



As the pandemic reaches its one-year mark, nursing home residents continue to face the significant challenges of prolonged isolation. With limited and circumscribed exceptions, most have not been able to receive loved ones or other visitors. Essential caregiver programs are widely looked to as a solution. As many as 17 states have some type of program that allows an essential or designated visitor, under specified circumstances.

But what are the characteristics and parameters of these programs? What are Essential caregivers permitted – and required – to do? Do the programs comply with CMS visitation guidance? Do they differ from state to state? This paper aims to answer some of these basic questions.

Note: Individual provider communities, states, and localities have established different visitation programs and policies that apply to other long-term care settings, such as assisted living. Some of the programs described in this paper apply to nursing homes as well as other long-term care settings, but the focus of this paper is Essential caregiver programs in nursing homes.

BACKGROUND

The coronavirus pandemic has ravaged the world and, unfortunately, the United States has been at the forefront of the devastation. As we crossed the one-year mark of coronavirus in the U.S., more than 27 million cases had been reported with 470,000 deaths¹. Understanding that residents in our nation’s nursing homes were particularly at risk due to the congregate nature of the setting and the vulnerability posed by underlying conditions, the Centers for Medicare and Medicaid Services (CMS) took swift and decisive action when the threat emerged.

Within days of the identification of the first U.S. outbreak, coincidentally located in a nursing home, CMS issued [guidance to screen and limit](#) staff and visitors with symptoms or exposure to COVID-19. Nine days later, this guidance was updated to [fully restrict visitors](#) and significantly limit staff by restricting non-essential healthcare personnel, among other operational modifications aimed at stemming the tide of this crisis. As cases around the country soared, personal protective equipment (PPE) dwindled, and hospitals overflowed, these “temporary” mitigation measures continued and created a second pandemic of social isolation and loneliness.

Noting the consequences of this prolonged social isolation, CMS provided a path toward [reopening](#) in May 2020. This plan included a phased approach to reopening our nation’s nursing homes that tracked along-side former President Trump’s plan for Opening Up America Again. The CMS plan considered factors such as community prevalence, hospital capacity, nursing home case status, and access to PPE and testing. However, cases around the country soared, PPE dwindled, hospitals overflowed, and visitor restrictions continued.

In September 2020, a full six months after the visitation restrictions were first put in place, CMS issued new [visitation guidance](#) to immediately begin reuniting nursing home residents with loved ones by permitting visitation under certain parameters. While outdoor visitation was immediately available to all residents who were not on COVID-19 related transmission-based precautions due to a confirmed or

suspected case of COVID-19 or unknown COVID-19 status following admission or re-admission to the nursing home, indoor visitation was more limited. Parameters for indoor visitation included consideration of county positivity rates, the nursing home's outbreak status, and the ability of the nursing home, residents, and visitors to adhere to core infection control principles.

ESSENTIAL CAREGIVER PROGRAMS EMERGE AS A SOLUTION

Concurrently, a number of states covering each of the 10 CMS regions have created essential caregiver programs to allow residents access to visitors outside of the CMS guidelines. These programs have been established through various governmental avenues. While a handful of states have attempted legislation, none have successfully legislated an essential caregiver program to date. Three states have issued executive orders, one state has issued emergency rulemaking, and the majority of states (13) have pursued regulatory guidance from their state's Department of Health. For the purposes of this paper, we will discuss only the programs that are currently in effect.

"Essential caregivers" seems to be the most commonly employed term for this special designation of visitor, but because there is no specific federal program, the language varies among states. These individuals may also be called "essential visitors," "designated visitors," "essential support persons," or "designated support persons." The role may be outlined in specific essential caregiver programs developed at the state level or referenced in state-level nursing home visitation or reopening guidelines.

In the 17 programs LeadingAge reviewed, we found that while most programs are consistent with each other and reflect CMS visitation guidance in many ways, there are significant ways in which some essential caregiver programs deviate from CMS guidance.

ESSENTIAL CAREGIVER PROGRAM CHARACTERISTICS

Nearly all states require each participating nursing home to establish policies and procedures outlining the essential caregiver role, including how the individual will be designated and utilized. The focus of the programs is on person-centered care and programs require the resident's or resident representative's input on the individuals who are designated to serve in this role. That said, states have guidelines in place about what the essential caregiver role looks like.

