



Statement in Support of the Essential Caregivers Act (H.R. 3733)
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National Consumer Voice for Quality Long-Term Care

The National Consumer Voice for Quality Long-Term Care (Consumer Voice) is writing in strong support of the *Essential Caregivers Act* (H.R.3733) introduced by Representative Claudia Tenney. Consumer Voice is the leading national voice representing consumers in issues related to long-term services and supports. We advocate for quality care, quality of life, and the rights of nursing home residents and other long-term care consumers.

The *Essential Caregivers Act* would ensure that nursing home residents are never again left completely without life-sustaining assistance and support from visitors during a public health emergency.

Essential caregivers are individuals, designated by a resident, who can have access to the resident to assist with the tasks of daily life, and provide emotional support and/or companionship during a public health emergency. The resident would be able to appoint two individuals to serve as their essential caregivers. Very often they will be family members. Visits from essential caregivers would be guaranteed whenever a public health emergency is declared as long as they follow the same safety protocols as staff.

This access is critical and necessary because we now know that banning all visitors or severely restricting visitation can be as dangerous as the spread of the infectious disease or other disease the ban is seeking to prevent. When visitation is shut down or significantly curtailed:

- **Residents experience harm from social isolation.** Research indicates that social isolation negatively impacts health, contributing to increased risk of chronic illness, cardiovascular disease, and stroke; hastening of cognitive decline; and heightened prevalence and severity of depression and anxiety.¹
- **Residents are deprived of critical help from family in meeting their needs.** Family members play a crucial role in the support and well-being of nursing home residents. They help residents eat, drink, turn over in bed, dress in clean clothes, get to the bathroom, groom themselves, and stay connected. When facilities are severely short staffed, as they have been during the COVID-19 pandemic, this assistance becomes vital – even life-sustaining. Without it, many residents do not receive even the most basic of care.
- **Poor care or lack of adequate care goes unchecked.** Not only do family members provide important hands-on assistance, they also help ensure the resident receives quality care. When they are not physically present, they can no longer oversee and directly monitor their loved one's condition. As a result, resident care can deteriorate because families are unable to detect

¹ <https://www.nap.edu/read/25663/chapter/3>

and report concerns.

During the COVID-19 pandemic, the impact of isolation, lack of family support and assistance, and poor care on residents has been horrific. Information from a survey of family members published in two reports by Consumer Voice, the first in January 2021 and the second in June 2021, found that shutting down visitation had a devastating effect on residents:

- In the January 2021 report, families indicated that many residents had declined substantially both physically and cognitively/mentally. They also reported that residents had lost significant amounts of weight; lost their ability to walk, stand, and sit up; developed pressure ulcers; become incontinent; and had not been bathed or had their teeth brushed with any regularity. A considerable number became depressed and despondent, with residents with dementia becoming unresponsive and losing their ability to speak.
- The report from June 2021 showed that even though CMS had eased visitation restrictions, there had been little change. 78% of family respondents indicated their loved ones had experienced physical decline. 79% of family respondents reported that their loved one's mental status had declined, with numerous residents feeling abandoned, seeming depressed, and in some instances, suicidal. Residents with dementia and other cognitive impairments suffered precipitous declines, often becoming completely disengaged.

For many residents, the harm they have experienced is irreversible. For others, it has been fatal.

Our surveys, along with accounts from residents, families and advocates nationwide, demonstrate that depriving residents of visitors who provide assistance with tasks of daily life, emotional support, or companionship, threatens their well-being and their lives.

We cannot permit residents to suffer in this way ever again. Residents must be given a statutorily protected right to access essential caregivers during public health emergencies - a right that cannot be waived, modified by federal or state government, or subject to facility discretion. Because even when CMS no longer completely banned visitors, revised CMS guidance created loopholes that were then used by nursing homes to restrict the length, frequency, and location of visits. These restrictions - for example, 30-45 minutes visits only once or twice a week - have made it impossible for family members to assist residents who have declined and/or experienced such extreme distress this year.

The *Essential Caregivers Act* provides a commonsense way to ensure that residents will remain safe during the next public health emergency without facing the isolation and neglect that caused so many to suffer during the COVID-19 pandemic.
