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## So Many Have Died: COVID-19 in America's Nursing Homes

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# So Many Have Died

## COVID-19 in America's Nursing Homes

By David English

**A**s of the date of this writing in late September 2020, over 77,000 residents and staff of long-term care facilities have died of COVID-19 with more to come. This article will describe the reasons for this mass wave of death and provide practical suggestions for attorneys who represent a resident or family members of residents.



But, before diving into the numbers, we should put names on some of the victims. I have chosen to focus on James Miller and Emilio DiPalma, who were members of America's Greatest Generation. Jim Miller was among the first troops onshore at Utah Beach on D-Day and later was among the liberators of Nordhausen Concentration Camp. Photos of the liberation that he donated are part of the collection at the US Holocaust Museum. Lio DiPalma was a military guard responsible for guarding the Nazi Hermann Goering. Jim, who died on March 30, 2020, and Lio, who died on April 8, 2020, were both residents of the Holyoke Soldiers' Home in Holyoke, Massachusetts. Of the 210 residents at the Holyoke Soldiers' Home on March 29, 2020, 74 subsequently died of COVID-19.

Unfortunately, the torrent of deaths at the Holyoke Soldiers Home is not an isolated incident. The official count is maintained by the Center for Medicare and Medicaid Services (CMS). Although the first reported incidents of COVID-19 in nursing homes occurred at the end of February, CMS waited until May 8 to issue an interim rule requiring that nursing homes report COVID-19 cases. The first official set of statistics, published in early June, showed that as of May 31, 2020, 31,782 nursing home residents had died of COVID-19. This is more than 2 percent of the national nursing home population of approximately 1.3 million. Also, CMS reported that over 400 staff had died.

But we know that the CMS figures are too low. Estimates of the actual number of deaths as of May 31, 2020, range from 40,000 to 50,000. A primary reason for the undercount is that nursing homes were required to report only deaths that occurred after May 8, 2020, the date CMS issued the interim rule. Facilities could but were not required

to report deaths that occurred earlier. There is no way to determine or even reliably estimate how many of the 31,782 reported deaths occurred before May 8. Second, CMS counts only deaths at Medicare/Medicaid certified nursing homes. Deaths at assisted living facilities, which are not regulated by CMS, are excluded. But even among nursing homes, 12 percent of them did not file a report. There is also great variability on how states count nursing home deaths. Nursing home residents who were transferred to and then died in a hospital are not counted in many states. States also vary on whether they count only those confirmed to have died from COVID-19 or also count those who probably died from COVID-19 but were never tested.

Frustrated by the lack of comprehensive data from the federal government and states, the *New York Times* assembled its own database. See <https://nyti.ms/3odBgDT>. This database is not limited to deaths at nursing homes but also includes certain assisted living facilities. The *New York Times* found that as of June 25, 2020, at least 54,000 residents and staff at long-term care facilities had died of COVID-19, constituting 43 percent of all COVID-19 deaths. By September 16, this number had increased to 77,000, although the percentage of all COVID-19 deaths had decreased to 40 percent.

Despite its problems, the CMS data does offer the advantage of being broken down by individual facilities. See <https://www.medicare.gov/nursinghomecompare/search.html>. (Nursing Home Compare). But this tool at Nursing Home Compare should be approached with caution. If the nursing home did not report to CMS at all or if the facility reported only deaths that occurred after May 8, 2020, the individual facility reports will mirror the undercounting. Life Care Center of Kirkland, Washington, was the first US nursing home to have a major outbreak of COVID-19. As of April 2, 2020, the Life Care Center had been linked to 37 COVID-19 deaths. But the entry for the Life Care Center at the CMS site states that it had zero COVID-19 fatalities.

Nursing home death rates from COVID-19 vary by state. The *New York Times* reported on September 16, 2020, that in 18 states, COVID-19 deaths in long-term care facilities accounted for more than half of all COVID-19 deaths. In New Hampshire and Rhode Island, deaths in long-term care facilities accounted for more than 75 percent of COVID-19 deaths statewide. But these numbers also gave an incomplete picture. Five states did not report.

The high death rates in nursing homes are not solely an American phenomenon. Over half of all COVID-19 deaths in Canada and in several European countries have occurred in care homes. The United Nations has taken note and in May 2020 issued a policy brief describing this worldwide phenomenon, "The Impact of COVID-19 on Older Persons" (see <https://bit.ly/3oiFFpj>).