The essential caregiver role is distinguished from a general visitor by the emphasis on the caregiver's provision of support or assistance with Activities of Daily Living (ADLs). This support may take the form of companionship; however, in some states the companionship appears to be related to and essential for the provision of care or the well-being of the resident beyond solely addressing loneliness and social isolation. Some states have made the essential caregiver program optional and many states give the nursing home discretion in determining whether an essential caregiver would be appropriate for a given resident. Examples of this would be the language included in state programs such as Delaware's that emphasize the need for companionship or assistance with activities requiring "one-on-one direction" and state, "The goal of such a designation is to help ensure these high-risk residents continue to receive individualized, person-centered care." Similar language can be found in programs in Indiana, Minnesota, and Nebraska.

Nearly all states specify that the essential caregiver is an individual who was providing care in this capacity prior to the pandemic or who had an established relationship with the resident prior to the pandemic and can address care-related needs that have arisen during the pandemic. With most states

emphasizing the importance of an essential caregiver program to providing person-centered care, several states require that the essential caregiver's participation be addressed in the resident's care plan. A few states, such as Rhode Island, require a specific essential caregiver agreement. The possible implications of such an agreement are addressed in the "Special Considerations" section.

All states require adherence to CMS's infection control core principles of visitor screening, universal face masking or face covering, and hand hygiene. Most states require the use of PPE as indicated for COVID status or care task and, notably, Missouri requires essential caregivers to wear all PPE at all times while in the nursing home. While essential caregivers are not required to maintain social distances between themselves and the resident for whom they are providing care, essential caregivers are expected to maintain social distances between themselves and staff and all other residents.

Consistent with CMS visitation guidance, most essential caregiver programs limit movement of the essential caregiver within the nursing home and may even limit caregiving to the resident's room or another designated space. Addressing the reality of shared rooms, Arizona stipulates that essential caregivers are not permitted to enter the room when a roommate is present and may enter in the roommate's absence only with prior approval from the roommate or roommate's resident representative. The length of time an essential caregiver may stay in a shared room is also limited.

CMS requires basic instruction and education for all visitors on infection control and hand hygiene; a handful of states require additional training for essential caregivers. One example is Florida, that not only requires actual training for essential caregivers on infection prevention and control, hand hygiene, social distancing, and PPE, but requires essential caregivers to sign acknowledgement that they have been trained on these topics and understand applicable nursing home policies.

Also consistent with CMS visitation guidance, most essential caregiver programs allow the nursing home to restrict or revoke the essential caregiver's visitation privileges if, after consultation, the essential caregiver is unable or unwilling to follow infection control practices.

Nearly all states require that essential caregiver visits be scheduled, and nursing homes must allow evening and weekend scheduling to accommodate for essential caregivers' other responsibilities such as work schedules and childcare. All states give nursing homes discretion over certain aspects of scheduling to ensure a safe environment that is accessible for all. The most common limit is allowing the nursing home to limit visits based on the total number of essential caregivers in the nursing home at one time. This is consistent with CMS visitation guidance that recommends nursing homes limit total numbers of visitors in a nursing home at one time. A related limit would be allowing the nursing home to set time limits for visits to ensure that all essential caregivers have the opportunity to visit without exceeding total capacity, also consistent with CMS visitation guidance.

While a few states limit the number of essential caregivers that may visit a given resident at a time, this is generally addressed either by the state setting a limit on the number of individuals a resident may designate as an essential caregiver (generally only 1 or 2 individuals), or by the CMS visitation guidance that recommends nursing homes limit the number of (general) visitors per resident at a time.

COMPARISON OF ESSENTIAL CAREGIVER PROGRAMS AND CMS GUIDELINES

In the [September 2020 visitation guidance](#), CMS explicitly stated that it does not recognize a special category of visitor for “essential caregivers.” These visitors are permitted according to general visitation guidance and have no special privileges beyond general visitation guidance as set forth by CMS.

As noted above, essential caregiver programs tend to generally follow CMS visitation guidance. All visitors are screened and expected to comply with core infection control principles. Those who are unable to comply are restricted. Visits are scheduled and limited in size, length, and overall number of visits at a given time. Nursing homes have flexibility to enforce these limits in a manner that best adheres to infection control principles and ensures a resident’s right to visitation.

