

March 3, 2021

Elizabeth Richter
Acting Administrator
Centers for Medicare and Medicaid
7500 Security Boulevard
Baltimore, MD 21244

Dear Acting Administrator Richter:

On March 13 it will be one year since nursing home doors closed and in-person visits were banned by state and federal officials. Although put in place to protect residents, the visitation ban itself has resulted in residents declining, suffering and dying from isolation, loneliness, neglect and poor care—in many cases confined to their rooms in virtual solitary confinement for weeks or months. The National Consumer Voice for Quality Long-Term Care (Consumer Voice), a national organization that advocates for quality care for nursing home residents, and the undersigned organizations and individuals, call on you to take immediate measures to safely open the doors of nursing homes and end the damaging toll of isolation and neglect on residents.

The impact of the lockdown has been devastating:

- More than 40,000 excess deaths in nursing homes not attributable to COVID-19 had occurred as of November 2020;¹ some death certificates list the cause of death as “social isolation/failure to thrive related to COVID-19 restrictions.”²
- Nursing home residents are experiencing intense emotional and mental distress.
 - In a survey of family members conducted by the Consumer Voice, 91% of respondents said their loved ones’ mental status had declined.³
 - Reports to the Consumer Voice from family members and long-term care ombudsmen describe residents as depressed and despondent.
 - A recent survey of residents found they felt significantly lonelier since the visitation restrictions were implemented.⁴

¹ Not just COVID: Nursing home neglect deaths surge in shadows. AP. November 18, 2020. Matt Sedensky and Bernard Condon. <https://apnews.com/article/nursing-homes-neglect-death-surge-3b74a2202140c5a6b5cf05cdf0ea4f32>

² The hidden COVID-19 health crisis: Elderly people are dying in isolation. NBC News. October 27, 2020. Suzy Khimm. <https://www.nbcnews.com/news/us-news/hidden-covid-19-health-crisis-elderly-people-are-dying-isolation-n1244853>

³ The Devastating Effect of Lockdowns on Residents of Long-Term Care Facilities During COVID-19: A Survey of Residents’ Families, p. 1. January 15, 2021. National Consumer Voice for Quality Long-Term Care. https://theconsumervoiced.org/uploads/files/issues/Devastating_Effect_of_Lockdowns_on_Residents_of_LTC_Facilities.pdf

The National Consumer Voice for Quality Long-Term Care (formerly NCCNHR) is a 501(c)(3) nonprofit membership organization founded in 1975 by Elma L. Holder that advocates for quality care and quality of life for consumers in all long-term-care settings.

- Some residents have expressed a desire to die rather than continue living in isolation.⁵
- Residents with dementia are experiencing rapid decline and memory loss, becoming unresponsive and even losing their ability to talk.^{6 7}
- Residents have significantly declined in both their physical abilities and their physical appearance. They are losing large amounts of weight, becoming dehydrated, losing their ability to walk, stand, and sit up, and developing pressure ulcers and contractures. Some are not being bathed or having their teeth brushed.⁸

Several factors have accelerated decline and hastened death of residents during the past year. First, the decline in the number of qualified staff to provide basic assistance with daily living activities and skilled nursing care has severely affected residents. From June 7, 2020 through January 1, 2021, nursing homes have reported on average a 19 percent shortage of nurse aides and a 16 percent shortage of nurses.⁹ In numerous facilities, the shortage of certified nursing assistants has been so severe that temporary nurse aides (TNAs) were hired, but given so little training that residents report that some TNAs lack the skills to assist them. A second factor is the lack of monitoring, advocacy, assistance and support provided by family members. Families inform staff about their concerns when loved ones do not receive required care, and many provide care themselves when there are not enough staff. Without family visitors, residents may not receive that care at all. Finally, the absence of regular onsite visits by state surveyors and advocacy by long-term care ombudsmen, especially in the absence of family oversight, mean that serious problems go undetected, unchecked and unaddressed.