Although the natural inclination is to focus on the elderly, who constitute the majority of nursing home residents, younger residents with disabilities also have a higher rate of infection. Outbreaks of COVID-19 have been reported in state-operated facilities for the developmentally or intellectually disabled. For example, the *Chicago Tribune* reported on May 22, 2020, that one in five residents of group homes in Illinois had tested positive for COVID-19. See Jennifer Smith Richards & Jodi S. Cohen, "Our Residents Are in Crisis": In State-Run Homes for Adults with Disabilities, COVID-19 Spread Quickly, *Chi. Trib.*, May 22, 2020. The death rate among individuals with developmental disabilities who catch the virus is also significantly higher than among the general population. A study published in the *Disability and Health Journal* found that the fatality rate for COVID-19 was more than 50 percent higher than average for individuals with developmental disabilities between the ages of 18 and 74 and also higher for individuals with developmental disabilities under age 17. See Margaret A. Turk, et al., *Intellectual and Developmental Disability and COVID-19 Case-Fatality Trends: TriNetX Analysis*, *Disability and Health J.* (May 24, 2020).

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## Why So Many Deaths

The residents of nursing homes are mostly older and are more medically fragile than the general population. Based on CDC figures compiled through September 16, 2020, adults 65 and older accounted for 79 percent of COVID-19 deaths in the United States even though they constitute only 15.2 percent of the population. The top three underlying conditions for those hospitalized with COVID-19 (heart disease, chronic lung disease, and diabetes) also rise markedly with age. It is therefore not surprising that there is a high death rate among nursing home residents who have contracted COVID-19.

The more important question to ask and problem to address is why such a high percentage of nursing home residents have become infected. According to CMS, 223,626 nursing home residents had confirmed cases of COVID-19 through September 6, 2020, and there were also 132,911 suspected cases. When added together, the total indicates that close to 20 percent of America's nursing home population has contracted COVID-19.

This high infection rate results from a combination of factors:

- Problems with infection control in nursing homes, a long-time issue that the pandemic has exacerbated;
- Chronic lack of personal protective equipment (PPE);
- Failure to separate COVID-19 cases from non-COVID residents;
- Nursing home designs that make it easy for infections to spread;
- Staffing shortages made worse by the pandemic; and
- Inadequate testing.

Infection control has long been a chronic problem in nursing homes. In a report issued on May 20, 2020, the US Government Accountability Office (GAO) noted that an estimated 388,000 residents die yearly from infections. See U.S. Government Accountability Office, GAO-20-576R. The GAO also found that for the period 2013-2017, 82 percent of inspected nursing homes had at least



one infection control deficiency, and half of the homes had deficiencies in multiple consecutive years. Some infection control issues are very basic, such as handwashing. For a survey period ending on March 30, 2020, CMS found that 36 percent of facilities did not do proper handwashing. Other recommended steps include the use of masks to protect staff and residents from infections. But, as described in the CMS Commission report discussed below, lack of PPE remains a chronic issue in many nursing homes.

The failure to separate the sick from the well has been a contributing factor. In New York state early in the pandemic, nursing homes were forced to accept positive COVID-19 cases, thereby enhancing the transmission of the infection. One of the reasons for the high death rate at the Holyoke Soldiers' Home was the failure or perhaps impossibility of separating the COVID-19 residents from those not yet infected.

In recent years, there has been a "culture change" at many nursing homes. Part of this culture change is to make nursing homes more home-like. Ideally, living arrangements should be organized into apartment-like suites instead of large dormitories. The long hallways and large common areas in traditional designs make social distancing more difficult and facilitate the spread of infection. A study published in the *Journal of the American Geriatrics Society* in June 2020, examining data from

30 states, found that the infection rate from COVID-19 was significantly higher in larger facilities (over 150 beds) than in medium facilities (50-150 beds), which was in turn higher than at small facilities (under 50 beds). See Hannah R. Abrams, et al., *Characteristics of U.S. Nursing Homes with COVID-19 Cases*, *J. of the Am. Geriatrics Soc'y* (June 2, 2020).

