

## **ESSENTIAL CAREGIVERS CONGRESSIONAL BRIEFING**

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The Federal Nursing Home Reform Law, enacted in 1987, gives nursing home residents the right to “immediate access” to “immediate family and other relatives” 24 hours per day, seven days per week<sup>1</sup> as well as “immediate access” to any others they want to see.<sup>2</sup> Families are critical to the operations of nursing homes. They participate in assessment and care planning, help provide care to their loved one, provide important emotional support, and inform staff of issues and problems. The public oversight system also relies on families to talk with state surveyors (during surveys and otherwise) and to file complaints with the state department of health or federal government, as needed. Many family complaints alert government officials to the most serious problems in nursing facilities.

When the public health emergency was announced in March 2020, families were absolutely and completely barred.<sup>3</sup> Although the federal government lifted the ban a year later, in March 2021,<sup>4</sup> the ban on families continues in far too many facilities in practice. Many facilities, even now, continue to limit the frequency and duration of visits, telling families that they can visit for 40 minutes once or twice a week and not at all on weekends.

While limitations on who could come into facilities may have made some sense at the very beginning of the pandemic, when little was known about COVID-19 and how it spread, these limitations have made less and less sense over time, as we learned more about COVID and how to protect against it and as vaccines became available. We also know that families were needed more than ever during the pandemic. Insufficient staffing levels, always a problem at nursing homes, became more serious and more pervasive during the pandemic, as staff members themselves became sick and left their jobs. New staff – often aides hired without sufficient training and agency staff – did not know the residents or how to take care of them.

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<sup>1</sup> 42 C.F.R. §483.10(f)(4)(ii)

<sup>2</sup> 42 C.F.R. §483.10(f)(4)(iii) provides “immediate access” to “others visiting with the consent of the resident, subject to reasonable clinical and safety restrictions and the resident’s right to deny or withdraw consent at any time.”

<sup>3</sup> CMS, “Guidance for Infection Control and Prevention of Coronavirus Disease 2019 (COVID-19) in Nursing Homes,” QSO-20-14-NH (Mar. 13, 2020), <https://www.cms.gov/files/document/qso-20-14-nh-revised.pdf>

<sup>4</sup> CMS, “Nursing Home Visitation – COVID-19 (REVISED),” QSO-20-39-NH (rev. Mar. 10, 2021), <https://www.cms.gov/files/document/qso-20-39-nh-revised.pdf>

But one of the most serious consequence of the ban, we know now, is that residents suffered tremendously from social isolation, loneliness, and neglect. As families have begun to see their relatives in person, they have reported enormous physical and mental declines. Multiple reports, from government agencies and elsewhere, tell the same story over and over.

Last fall, the Associated Press reported that “for every two COVID-19 victims in long-term care, there is another who died prematurely of other causes.”<sup>5</sup> The nursing home expert<sup>6</sup> consulted by the Associated Press estimated that there had been 40,000 “excess deaths” since March 2020.

Surveys of residents and some surveys of family members as well, reported by Human Rights Watch,<sup>7</sup> Altarum,<sup>8</sup> and the National Consumer Voice for Quality Long Term Care,<sup>9</sup> and other witnesses<sup>10</sup> all describe the social isolation and loneliness of residents and the resulting physical and mental decline and failure to thrive.

Consumer Voice and other advocates for residents have called for a full restoration of visitation in nursing homes.<sup>11</sup> Full restoration of rights now is key. But what happens in the next public health emergency?

The Essential Caregivers Act of 2021, H.R. 3733, says unequivocally that we cannot ever again totally ban families. Regardless of any public health emergency, the bill guarantees that all residents can choose up to two people as essential caregivers who can provide them with assistance 12 hours each day and for an unlimited number of hours at the end of a resident’s life. Essential caregivers must follow appropriate safety protocols. The legislation is critical for residents and their families and the Center for Medicare Advocacy strongly supports its enactment.

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<sup>5</sup> Matt Sedensky and Bernard Condon, Associated Press, “Not just COVID: Nursing home neglect deaths surge in shadows” (Nov. 19, 2020), <https://apnews.com/article/pandemics-us-news-coronavirus-pandemic-daac7f011bcf08747184bd851a1e1b8e>

<sup>6</sup> Stephen Kaye, professor at the Institute on Health and Aging, University of California, San Francisco analyzed data from 15,000 facilities for the Associated Press.

<sup>7</sup> Human Rights Watch, *US: Concerns of Neglect in Nursing Homes: Pandemic Exposes Need for Improvements in Staffing, Oversight, Accountability* (2021), <https://www.hrw.org/news/2021/03/25/us-concerns-neglect-nursing-homes>

<sup>8</sup> Altarum, *Experiences of Nursing Home Residents During the Pandemic; What we learned from residents about life under Covid-19 restrictions and what we can do about it* (Special Report, Oct. 2020), [https://altarum.org/sites/default/files/uploaded-publication-files/Nursing-Home-Resident-Survey\\_Altarum-Special-Report\\_FINAL.pdf](https://altarum.org/sites/default/files/uploaded-publication-files/Nursing-Home-Resident-Survey_Altarum-Special-Report_FINAL.pdf)

<sup>9</sup> Consumer Voice, *The Devastating Effect of Lockdowns on Residents of Long-Term Care Facilities During COVID-19* (Jan. 15, 2021), [https://theconsumervoice.org/uploads/files/issues/Devastating\\_Effect\\_of\\_Lockdowns\\_on\\_Residents\\_of\\_LTC\\_Facilities.pdf](https://theconsumervoice.org/uploads/files/issues/Devastating_Effect_of_Lockdowns_on_Residents_of_LTC_Facilities.pdf)

<sup>10</sup> Brianna Cocuzzo, Algevis Wrench, and Chasity O’Malley, “Balancing Protection from COVID-19 and the Need for Human Touch in Nursing Homes,” *J Am Geriatr Soc.* 2020 Oct 1:10.1111.jgs.1681, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7646659/>

<sup>11</sup> See Letter to Lee Fleisher, Chief Medical Officer, Centers for Medicare & Medicaid Services (CMS) and Evan Shulman, Director, Division of Nursing Homes, Quality, Safety & Oversight Group, CMS (Jun. 11, 2021), from California Advocates for Nursing Home Reform, Center for Medicare Advocacy, Justice in Aging, Long Term Care Community Coalition, Michigan Elder Justice Initiative, and Consumer Voice.