CMS acknowledges that physical separation from family and other loved ones has taken a physical and emotional toll on residents.¹⁰ The September 17, 2020 CMS guidance on visitation was an attempt to provide “reasonable ways” for a nursing home to safely conduct in-person visits. However, the guidance is not working. There are states that refuse to implement the guidance, and nursing homes that ignore it. Whether to allow visits, and their frequency and length, often seem to be based on arbitrary decisions of corporate offices and nursing home administrators rather than on the CMS guidance, and facilities’ visitation rules are established largely without regard to residents’ needs and person-centered care. In addition, facilities regularly deny compassionate care visits in situations that are clearly appropriate and critically important to residents and their close family members, causing residents with the greatest needs to decline further and even to die. Residents and their families in these situations have no meaningful recourse because the CMS guidance is not enforced.

⁴ Experiences of Nursing Home Residents During the Pandemic. October 2020. Altarum. https://altarum.org/sites/default/files/uploaded-publication-files/Nursing-Home-Resident-Survey_Altarum-Special-Report_FINAL.pdf

⁵ Devastating Effect of Lockdowns, p. 3.

⁶ Ibid.

⁷ ‘We Are Going to Keep You Safe, Even If It Kills Your Spirit.’ Opinion. New York Times. February 19, 2021. Katie Engelhart.

⁸ Devastating Effect of Lockdowns, pp 2-3.

⁹ COVID-19 Nursing Home Dataset. <https://data.cms.gov/Special-Programs-Initiatives-COVID-19-Nursing-Home/COVID-19-Nursing-Home-Dataset/s2uc-8wpx>

¹⁰ CMS Memo to State Survey Agency Directors. QSO-20-39. September 17, 2020. <https://www.cms.gov/files/document/qso-20-39-nh.pdf>

CMS must make visitation mandatory. It is time to open nursing home doors in a safe and sensible way. The visitation ban was imposed to protect residents from harm and death due to COVID. Yet the decline, harm, and death of residents from isolation and neglect is just as serious and significant as harm or death due to COVID.

The time has also come because the risk-benefit analysis has been altered by the implementation of the vaccine to prevent COVID-19 and the reduced risk of contracting and dying from the virus. According to a Kaiser Family Foundation analysis, resident deaths from COVID-19 in nursing homes have decreased by two-thirds (66%) since vaccination efforts began in late December, and new cases of the novel coronavirus among residents have fallen even more sharply, by 83 percent.¹¹ In addition, findings from a recent analysis of the relationship between COVID-19 vaccinations and spread in long-term care facilities indicate that transmission may decline within three weeks after residents receive the first dose of the vaccine.¹² This is bolstered by early results on lab-tested infections that show the vaccine may also prevent asymptomatic carriers from spreading the virus.¹³

Although the risk to residents from COVID is decreasing, the risk to residents of social isolation and neglect is continuing. Research underscores the ongoing harm of social isolation and neglect/abuse:

- Social isolation and loneliness have negative effects on older adults in general¹⁴ that are exacerbated for persons residing in long-term care settings.¹⁵
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- The link between inadequate staffing levels and poor care outcomes, such as malnutrition, dehydration, and pressure ulcers, is well-established.¹⁶
- A 2018 Human Rights Watch report that documented abuse in nursing homes found that people without family or friends who visit or communicate with staff, and who have language barriers or disabilities that make their ability to communicate with others difficult, are some of the most at risk for maltreatment.¹⁷

¹¹Is the End of the Long-Term Care Crisis Within Sight? New COVID-19 Cases and Deaths in Long-Term Care Facilities Are Dropping. Kaiser Family Foundation. February 24, 2021. Priya Chidambaram, Rachel Garfield, Tricia Neuman, Larry Levitt.

¹²Nursing Home Resident and Staff Covid-19 Cases After the First Vaccination Clinic. The Center for Health Policy Evaluation in Long-Term Care. The Center for Health Policy Evaluation in Long-Term Care. February 4, 2021. Prepared by Marsida Domi, MPH Michael Leitson, MS David Gifford, MD, MPH Kiran Sreenivas, MS. <https://www.ahcancal.org/Data-and-Research/Center-for-HPE/Documents/CHPE-Report-Vaccine-Effectiveness-Feb2021.pdf>

¹³Pfizer-BioNTech Shot Stops Covid Spread, Israeli Study Shows. Bloomberg, February 21, 2021. Naomi Kresge and Jason Gale. <https://www.bloomberg.com/news/articles/2021-02-21/pfizer-biontech-shot-stops-covid-s-spread-israeli-study-shows>

¹⁴ Social Isolation and Loneliness in Older Adults: Opportunity for the Healthcare System. Ch.3.pp 49-61.