In 1987, the federal Nursing Home Reform Act was enacted into law as part of OBRA-87. A principal purpose of the Nursing Home Reform Act was to assure adequate staffing in nursing homes. That goal was never achieved. There is a chronic shortage of qualified staff in many nursing homes, and high turnover is a decades-old issue. These problems have been exacerbated by COVID-19. Staff who have been quarantined are not easy to replace, and some staff members are reluctant to place their lives at daily risk of infection.

Testing must be a priority. CMS has recommended that all residents be tested and that staff be tested weekly. Testing allows for the isolation of infected residents and staff and, if the virus is caught early enough, enables effective contact tracing to determine others whom that person might have infected. News reports from numerous sources indicate that many states have struggled to meet the CMS testing standard.

Fortunately, on July 22, 2020, the Trump administration announced an

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initiative that responds to some of the above issues. Under the initiative, \$5 billion of CARES Act funding is being made available to Medicare-certified long-term care facilities and state veterans' homes to address COVID-19 issues. To receive funding, a nursing home must participate in COVID-19 training focusing on infection control and best practices. Among other things, the funding may be used to hire additional staff, including infection control consultants, and to provide additional services, such as technology, to enable residents to stay in touch with families.

The Trump administration initiative also finally requires, not merely recommends, that staff be tested weekly. The testing requirement applies to facilities in states with a test positivity rate of 5 percent or greater. To address equipment shortages, more than 15,000 testing devices are to be shipped to facilities.

### Social Isolation

To control the spread of COVID-19, visitors to nursing homes were banned beginning in mid-March 2020. This ban on visitors was not limited to family but also extended to court-appointed guardians and the long-term care ombudsman. Social isolation can lead to physical and mental decline and the loss of contact with family and others who will advocate for the resident's quality of care. Social isolation is even more extreme in facilities that can successfully socially distance their residents and thereby better protect them from infection. In those facilities, the residents are not only separated from

family but also other residents. This ban was lifted on September 17, 2020, when CMS issued guidance permitting outdoor visitation whenever possible. The availability of indoor visitation is guided by a list of factors including the infection rate in the facility, the positivity rate in the county, and whether the visit is for compassionate care at the end of life. But as nursing homes implement this guidance, the challenge remains on how to best protect the residents from infection.

### The CMS Commission Report

On April 30, 2020, the Trump administration announced the formation of a commission to develop recommendations on how to better address COVID-19 in nursing homes. Of the Commission's 25 members, 14 were from the long-term care industry or trade organizations representing the long-term care industry. The final report of the Coronavirus Commission on Safety and Quality in Nursing Homes was released on September 16, 2020.

The report makes numerous positive recommendations. But funding sources to fully implement the recommendations are not specified, and the report does little to set higher standards or to hold nursing homes accountable for their actions. Among the recommendations:

- A national testing strategy should be established.
- CMS should assume responsibility to ensure and sustain a three-month supply of PPE.

- More support should be provided to ensure 24/7 RN staffing.
- Nursing homes should employ infection control specialists with educator capabilities.
- Steps should be taken to professionalize the job of a certified nurse assistant (CNA).

### Looking Forward

The nursing home industry is one of the more heavily regulated industries in the country. The Nursing Home Reform Act of 1987 prescribed a bill of resident rights and standards for adequate staffing and resident care. But the lofty ambitions of the Act have not been achieved, as the massive number of deaths from COVID-19 has laid bare. Perhaps it is time for different approaches. One step would be to improve programs that keep people out of nursing homes. A substantial majority of the elderly prefer living in their own home or community to placement in a nursing home. Yet the current funding model favors nursing home placement over less restrictive alternatives. Medicaid pays for the care expenses for a majority of nursing home residents, yet Medicaid Home and Community-Based Services (HCBS), a program designed to keep people out of nursing homes, is starved for funds.

A second step would be to rethink the concept of the traditional nursing home. The Green House project, which originated in 2003, is a possible model. Instead of large dormitory structures with long halls and large common areas, Green Houses are facilities with 10 or 12 residents who each have a single room and private baths. A 2011 study found that the costs of operating a Green House are comparable to those of a traditional nursing home. See Jenkens, et al., *Financial Implications of THE GREEN HOUSE® Model*, 19 *Seniors Housing & Care J.* 3 (2011). In addition to providing more of the ambiance of a family home, the risk of infection is also less. As of May 31, 2020, among 1862 residents at 178 Green House homes, only one resident had died of COVID-19.

