



CALIFORNIA ADVOCATES FOR NURSING HOME REFORM

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March 21, 2022

Adrin Nazarian, Chair
Assembly Committee on Aging & Long-Term Care
1020 N Street, Rm. 153
Sacramento, California 95814

sent via CA Legislature Position Letter Portal

RE: AB 2546 (Nazarian) – Support

Dear Chairperson Nazarian:

California Advocates for Nursing Home Reform (CANHR) wholeheartedly supports and is proud to sponsor AB 2546, a bill that would sustain the most important relationships for long term care facility residents when they are needed most. The bill ensures residents have access to critical designated support persons during a public health emergency when access might otherwise be curtailed.

Support Person Visitation is Vitally Important to Long Term Care Residents.

It's nearly impossible to understate the importance of visitation in long term care facilities. These facilities are home to over 250,000 Californians, who enjoy the company of family, friends, and other visitors just as anyone else does. The ability to host visitors and share personal moments with loved ones is a key to making long term care facilities more homelike.

Aside from the obvious psychological benefits that visitation and in-person companionship provide, visitation is also often vital to the well-being of residents. Visitors provide direct care that is not only supplemental to that provided by the facility staff, but essential to residents' health and safety. Visitors provide food and feeding assistance, help with grooming, toileting, and exercise, turning and repositioning for skin integrity, and myriad other care services. In addition, visitors' observations, supervision, and advocacy ensure residents are getting their basic care delivered appropriately and as needed. A recent study in Health Affairs found that 'family members are an invisible workforce in nursing homes and residential care facilities, providing considerable front-line work for their loved ones.'¹

¹ "Informal Caregivers Provide Considerable Front-Line Support in Residential Care Facilities and Nursing Homes," Health Affairs, January 2022. The study found that more than half of residents received care from family or friends ranging from *65 hours per month* per resident in residential care to *37 hours per month* per resident in nursing homes.

The full scope of services provided by family and friends of long term care facility residents was significantly underappreciated until it was taken away during the pandemic.² The loss of these services has been a primary cause for making the last two years the worst time in the history of long term care.

Until the Pandemic, the Law Recognized the Critical Importance of Visitation.

Federal and state laws have long-recognized the critical importance of visitation to the lives and well-being of long term care residents. These laws give residents nearly unfettered rights to in-person access to family, friends, and other key visitors.³ Visitation is a cherished right and given special protections because of its importance in maintaining residents' most important relationships and connections to their community as well as its association with better overall resident health.

During the Pandemic, Visitation Rights Have Been Foolishly Disregarded by Policymakers.

When the COVID-19 pandemic started in the United States, one of the first moves public health authorities made at the federal, state, and local levels was to shut down all long term care facility visitation. Given the lethality of COVID for older adults and the crowded conditions in facilities, creating protective bubbles made some sense as a short-term, emergency measure. But as weeks turned to months and months turned to years, the visitation lockouts were increasingly ineffectual, cruel, and ultimately hurt residents more than they helped them. COVID ran amok in long term care facilities anyway, brought in by staff people, and killed thousands of residents who were also suffering from inescapable isolation and depression.

The visitation lockouts demonstrated a lack of understanding of the importance of support persons to the well-being of long term care facility residents. Local public health officers, most of whom had never set foot in a long term care facility in an official capacity, governed based on myopic concerns about infection rates, with no regard to resident quality of life and ignorant to the amount of care that support persons provide to residents. The state Department of Public Health was more sensitive to the value of visitation but it largely failed to enforce visitation rights, leaving residents at the mercy of facilities' do-it-yourself policies, many of which were designed to keep visitors out.

The visitation lockouts also revealed a tremendous amount of ageism among public health officials. Long term care facility residents are often the targets of rules made to protect them but completely without their input. Residents were "cohorted" by COVID status (infected, exposed, negative) but were unable to cohort by risk tolerance the way the rest of society was. Other care settings, such as hospitals, had far more tolerant visitation rules even though many of their patients were more vulnerable to COVID.

² See, "Nursing Home Patients Are Dying of Loneliness," New York Times (12/29/2020), <https://canhrnews.com/nursing-home-patients-are-dying-of-loneliness/>

³ For a comprehensive review of the visitation rights of long term care residents, see CANHR's publication "[Your Right to Visit](#)."