¹⁵ Victor, C.R. (2012). Loneliness in care homes: a neglected area of research? *Aging Health*, 8(6), 637-646. <https://doi.org/10.2217/ahe.12.65>

¹⁶ Appropriate Nurse Staffing Levels for U.S. Nursing Homes. Health Services Insights Volume 13: 1–14. Charlene Harrington, Mary Ellen Dellefield, Elizabeth Halifax, Mary Louise Fleming, Debra Bakerjian. June 29, 2020. <https://journals.sagepub.com/doi/full/10.1177/1178632920934785>

¹⁷ "They Want Docile:" How Nursing Homes in the United States Overmedicate People with Dementia. Human Rights Watch report. February 5, 2018. <https://www.hrw.org/report/2018/02/05/they-want-docile/how-nursing-homes-united-states-overmedicate-people-dementia>

The therapeutic value of nursing home visitation in normal circumstances has not been given sufficient consideration in developing pandemic policy. One study that examined the impact of visitation on resident well-being found that increased frequency of visits resulted in lower levels of psychosocial impairment, suggesting that “visitation has a significant therapeutic influence on patient well-being.”¹⁸ Visits are in essence “medicine” that is critical to positive physical and mental health outcomes.

It is unclear when and potentially even whether COVID-19 will be eradicated. Epidemiologists suggest we may need to learn to live with this virus and mitigate its risks. Therefore, we must learn to mitigate the risk of coronavirus without subjecting residents to isolation policies that create an equal risk of decline, illness and death for many.

Opening nursing home doors must be done in a measured and safe way. The same screening and infection control practices required of staff should be applied to visitors. A facility could also require a negative COVID-19 test if it provided free rapid point-of-care testing or accepted proof of a negative test within the past 72 hours. Additionally, facilities should designate a staff person or volunteer to coordinate and facilitate visitation.

After twelve months of isolation, we must forge a path forward to provide residents the support they need and reconnect them with their families.

We request that CMS restore full visitation rights as soon as possible. In the interim, and during the Public Health Emergency only, we urge CMS to ensure that:

- **Each resident is allowed an essential support person (ESP).**¹⁹ More than one person may be designated as an ESP, but only one ESP per resident should be present at one time. The ESP must be allowed unrestricted access to residents to provide them physical and emotional support and meet their needs. ESPs should be treated as employees of the facility for infection control purposes, including routine COVID-19 testing and the wearing of PPE.
- **All residents are allowed indoor and outdoor visitation in addition to visits with an ESP.** Visitation must follow strict screening and infection control procedures. Length and number of visits must be in accordance with a resident’s needs and preferences but no less than one hour weekly. This one hour per week does not include visits from ESPs. Visits must continue regardless of outbreaks, county positivity rate, and staffing levels. A positive COVID test for a resident or staff person, or a county positivity rate greater than 10% may be factors in determining the level of visitation allowed, e.g. the number of visitors permitted at one time or the locations for visits, but must not suspend visitation.

¹⁸ Greene, V. L., & Monahan, D. J. (1982). The impact of visitation on patient well-being in nursing homes. *The Gerontologist*, 22(4), 418-423. <https://doi.org/10.1093/geront/22.4.418>

¹⁹ Federal regulations at 42 CFR 483.10(f)(4) give the resident the right to receive visitors of their choosing at the time of their choosing. This requirement has not been waived or rescinded. Thus, under this authority, residents may designate a person to provide them with essential supports.

Our full set of recommendations is set forth below in the Appendix.

Safe visitation and support for residents are possible without keeping nursing home doors tightly shut. Please take action to reunite residents with their loved ones after a year in which they have suffered from isolation, decline and often, dangerous neglect.

