to 2 hours – with most visits lasting 30-40 minutes. Several commented that facilities limit the hours during which visitation can occur, often permitting visits only during working hours or times that may not be convenient for family.

50% of respondents reported that the frequency of visitation is limited. The frequency of visits ranged from once a day to twice a month, with many reporting one to two times per week. Others indicated that visits had to be scheduled and visitation depended on the available slots in their facility.

Facilities also limit how many individuals can visit at any one time; 79% of residents reported that the number of visitors is restricted. Almost every resident stated they are limited to two visitors at a time.

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Resident comments included:

- *“My daughter has a hard time coming to see me because of the visiting hours 10am-6pm.”*
  - *“10am to 6pm – my family works.”*
  - *“Monday – Friday only. Scheduled time. 3pm is the latest time during the day. If visitors work, they can't make it.”*
  - *“Visiting is too restrictive – visits are only 1 hour and ends at 5pm.”*
  - *“Limited visits. Only once a week for 30 minutes.”*
  - *“Very limited hours. Monday to Friday. No evenings or weekends...”*
  - *“Don't understand why limited to 30 minutes when we are all vaccinated...”*
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## Touch

The current CMS guidance states that vaccinated residents may touch and hug their vaccinated loved ones. While 84% of respondents reported that they are vaccinated, only 68% indicated they could touch or hug their visitors.

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Resident comments included:

- *“They don’t abide by current CDC guidelines.”*
- *“Visitors and patients must observe a distance of 6 feet. This makes it hard to hug someone.”*
- *(When explaining why they couldn’t touch) “Because they said so.”*
- *“One hug, only briefly, no other touching.”*
- *“Against nursing home policy.”*

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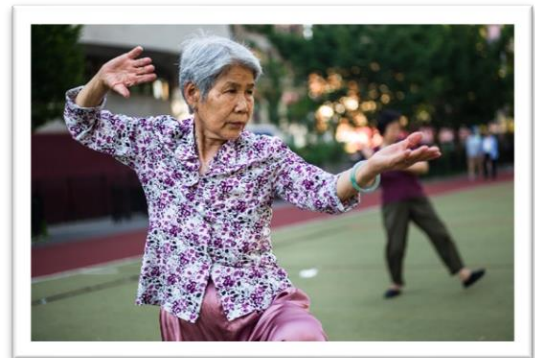
One resident noted that they were able to touch and hug, “but only because my visitor knew it was allowed. The facility tried to keep 6 feet between me and my visitor.”

## Private Visits

A large portion of residents are still not able to have private visitation. While 61% report that staff members are not present during their visits, 17% report that staff is present during their entire visit, and 22% report that staff is present during some of their visit.

## QUALITY OF LIFE

While visitation impacts many nursing home residents, quality of life within a facility impacts all residents, even those without family or friends to visit. In the first several months of the pandemic, Consumer Voice heard many stories about residents who were literally shut into their rooms – whose doors remained closed all day long, and who were unable to move around within their facility or go outside for fresh air. Given the importance of quality of life, our survey included questions to gauge what residents are experiencing now.

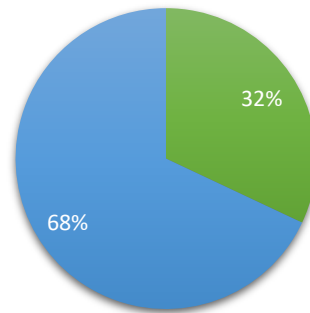


The March 2021 CMS guidance allows for communal activities and dining, stating that “residents who are fully vaccinated may dine and participate in activities without face coverings or social distancing... if unvaccinated residents are present during communal dining or activities, then all residents should use face coverings when not eating and unvaccinated residents should physically distance from each other.” However, the survey found that, while in some cases life is returning to normal, there are still many residents who lack autonomy over aspects of their daily lives that are significant to them.

## Getting Fresh Air

When asked whether they are able to go outdoors for fresh air as often as they like, only 32% of respondents answered yes. The majority, 68%, said, no.

## Can Residents Go Outside For Fresh Air As Often As They Like?



■ Allowed to go outside whenever they choose. ■ Not allowed to go outside when they choose.

