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RE: Call for CMS to Restore Nursing Home Residents' Full Right to Visitation

Dear Dr. Fleisher and Mr. Shulman,

In March 2020, the Centers for Medicare and Medicaid Services (CMS) issued guidance which closed nursing home doors, banned in-person visitation, and, in many cases, left nursing home residents confined to their rooms. While the guidance was initially put in place to protect residents from the impact of COVID-19, over time it has resulted in residents declining, suffering, and dying from isolation, loneliness, neglect, and poor care. With the success of vaccination efforts and the Centers for Disease Control and Prevention's (CDC) easing of masking and social distancing measures in nursing homes, it is time to remove restrictions on visitation rights. While recognizing that all visitation needs to comply with CDC Core Principles of Infection Prevention, our organizations call on CMS to take immediate action to restore nursing home residents' full right to visitation under the federal nursing home regulation 42 CFR §483.10(f)(4) and lay out a plan and timeframe for implementation.

Vaccines have completely changed COVID-19's impact on nursing homes. Over the past six months, new cases and deaths have fallen dramatically. The average new weekly cases in long-term care facilities (LTCF) in April 2021 were at 1.6 per 100,000, compared to 20.3 per 100,000 in December before the vaccine program began – new cases have dropped 92% in LTCFs¹. In

¹ 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/>

April 2021, five states reported zero LTCF deaths from COVID-19. Resident deaths across all states fell to 0.2 deaths per 100,000, a decline of 89% since the vaccination program began in December 2020.² This decline is larger than within the general community. Importantly, the New England Journal of Medicine is reporting that electronic health record data from Genesis Health care shows that this decline is occurring in both vaccinated and unvaccinated residents³, illustrating that the high rates of vaccinations, combined with mask wearing and infection prevention protocols, protect even unvaccinated residents from COVID-19.

Yet while the risk of contracting and dying from COVID has significantly decreased, the risks from isolation, loneliness, and neglect continue. While further guidance issued in September 2020 and March 2021 has allowed more indoor and outdoor visitation, it has done little to address the significant needs of many residents. This is in large part because the guidance gives facilities great discretion in scheduling visits and limiting the length, frequency, and location of visits. Consistent reports from family members, long-term care ombudsmen, and citizen advocates indicate that visits are significantly restricted both in duration and frequency. Some facilities are permitting visits for only 15 minutes once a week. Of greatest concern is the failure of the guidance to address those residents suffering the most from neglect and poor care – residents for whom one or two thirty-minute visits per week are not sufficient. Erratic and uneven implementation and enforcement of the guidance by CMS and state survey agencies have compounded the problem.

Since March 2020, the impact of the visitation lockdown has been devastating on residents and families. Prior to the most recent revision of the CMS guidance in March 2021, residents and their families reported that numerous residents had lost significant amounts of weight; lost their ability to walk, stand, and sit up; developed pressure ulcers; and not been bathed or had their teeth brushed with any regularity. Many had become depressed and despondent, with residents with dementia becoming unresponsive, and losing their ability to speak. One report last year estimated there had been at least 40,000 excess deaths not attributable to COVID-19 as of November 2020;⁴ some death certificates even listed the cause of death as “social isolation/failure to thrive related to COVID-19 restrictions.”⁵

² 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/>

³ Incident SARS-CoV-2 Infection among mRNA-Vaccinated and Unvaccinated Nursing Home Residents. Elizabeth M White, Carolyn Blackman, Stefan Gravenstein, Vincent Mor. New England Journal of Medicine. May 19, 2021. <https://www.nejm.org/doi/full/10.1056/NEJMc2104849?query=TOC>

⁴ 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>

⁵ 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>

Beginning in early May, the Consumer Voice began surveying family members of residents to understand the effect of the March 2021 changes. Of the over 300 responses received as of June 1, 2021:

- 79% of respondents have seen a decline in their loved one's mental status.
- 78% have seen a physical decline in their loved ones.
- One family member reported her father is depressed, not eating, and has lost weight. When she visits his clothes are dirty, his hands aren't washed, his fingernails aren't trimmed, and his glasses aren't clean. He was very witty before, but now struggles to hold a conversation. She says that when she first started visiting, he was okay, but now he says he misses his family and thought this would be over by now.
- Others report that their loved ones can no longer walk, just stare at the wall, can no longer have conversations, and suffer memory loss and hallucinations. One woman, who previously visited daily, wrote that her mother feels abandoned and no longer believes there is a pandemic.
- 59% of respondents said there did not appear to be sufficient staff in the facility to meet the residents' needs.
- 76% report time limits placed on indoor visitation. The average length of visits was 47 minutes, with visits ranging from 15 minutes to 2 hours.
- A family member noted that at the end of her visit, her loved one begged her to stay longer and couldn't understand why she had to wait so long for visits.
- On average, families were only allowed to visit twice a week.
- Multiple family members wrote that they wanted to help their loved ones with personal hygiene because their skin was unhealthy, their hair unkempt, and their nails not trimmed. Yet because visits were only 20 or 30 minutes once a week, there was not enough time to help family members with their personal care needs, like shaving or toileting.
- Some facilities are limiting visiting hours to narrow windows during the working day, making visitation impossible for people with daytime jobs. Additionally, some report that visitation is not allowed on weekends.

Residents are continuing to suffer from isolation and decline because of the limited visitation permitted in the current guidance. Many residents need daily visits and assistance that is not currently being provided by facilities. Further, despite the updated guidance, we have heard from families and ombudsmen that many compassionate care requests are still being denied or limited to end-of-life. Even when granted, many families often receive only one or two compassionate care visits which are not sufficient to help with their loved one's physical and emotional decline. Over the past year, facilities have reported significant staffing shortages which have contributed to the neglect residents have experienced. 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 some TNAs lack the skills to assist them⁶. Before the pandemic, facilities relied heavily on family members to provide care. Without the robust visitation permitted in the nursing home regulations, and failure to ensure adequate staffing levels, residents will continue to suffer.

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. CMS's guidelines have not evolved to reflect the incredible protection offered to residents by vaccines: facilities could limit resident visitation to 30 minutes per week in November / December 2020 at the frightening peak of COVID outbreaks in nursing homes and can still limit visitation to 30 minutes per week in June 2021 when cases are sparse and declining. CMS must restore full visitation rights to nursing home residents without delay and publicly set forth how and when it will make this happen. Residents have already waited too long.

Sincerely,

California Advocates for Nursing Home Reform
Center for Medicare Advocacy
Justice in Aging
Long Term Care Community Coalition
Michigan Elder Justice Initiative
National Consumer Voice for Quality Long-Term Care

⁶ Based on telephone and video communication with residents throughout the pandemic.