For questions or more information, contact Robyn Grant, Director of Public Policy & Advocacy at the Consumer Voice, rgrant@theconsumervoice.org.

Sincerely,

Organizations

California Advocates for Nursing Home Reform
Center for Advocacy for the Rights and Interests of the Elderly
Center for Medicare Advocacy
Friends of Residents in Long Term Care
Long Term Care Community Coalition
Michigan Elder Justice Initiative
Michigan Long-Term Care Ombudsman Program
Minnesota Office of Ombudsman for Long-Term Care
National Consumer Voice for Quality Long-Term Care
Office of the Texas Long-Term Care Ombudsman
Our Mother's Voice

Individuals

Beverly L. Laubert, Ohio State Long-Term Care Ombudsman
Mairead Painter, Connecticut State Long-Term Care Ombudsman
Denise Pensinger, Nursing Home Resident
Penny Shaw, Nursing Home Resident

cc: Dr. Lee Fleisher, Chief Medical Officer and Director of the Center for Clinical Standards and Quality, Centers for Medicare and Medicaid Services
Evan Shulman, Director, Nursing Home Division, Centers for Medicare and Medicaid Services
Rochelle P. Walensky, Director, Centers for Disease Control and Prevention

NATIONAL CONSUMER VOICE FOR QUALITY LONG-TERM CARE

VISITATION RECOMMENDATIONS

FOR NURSING HOMES DURING COVID-19

On March 13, 2021 it will be one year since nursing home doors closed and visits were banned by state and federal officials. Initially put in place to protect residents from COVID-19, the visitation ban has resulted in thousands of residents suffering and many dying from isolation, loneliness, and poor care. It is time to stop the suffering and safely open the doors.

We have learned from residents and their families that many residents are depressed, lonely, and despondent. A significant number have withdrawn and lost their will to live. Residents with dementia are experiencing rapid decline and memory loss, becoming unresponsive, and losing their ability to talk.

The harm is accelerated by inadequate numbers of staff and the lack of monitoring, advocacy and assistance frequently provided by family members. This absence has led to residents losing significant amounts of weight; becoming dehydrated; losing their ability to walk, stand, and sit up; developing pressure ulcers and contractures; and not being bathed or having their teeth brushed. In November 2020, it was estimated that there had been [40,000 excess deaths¹](#) not attributable to COVID-19 in nursing homes in 2020 as compared to 2019. A Consumer Voice [survey of families²](#) also found that residents were suffering from isolation and neglect.

While initially intended to keep residents safe from COVID-19, the harm, suffering and death of residents due to isolation and short staffing demonstrate that it is well past time to allow safe visits from families and essential support persons. By extending existing infection control and prevention protocols to families, we can begin to ensure residents are receiving the physical and emotional support and care they need. Every day more and more nursing home residents and staff are being vaccinated, and the risk of harm from infection is decreasing. At the same time, the risk of harm from isolation and neglect increases, as residents continue to go without care and companionship for a longer period of time. We cannot focus solely on COVID-19, while ignoring this other great risk. Steps must be taken immediately to stop the suffering.

We recommend that CMS adopt the following provisions in order to provide safe visitation and support for residents until full visitation rights can be restored.

ALLOW EACH RESIDENT TO DESIGNATE AN ESSENTIAL SUPPORT PERSON

An Essential Support Person (ESP) is an individual designated by the resident or the resident's representative to provide physical and/or emotional support, assistance, companionship, and/or help to meet the resident's needs.

¹ Not Just COVID: Nursing home neglect deaths surge in shadows. AP. November 19, 2020. Matt Sedensky and Bernard Condon.

² The Devastating Effect of Lockdowns on Residents of Long-Term Care Facilities During COVID-19: A Survey of Residents' Families. National Consumer Voice for Quality Long-Term Care. January 15, 2021.