When asked how often residents can go outside, respondents' answers varied. While 58% can go outside several times a day, 15% are not permitted to go outside even once a week.

Residents listed several reasons for not being permitted to go outdoors when they want; many of their responses referred to staffing issues as the problem.

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Resident comments included:

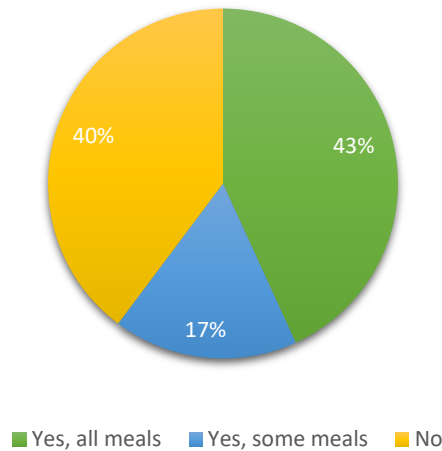
- *“Not enough staffing at the facility to assist me.”*
- *“Not enough staff to assist.”*
- *“The facility will only allow 30 minutes of guarded time outdoors per day.”*
- *“Staff is too busy.”*
- *“Staffing shortages, COVID guidelines for outside visits limited.”*
- *“Need a staff member.”*
- *“They don’t take us out!”*
- *“Not enough staff.”*
- *“Insufficient staffing to take residents out.”*
- *“Someone would have to take me. They ‘don’t have time.’”*
- *“Its too much work for them, residents left inside.”*
- *“Facility says can only go outside if chaperone staff available and residents must take turns – 300 bed facility... so cannot just go outside out of desire or need to feel sunshine and a bit of normalcy.”*

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### Eating In the Dining Room

CMS guidance allows for communal meals to resume with appropriate infection prevention measures, yet numerous residents report that this has not happened. 43% of respondents are permitted to eat all meals in the dining room; 17% report eating some meals in the dining room; and 40% are still not permitted to eat in the dining room at all.

## Can Residents Eat in the Dining Room?



When asked why they are not yet eating in the dining room, residents had varied responses.

Resident comments included:

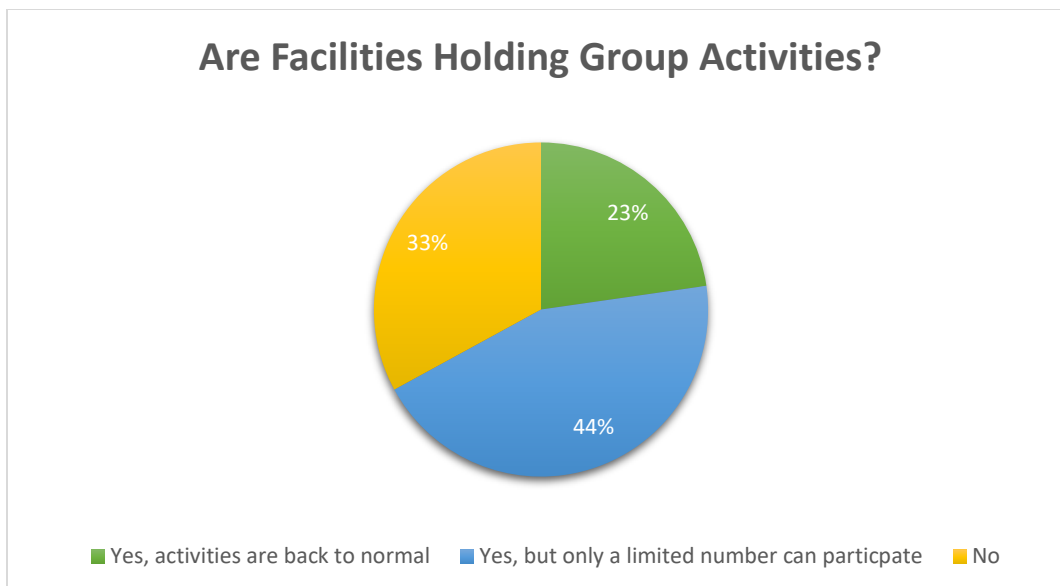
- *"I have not eaten in the dining room since the pandemic – staffing issues."*
- *"Social distancing is still observed at my facility. Our meals are served in our rooms..."*
- *"Not yet, but they are working on it."*
- *"Not serving in dining rooms yet."*
- *"No dining with others only in my room."*
- *"I have to eat in my room and they always run out of food and bring me things I didn't select that taste bad."*
- *"Meals are in rooms."*
- *"COVID shut down restrictions."*
- *"No one is allowed to go into the dining room."*