Despite these similarities, there are two significant ways in which essential caregiver programs divert from CMS visitation guidance. The first is visitor restrictions during an outbreak. CMS guidance states that nursing homes must restrict indoor visitation during an outbreak, with the exception of compassionate care visits. An outbreak is defined as one new case among staff or one new nursing home-onset case among residents. Residents who are admitted with a COVID-19 diagnosis or who are confirmed COVID-positive within 14 days of admission are not considered nursing home-onset cases and therefore do not constitute an outbreak. Slightly more than half of the essential caregiver programs we reviewed allow essential caregivers during an outbreak.

We note that despite allowing essential caregivers during an outbreak, the majority of states restrict essential caregivers for residents who are on transmission-based precautions. Residents may be on transmission-based precautions due to either a symptomatic or asymptomatic confirmed COVID-19 infection, development of symptoms consistent with COVID-19 that has not yet been confirmed by testing, or observation for development of COVID-19 infection in the 14 days following admission or re-admission to the nursing home.

One notable exception to essential caregiver restrictions for residents on transmission-based precautions is Indiana, which allows the essential caregiver to visit a resident on transmission-based precautions if the essential caregiver was previously COVID-positive, has recovered, and is within the 90 days following initial symptom onset (described by CDC as “natural immunity”). Another exception is Texas, which allows essential caregiver visits for residents who are symptomatic but not yet confirmed COVID-positive.

The second diversion from CMS visitation guidance – a diversion that is common in nearly all essential caregiver programs – is allowing essential caregiver visits without regard to the surrounding community’s case prevalence (more commonly referenced by the county positivity rate). CMS directs that indoor visitation is suspended when the positivity rate of the county in which the nursing home is located reaches 10% or greater. In order to determine county positivity rates, nursing homes may consult either [CMS data](#) or state/local public health data. Most states allow essential caregivers without regard to the county positivity rate.

SPECIAL CONSIDERATIONS

Noting CMS’s assertion that the essential caregiver is not a special visitation category, where does the role of the essential caregiver fall? In the new testing requirements under 42 CFR §483.80 Infection Control, CMS indicates that “staff” include individuals providing services under arrangement. CMS

additionally qualifies in [regulatory guidance related to testing requirements](#) that staff includes “caregivers who provide care and services to residents on behalf of the facility.” Under these definitions, would essential caregivers be considered staff? Particularly considering, as noted above, that a few states require an essential caregiver agreement.

We note that CMS requires routine testing of nursing home staff according to county positivity rates. Nursing homes in counties with high positivity (10% or greater) test staff twice weekly. Nursing homes in counties with positivity rates between 5-10% test staff once per week. Nursing homes in counties with low positivity rates (below 5%) test staff once per month. Yet fewer than half of the essential caregiver programs reviewed require testing of essential caregivers, with only one state, Michigan, requiring testing of visitors related to certain positivity rates. However, consistent with CMS visitation guidance, we note that several states that do not require testing essential caregivers at the state level allow flexibility for the nursing home to require testing or proof of testing at the nursing home-level.

CMS has stated that compassionate care visits are the only exception to visitation restrictions. Compassionate care visits are permitted during outbreaks, during times of high county positivity, and while residents are on transmission-based precautions. A small number of states indicate that an essential caregiver visit is or could be considered a compassionate care visit. While CMS does provide an example of compassionate care visits to include a resident who requires cueing for eating or drinking that was previously provided by a family member and/or caregiver(s) and is now experiencing weight loss or dehydration, CMS stipulates in this [Visitation FAQ](#) and has since verbally confirmed that compassionate care visits are not intended to be routine and should be allowed on a limited basis as an exception to visitation.

Should nursing homes designate essential caregivers for residents in a time-limited manner to address acute issues, such as weight loss or dehydration, only? What about residents for whom the need is ongoing? For example, residents with cognitive impairment who become combative during care and allow care only when a known loved one is present. Designating essential caregivers in a time-limited manner seems contrary to the nature of the role, particularly when so many programs indicate, as in New Jersey, that essential caregivers should be committed to providing assistance with care. Programs in Indiana and Texas explicitly state that the essential caregiver is someone who has been designated to provide regular care and support to the resident.

