DEAR DR. JEFF

By Jeffrey Nichols, MD, CMD

The Nursing Home in The Community

Dear Dr. Jeff: *The nursing home where I work has given excellent, person-centered care to a large and diverse group of residents for many years. Our CMS ratings are always four or five stars. During the pandemic, our staff has literally risked their lives and endangered their families to care for frail residents, including many whose COVID status was unknown because we could not get access to tests or were forced to accept them before test results were known. Yet our reputation in the community remains poor. Rather than recognition and praise, local politicians refer to nursing homes as "failures." Community newspapers are equally negative. Those who live in the surrounding neighborhoods have either not heard of us or say negative things in online chat groups or in remarks which our staff overhear. Hospital doctors and nurses, despite the great care we have given their patients, are equally dismissive. All this makes it hard to maintain morale, retain medical and nursing staff, or recruit for vacant positions. Is there anything that you can suggest to help turn this situation around?*

Dr. Jeff responds:

The abysmally low status of long-term care, and particularly of nursing homes, in our society is sadly nothing new. Long-term care in general, and nursing homes in particular, have been associated in the popular mind with three factors that our society scorns and dreads: poverty, disability, and death. We are a society that admires and honors youth while it ignores and denies the inevitability of aging and death. Health and wealth are signs of divine grace and providence, while sickness and poverty suggest moral unworthiness. Implicitly or explicitly, the sick and disabled are blamed for their condition.

Regardless of the quality of the care provided, the comfort of the physical plant, or the level of care that might be required, families often promise loved ones that no matter what happens they will never put them in a nursing home. Our residents themselves often feel angry and guilty because they lack a family prepared to care for them at home or the funds to pay for the level of care that they would require at home. Those who are sufficiently cognitively intact to understand the process are usually devastated to learn that the hard-earned savings accumulated over a lifetime of work — under the illusion that they would be able to support themselves in their old age and perhaps leave something to their grandchildren — will disappear in a few months as they "spend down" to Medicaid eligibility levels.

Housing the Indigent

Nursing homes in our society evolved out of Victorian institutions like the poorhouse and the workhouse, with obvious negative associations. Survival into old age was rather uncommon, although by no means unknown. Many of those depicted as elderly in

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19th-century literature, from the wealthy but bedridden Miss Havisham in Dickens's novel Great Expectations to the toothless grandmothers who slept on top of the stove and sucked eggs in Russian novels, were probably in their 40s or 50s.

Prior to the 1950s, medicine had relatively little to offer for diseases of the elderly. Seniors were more likely to live in the same communities as their families, and expectations that family members would take them in and provide care were matched by the lack of anyplace else for them to go. Board and care facilities existed for the small number of seniors who could not live alone and lacked extended family to provide care. Institutions such as "Homes for Retired Gentlewomen" provided discounted care supported by charitable contributions for "respectable" but socially isolated women who were no longer able to support themselves independently.

The United States inherited the tradition of the British Poor Laws in which parishes were responsible for facilities to house the impoverished sick and elderly. Understandably, medical services these institutions provided were rare or absent, and the living conditions were typically much worse than the comparative freedom and support afforded in debtors' prisons. Because the United States lacks an established religion, the obligation for maintaining such facilities typically fell on individual counties, hence the creation of county homes. (In altered form, many of these facilities survive today.) They were often deliberately unpleasant and unattractive to discourage their use by any but the desperate.

New Deal programs such as social security shifted some impoverished residents back into the community, leaving those who were also physically dependent institutionalized. The conditions typically improved, and some counties made serious efforts to provide at minimum clean and decent surroundings with sufficient and nutritious food. Still, their services were typically associated with a social stigma.

Medical Care and Moral Worth

Since the creation of Medicare and Medicaid in the 1960s, the cost of services for the elderly was transferred from the counties to federal and state budgets (although some states still required individual counties to contribute a share of Medicaid costs). Nursing home care became an aspect of medical care rather than purely a social service. But the artificial distinction between acute care for the elderly and chronic medical care for the sick and disabled was created.