The visitation lockouts were not only misguided because they failed to prevent COVID outbreaks and deprived residents of the kinds of direct care that support people provide, they also cut visitation at a time when it was never more important. During the pandemic, facilities were rife with understaffing as care workers were forced to stay home with children out of school, were sick themselves, or simply quit their jobs. New staff were hired but lacked the skill of their predecessors as policymakers granted emergency exemptions to caregiver training requirements. Additionally, government regulators and long term care Ombudsman programs were sidelined for months - meaning the typical oversight meant to ensure basic care is delivered was missing.

Long Term Care Facility Residents Suffered Due to the Policies Meant to Protect Them.

The imposition of visitation bans has deprived long term care facility residents of seeing the people who know them best, who love them most, provide critical care, and often serve as their eyes, ears, and voices. This deprivation has been catastrophic. Countless residents and their loved ones across the state have reported horrific symptoms of neglect including significant weight loss; the loss of the ability to walk, stand, and sit up, atrophied muscles, painful pressure sores, no bathing, and dental decay. Many residents have become depressed and despondent while residents with dementia have become unresponsive or lost their ability to speak. One report estimated there had been at least 40,000 excess nursing home deaths not attributable to COVID-19 in just the first eight months of the visitation lockout, with resident death certificates listing the cause of death as social isolation or failure to thrive related to COVID-19 restrictions.⁴

The National Consumer Voice for Quality Long Term Care (“Consumer Voice”) surveyed family members of long term care facility residents to understand the effect of pandemic-related visitation restrictions and found:

- 73% observed declines in their loved one’s mental status;
- 73% observed declines in their loved one’s physical functioning;
- 59% said there did not appear to be sufficient staff in the facility to meet the residents’ needs;
- 77% reported time limits placed on visitation, with some visits being limited to fifteen minutes or visiting hours so limited that visitation has been impossible for people with jobs.
- Even residents at the end of life are denied visitation. “Compassionate care visits” are often blocked or extremely limited, meaning residents are dying alone.

Consumer Voice also analyzed publicly reported nursing home quality data and confirmed what had already become obvious: visitation lockouts kept residents from the caregivers who were essential to their well-being and their well-being subsequently suffered.⁵

⁴ “Not just COVID: Nursing home neglect deaths surge in shadows,” *AP News*, (11/18/2020) <https://apnews.com/article/nursing-homes-neglect-death-surge-3b74a2202140c5a6b5cf05cdf0ea4f32>

⁵ “Inadequate Staffing During the COVID-19 Pandemic and Its catastrophic Effect on Nursing Home Residents.” <https://theconsumervoice.org/uploads/files/issues/suffering-in-lockdown.pdf>

AB 2546 Will Ensure the Horrible Visitation Lockouts Will Never Happen Again.

The pandemic has been tough on everyone. But it had been indescribably devastating for long term care facility residents. They've lived in sickness, in fear, and without power - and for a *third year now* - they have lived alone, cut-off from the people who mean the most. Long term care facility visitation during the pandemic has been unceasingly frustrating. Residents have dealt with literally dozens of new iterations of visitation rules from federal, state, and local governments. Residents have suffered as control of visitation was often delegated to facilities with their own fluctuating and self-interested visitation policies. And for months at a time, visitation has simply been unavailable at all.

The unfathomable and unconscionable visitation limitations have exacted an incalculable toll on the health and well-being of hundreds of thousands of residents throughout the state and continue to be facilitated by a frustrating dispersion of uncoordinated federal, state, and local guidance and an appalling lack of rights enforcement.

AB 2546 gives every resident of a nursing home or assisted living facility the right to in-person, onsite, and unscheduled access to a minimum of two resident-designated support persons during any public health emergency in which residents' normal visitation rights are curtailed. The support persons may be required to adhere to the same, but not greater, infection control protocols required of facility staff but may not be restricted as to the time, frequency, physical contact, or proximity of their visits and support. AB 2546 also guarantees residents have the right to leave the facility on outings, so long as reasonable infection control precautions are taken.

AB 2546 ensures long term care facility residents a necessary minimum level of support during public emergencies from the people they love and trust most.

Please vote "aye" on AB 2546.

Sincerely,

A handwritten signature in black ink that reads "Anthony Chicotel". The signature is written in a cursive, flowing style.

Anthony Chicotel
Senior Staff Attorney