- Each resident must be allowed an ESP. More than one person may be designated as an ESP, but only one ESP per resident may be present at any one time.
- No limits can be placed on the frequency, length, and time of ESP visits, except by the resident.
- The location of the ESP visit inside the facility should be based on the resident's needs and preferences. Outdoor visits must be permitted, but not required.
- The ESP must adhere to the same screening, testing, infection control procedures and PPE requirements as staff. The cost of testing and PPE must be borne by the facility. ESPs must be allowed to use their own PPE if a facility is experiencing a shortage.
- Physical distancing is not required between the ESP and the resident they are supporting, however they must physically distance from others in the facility.
- ESP visits are not contingent on county positivity rates, facility COVID-19 outbreaks, individual resident COVID-19 status, or staffing levels.

GENERAL VISITATION MUST BE EXPANDED

Nursing homes must allow indoor visits and outdoor visits for all residents.

Visitors must adhere to the following Core Principles of COVID-19 Infection Prevention:³

- Screening of all who enter the facility for signs and symptoms of COVID-19 (e.g., temperature checks, questions or observations about signs or symptoms), and denial of entry for those with signs or symptoms;
- Hand hygiene (use of alcohol-based hand rub is preferred);
- Face covering or mask (covering mouth and nose); and
- Social distancing at least six feet between persons.
- If a negative COVID-19 test is required for visitation, the facility must offer a rapid point-of-care test at the facility's expense. If a visitor provides documentation of a negative COVID-19 test taken within the previous 72 hours, the facility must accept this as proof of a negative test.
- PPE and infection control supplies must be provided at the facility's expense. If a facility is experiencing a shortage of PPE, it must allow visitors to use their own.
- The nursing home must designate a person to coordinate and facilitate visitation. Their name and contact information must be shared with residents and their families.
- The visitation location must be individualized, accommodate the resident's needs and preferences, and allow for privacy. Staff must respect residents' rights to privacy during the visit. The preferences and privacy of a resident's roommate must also be considered when determining the location of the visit.
- When determining the number of visitors allowed in the nursing home at any one time, the nursing home should consider the capacity of visitation areas or common areas, and the ability to ensure social distancing and implementation of infection prevention protocols. Visits occurring in a resident's room should not factor into the number of visitors permitted.
- When determining the number of visitors per resident at any one time, facilities should take into consideration:

³ QSO-20-39-NH, Centers for Medicare and Medicaid Services, Memo to State Survey Agency Directors, September 17, 2020.

- The resident's needs and preferences.
- The location of the visit, i.e. the resident's room vs. a common area.
- Accommodations to support the visits as needed; for example, the elderly wife of a resident who needs assistance walking or being wheeled to the visit.
- Each resident should have the ability to see visitors for at least one hour weekly, dependent on the residents' needs and preferences. This one hour per week does not include visits from ESPs, non-essential health care personnel, therapy personnel, hospice, home care, dialysis, representatives of the Long-Term Care Ombudsman Program, state surveyors, beauticians, and chaplains/spiritual advisors.
 - Daytime, evening, and weekend hours must be made available for visits.
- Visits must continue regardless of outbreaks, county positivity rate, and staffing levels. A positive COVID test for a resident or staff person, or a county positivity rate greater than 10% may be factors in determining the level of visitation allowed, e.g. the number of visitors permitted at one time or the locations for visits, but must not suspend visitation.

END-OF-LIFE VISITS CANNOT BE LIMITED

- End-of-life visitation cannot be limited to persons enrolled in hospice, or to a resident's last days or hours.
- When a resident is at their end of life or is receiving hospice services, the facility must permit persons of the resident's choice to be at the resident's bedside. The resident representative must be notified when a substantial change in condition occurs that indicates that a resident's end of life may be approaching.
- Facility policies must not restrict the number, frequency, length, or time of visits or the number of visitors.

ENTRY OF OTHER PROVIDERS OF SERVICE AND REPRESENTATIVES OF AGENCIES/PROGRAMS

Others must also be permitted to enter the facility, with screening, PPE, and implementation of infection prevention protocols. This includes, but is not limited to, essential health care personnel, therapy personnel, hospice, home care, dialysis, representatives of the Long-Term Care Ombudsman Program, state surveyors, beauticians/barbers, and chaplains/spiritual advisors.

For more information, contact:
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