The Medicare Extended Care benefit provided extremely limited coverage for brief periods in skilled nursing facilities, but only when tied to acute care. The irrational dichotomy reinforced the invidious distinction between care for acutely ill ("really" worthy) seniors and care for the chronically ill whose illness reflected badly on the lives they'd lived and whose lack of family or funds to care for themselves had left them paupers and wards of the state.

Of course, these artificial categories reflect false notions of disease pathology and individual moral worth. Unfortunately, any approach to improving the status of long-term care institutions and our staff within our communities and our country requires that we understand the historical basis of this status, which is not based on our quality of care or any real understanding of who we serve or what we do. We must face the reality that we are associated with an array of concepts that the public abhors: poverty, loss of independence, chronic disability, and death.

Unfortunately, the world of nursing homes has done little to overcome many of these prejudices. As I had suggested in an earlier column (Caring 2020;21[6]:7) most facilities only hurt themselves further through the closed-mouth, "no comment" approach to the crisis we faced in the early waves of the COVID-19 pandemic, when vague references to the Health Insurance Portability and Accountability Act of 1996 (HIPAA) and patient privacy were used to prevent families, friends, and the general community from an awareness of the

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devastation and stress going on within our walls. This was sadly consistent with the approach most have taken for many years.

Community Outreach

Except for marketing done to discharge planners, or the occasional advertisement with a picture of the chandelier in the lobby, most nursing homes have only minimal contact with the communities where they are located. Most nursing home residents even before the 2020 quarantine had minimal contact with family, friends, clubs, religious congregations, neighbors, or the other key elements of their previous community life.

Before changing federal regulations forced facilities to drop restrictive visiting hours, many facilities strictly limited entry. Few genuinely encouraged visiting, even without formally posted hours; almost none made serious outreach efforts to bring visitors in. Unless individuals have a family member or close friend admitted to your building, even those who live within a block or two of your front doors are unlikely ever to come inside your building. Why be surprised that they readily accept the stereotype that your residents are an undifferentiated mass of confused, frightened elderly in johnny coats calling out for help while they lie in beds soaked with urine and feces?

In many neighborhoods or towns large employers are important anchors for the community, yet our long-term care facilities — which are, in fact, among the largest employers — remain invisible. Even when owned by a large national chain, every facility is a standalone institution and ought to be part of its local community. When the current pandemic is over, as facilities reopen to the public they should not only welcome back family and friends, but also invite and welcome an entire population that does not know us and regards us with suspicion.

Most nursing homes have activities space that goes unused in the late afternoon and evenings but could and should be available for use by any number of organizations. Although the residents have a right to privacy in their own rooms, they would benefit from having younger people around and, depending on the activities, might be able to participate in some. We need to sponsor Little League and basketball teams and arrange a few vans for residents to attend their games. The teams could come back to the home to celebrate victories with the residents. We should help sponsor and offer space to Boy Scout and Brownie troops to meet in our buildings. If your facility has an auditorium or large activity space, it might be ideal for local music school recitals.

Moreover, our residents are a large potential reservoir of local voters; facilities should make a major push to ensure that after new residents have moved into the nursing home, they reregister at their new address. Although many nursing home residents are cognitively impaired, age and mobility impairment should not by themselves prevent civic engagement. The growing number of younger residents also includes large numbers whose needs are also ignored by the political system.

Former Speaker of the House Tip O'Neill is famous for the phrase "all politics are local." If we hold candidate nights at which residents, families, friends, and employees can hear from and question local political candidates, the needs of long-term care would hold a higher place in their political agendas. Your local assembly member or city council are more likely to become allies and advocate for your needs if they know more about you — who you are, what you do, and the significant role you already play in the community and their district.

You are rightfully proud of the care that you and your team provide. We all know that this is not easy work in the best of times (which these certainly are not), and sometimes accomplishments need to be boasted about. As we proceed with the delivery of person-centered care, we also need to move ahead with community-centered care. Given the history of suspicion and negative perceptions, we need to be welcoming to all. If we are not wide open to the public, we can hardly blame them for accepting what others say about us.