## Group Activities

Activities are not back to normal in the majority of facilities, despite the updated CMS guidance. 44% of respondents reported that only a limited number can participate in activities, and 33% reported that there are no group activities at all. Only 23% of residents responding reported that activities are back to normal.



## Are Facilities Holding Group Activities?



For most residents, there are few, if any, communal activities to engage in.

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Resident comments included:

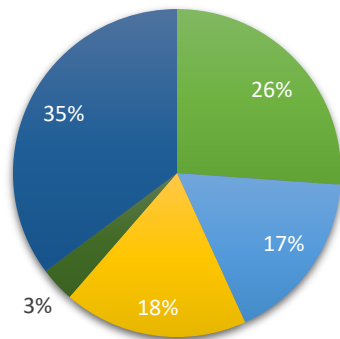
- *"My facility has no group activities, we are supposed to stay in our rooms..."*
- *"No staff to help."*
- *"Very little communal activity."*
- *"The activities director quit."*
- *"Only bingo 3 times a week & limited number of people. No other activities are happening."*
- *"Not allowed yet."*
- *"Don't know why except not enough staff."*
- *"No activities outside room and no one available to help. Paint is dropped off without much assistance. Coloring pages are dropped off. Bingo is on TV. I can't hear it or see it very well." Very frustrating and I quit."*
- *"They have doorway activities but I can't participate because I am in a wheelchair. You can't see the other residents."*
- *"No group activities. We stay in our rooms and games are played over the intercom."*

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## Spending Time with Other Residents

When asked whether they are permitted to visit with and spend time with other residents in their own facility, 35% reported that they are still not allowed to spend any time with other residents; 3% reported they can visit rarely; 18% reported they can visit sometimes; 17% reported they can visit frequently; and 26% reported they can visit as often as they like.

## Are Residents Able to Visit with Other Residents?



■ Yes, as often as we like    ■ Yes, we can visit frequently    ■ Yes, we can visit sometimes  
■ Yes, we can visit rarely    ■ No

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### Resident comments included:

- *"The facility would rather not have people visit in other people's rooms, but they don't have the staff to enforce it."*
- *"I would like to visit with other residents."*
- *"They say maybe next week but next week never comes."*
- *"They keep us in our rooms."*
- *"I'm pretty much confined to my room."*
- *"No resident interaction."*
- *"As long as we are not in quarantine."*
- *"Facility wants us to stay in our rooms. This isn't right."*

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### Facility communication:

Residents were asked if their facility communicates with them as often as they would like, for instance, by sharing updates and answering questions. The answers varied, with 20% reporting that their facility communicates all information; 18% reporting that their facilities communicate some information; 40% reporting they have to ask for information; and 22% reporting that their facilities share no information.

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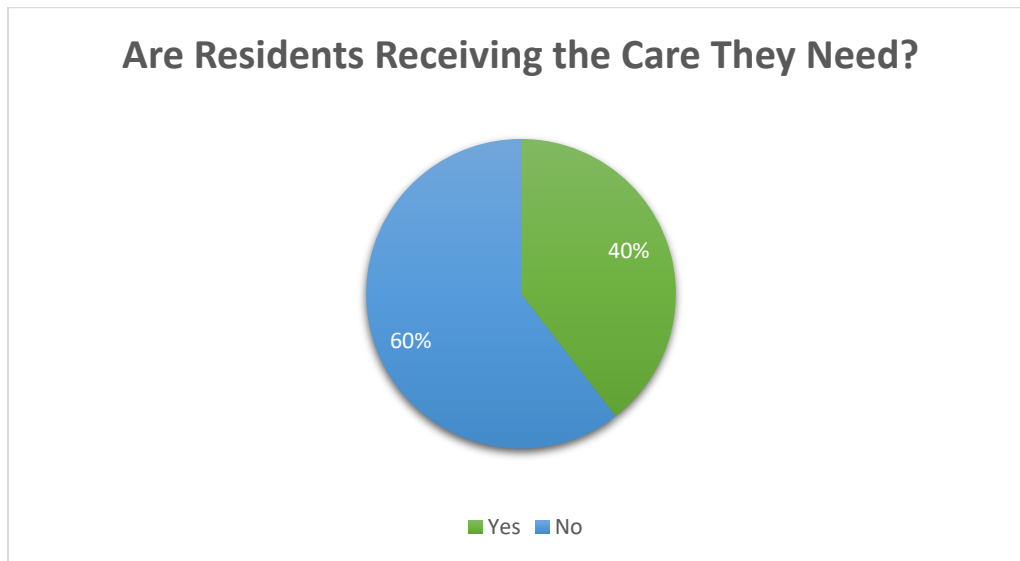
### Resident comments included:

- *"I have to continually ask and I don't always get answers, or the answers differ from day to day, or person to person."*
- *"Open communication is not regularly practiced at this facility. A patient has to be vigilant and keenly aware of surroundings, asking questions repeatedly to get proper answers."*
- *"They don't bother talking to me because I can't hear. I lost my hearing aids."*
- *"I don't even know what to ask. I feel like I'm in jail."*
- *"Only people that ask or know will be given the most current guidelines. Otherwise, you're still sitting on the porch with a mask and six feet of distance or doing window visits."*
- *"They don't inform residents and family members of any information."*



## Level of Care Received

When asked if they felt they were receiving the care they need from their facility when they need it, the majority of residents - 60%- answered no. 40% said yes. A significant number of responses refer to staffing shortages.



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### Resident comments included:

- *“The people are nice, but turnover is bad, so staff is either missing or frequently poorly trained. They tell me they don’t receive much communication either.”*
  - *“Often left in soiled briefs, left in bed too long or in the chair too long, nurse call light not always answered, waiting for hours for a staff member to answer my call light on evenings and weekends.”*
  - *“I feel the quality of care is poor.”*
  - *“My facility is very short staffed. They over work the staff that to the point that they want to quit working at the facility. Even agency staff wants to leave because they are taking care of 20 residents alone at times.”*
  - *“Just now saw a podiatrist only because my family pushed and pushed. Still haven’t seen a dentist but one is coming only because my family scheduled it.”*
  - *“We are always short on staff, especially CNAs.”*
  - *“They don’t have no time for me.”*
  - *“Not enough baths. Have to ask for bed linen to be changed.”*
  - *“Don’t give me a bath.”*
  - *“They bring meals cold – they are rough and shorthanded. There never seems to be enough help. They take too long to answer call lights.”*
  - *“A lot of problems with call light answering in a timely manner. Often the aid will come in and ask what I need, turn off the light and say they’ll be back, but never come back or take a long time to come.”*
  - *“Staffing issues.”*
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## CONCLUSION

Despite changes to the CMS guidance and the success of vaccines, many residents are living in situations where they are still severely restricted, not just in terms of visitation, but also with what they can and cannot do. Many are unable to go outside and visit friends when they want. Many cannot dine communally or participate in group activities. The changes in the guidance have not translated into significant improvements for residents. While the risk of contracting and dying from COVID-19 has significantly decreased, the risks from isolation, loneliness, and neglect continue.

Because of this, we believe it is crucial that surveyors begin focusing on residents' quality of life. While infection control surveys were prioritized throughout the pandemic because residents were at serious risk of contracting and dying from COVID-19, residents are now suffering deeply from the impact of almost 18 months of isolation. We urge CMS to develop and conduct a quality of life survey that evaluates key elements in this area, including but not limited to, whether:

- Residents have an appropriate person-centered care plan that is being properly implemented.
- Facilities are actively mitigating the impact of isolation by engaging residents in communal activities and dining, as appropriate.
- Residents' rights to self-determination and choice are being respected and upheld.

In addition, Consumer Voice recommends the following:

### Visitation

- Restore full visitation rights to nursing home residents without delay. Consumer Voice, along with other advocacy groups, has [called on CMS](#) to take this action.
- 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 H.R. 3733; 117<sup>th</sup> 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.