## Practical Steps

There are numerous practical steps an attorney can take in advising residents and potential residents and their families concerning issues relating to COVID-19. Perhaps the most important is guidance on the selection of a nursing home or other long-term care facility. Relevant factors include not only the convenience of location and size but also whether there is a history of violations, their type and severity, and their recurrence, particularly issues relating to infection control. Much of this information can be found at Medicare Nursing Home Compare at [medicare.gov](https://www.medicare.gov) although, as discussed above, the data relating to COVID-19 is incomplete.

For residents already in a facility, guidance can be provided on ways to stay connected with family and other significant contacts. In addition to the limited visits authorized by the CMS guidance of September 17, 2020, methods for family and others to stay connected with the resident include handwritten letters and cards, using the telephone, email, or other technology for residents who have access, and visiting through the window. Able residents should practice self-protection to the extent feasible. This includes washing their hands frequently, practicing social distancing, and asking facility staff to schedule regular time for family communication.

More often, an attorney won't become involved until concerns have arisen. When problems arise, the attorney should first advise the client to try informal methods of resolution. This includes speaking with the director of nursing or nursing home administrator and involving the long-term care ombudsman. Not all facilities have residents' councils and in those that do they are not always effective, but residents' councils can be a useful forum for resolving concerns. Should informal resolution fail, more formal methods for addressing concerns include filing a complaint with the state survey agency or filing a complaint under the facility grievance procedure. Litigation should be viewed as a last resort.

The local ombudsman can be particularly effective as a go-between, a mediator of disputes, and a general source of information. Under the ombudsman program, which is administered by the federal Administration on Independent Living, an ombudsman, who is usually a trained volunteer, is assigned to each Medicare or Medicaid-certified facility. Information on the ombudsman program is available at the National Long-Term Care Ombudsman Resource Center (NORC), [www.ltombudsman.org](https://www.ltombudsman.org). To locate an ombudsman program for a particular locale, click "Visit Our Map."

The following organizations have resource pages devoted to COVID-19 and long-term care facilities. These organizations also provide extensive information on facility selection, rights of residents, ways family can stay involved, and methods for resolving disputes:

- National Consumer Voice for Quality Long-Term Care, <https://theconsumervoice.org/>
- Justice in Aging, <https://www.justiceinaging.org/>
- Center for Medicare Advocacy, <https://medicareadvocacy.org/>
- Long-Term Care Community Coalition, <https://nursinghome411.org/>

## Conclusion

On July 23, 2020, the CDC predicted that COVID-19 will be among the top ten causes of death in the United States in 2020. The CDC was being conservative. For 2020, COVID-19 will be the third leading cause of death, well below heart disease (655,381 deaths in 2018, the latest year available) and cancer (599,274 deaths) but ahead of such others as accidental death (167,127 deaths), chronic lower respiratory disease (159,486 deaths), stroke (147,810 deaths), and Alzheimer's disease (122,019 deaths).

Given the high morbidity of COVID-19 and the fragility of the nursing home population, the 70,000 plus deaths that have occurred in nursing homes as of late September 2020 should perhaps

not be a surprise. But it wasn't inevitable. On July 24, 2020, the *Washington Post* ran a story on the Maryland Baptist Aged Home, which is located in a lower income neighborhood in West Baltimore. See Rebecca Tan, *In Baltimore, a Struggling Black-Owned Nursing Home Keeps COVID-19 at Bay*, *Wash. Post*, July 24, 2020. The Baptist Aged Home as of that date had experienced no cases of COVID-19. The facility is small, with only 29 residents. Following the first national reports of outbreaks in late February, the facility ordered PPE two weeks before the first infections were reported elsewhere in Baltimore. The facility also acted quickly to bar all visitors and stop communal meals. The staff is encouraged to stay home except for work and to keep their distance from others, including their own families if necessary. Most importantly, the Baptist Aged Home tests all residents regularly and 10 years ago added to its staff a nurse specializing in infection control. The experience of the Baptist Aged Home and the steps it has taken provide a useful model for other facilities to emulate and also provides a useful model for attorneys and their clients to consult when selecting a nursing home. ■