If a state does not consider essential caregivers as staff, subject to testing and training, and determines that the essential caregiver program did not meet the description of a compassionate care visit given the routine nature of the visit, are caregivers simply “visitors?” How then does the state allow for essential caregiver visits during outbreak, high positivity, and transmission-based precautions?

DISCUSSION

While the detrimental impact of social isolation resulting from visitor restrictions cannot be overstated, many state policy makers, providers, and other stakeholders continue to grapple with how best to manage the implications. Essential caregivers may be a step in the right direction, but there are numerous issues to be considered and more data are needed. We have examined the requirements of available programs, but how do these programs actually look in practice? What modifications must be made to programs at the state level, and in what ways might CMS modify visitation restrictions at the federal level based on what we learn from essential caregiver programs?

Most of the programs described in this paper were developed and put in place in the second half of 2020. The Pharmacy Partnership for Long-Term Care began vaccinating residents and staff in nursing homes (and other settings) on December 21, 2020, within 10 days of the FDA granting Emergency Use Authorizations for Coronavirus vaccines (Pfizer on December 11 and Moderna on December 18). However, CMS visitation guidance has not been changed despite the majority of residents and increasing numbers of staff members being vaccinated and building evidence regarding the effectiveness of vaccines in preventing severe illness.

It is likely that CMS will continue to be pressed by stakeholders to review the guidance. If CMS changes its visitation policies, essential caregiver programs will be able to change accordingly or they may not be needed at all. Before we can return to pre-COVID visitation practices, we need more of the general population vaccinated and we need data on transmissibility. However, with the majority of nursing home residents vaccinated, is there room to be flexible? Can essential caregiver programs be employed to bridge the gap between visitor restrictions and open visitation in a meaningful way?

Further, this paper primarily examined programs created for nursing homes. While some states include assisted living in these programs, there are likely other states that have created separate programs for non-nursing home settings. In the very least, states have had to issue visitation guidelines for settings that are not regulated at the federal level in the way that nursing homes are. What can be learned from examining these other programs?

We acknowledge that at the core of the issue, essential caregiver programs and visitation are controversial. In a world of absolutes, we are setting health against well-being. In order to keep residents “healthy” by attempting to isolate them from the virus, we are sacrificing their well-being by isolating them from their loved ones. How do we weigh these core principles against each other? There seems to be no room for both in our current scenario.

To move forward, we must confront these questions. Most immediately, nursing homes choosing to implement an essential caregiver program must balance state and federal compliance. States developing these programs must carefully consider public health recommendations and weigh risks versus benefits. Careful planning and evaluation will help us address these issues more effectively during the next pandemic.

Resources

Arizona [Department of Health Services Visitation Guidance](#)

Delaware [Health and Social Services Reopening Plan in Long Term Care Facilities](#)

Florida [Division of Emergency Management Emergency Order](#)

Illinois [Department of Public Health Essential Caregiver Guidance for Long-term Care Facilities](#)

Indiana [State Department of Health Essential Family Caregivers in Long-term Care Facilities](#)

Michigan [Department of Health and Human Services Requirements for Residential Care Facilities](#)

Minnesota [Department of Health Essential Caregiver Guidance for Long-term Care Facilities](#)

Missouri [Department of Health and Senior Services Guidance for Long-term Care Facilities to Establish Essential Caregiver Programs and to Allow Visits](#)

Nebraska [Department of Health and Human Services Essential Caregiver Guidance for Long-term Care Facilities](#)

New Jersey [Department of Health Executive Directive No. 20-026](#)

Oklahoma [Department of Health COVID-19 Phased Reopening Guidance for Long-term Care Facilities](#)

Oregon [Department of Human Services Executive Letter from Mike McCormick, Interim Director of APD](#)

Rhode Island [Department of Health Essential Caregiver Program for Nursing Homes and Assisted Living Facilities](#)

South Dakota [Back to Normal Long-Term Care Reopening Plan](#)

Tennessee [Department of Health Increased Visitation in Long Term Care Facilities](#)

Texas [Department of Aging and Disability Services COVID-19 Emergency Rule](#)

Washington [Department of Health Safe Start for Long Term Care Recommendations and Requirements](#)