

Hospice care needs saving

By Ira Byock

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Hospice in America is gravely ill.

An extensive investigation jointly published by [The New Yorker](#) and [ProPublica](#) documented outright fraud, predatory practices, and flagrant mistreatment by specific publicly traded and private equity-owned hospice companies.

As a palliative care physician who has contributed to hospice care and kept my finger on its pulse for more than four decades, I have been dismayed to witness the increasing frequency and severity in lapses in this type of care. I applaud the media for calling attention to deficiencies that can harm people during the most vulnerable times in their lives. I am hopeful that the article will spark a long-overdue internal reckoning by the field — *my field*— and the industry we gave rise to.

Key hospice and palliative care associations need to express contrition and commit to do whatever is necessary to protect and rebuild trust with the public. Instead, one [official response](#) from the National Association for Home Care and Hospice and the National Hospice and Palliative Care Organization mostly complained that the article unfairly characterized the industry due to the acts of a few bad actors. Another, from the American Academy of Hospice and Palliative Care Medicine, discouraged members from calling attention to the piece on social media.

Hospice in the United States began in the mid-1960s as a [social movement](#) to improve care for dying people, and gradually became a vital component in the health care continuum. In England, where modern hospice originated, early ones were special facilities created to care for dying people. In the U.S., hospice developed instead as specialized clinical programs, comprised of interdisciplinary clinical teams of nurses, doctors, social workers, chaplains, and others who cared for people mostly in their own homes.

During the 1980s and 1990s, hospice programs earned reputations for excellence and reliability. While some still offer excellent care, quality varies widely from program to program. In 2019, the Office of Inspector General of the U.S. Department of Health and Human Services [reported](#) that more than 80% of hospice programs were failing in some way, including nearly 20% that demonstrated one or more serious deficiencies.

Especially egregious are failures to rescue patients from suffering with out-of-control pain, breathlessness, agitated delirium, or other miseries.

Carly Wray, a television writer-producer, contacted me in the summer of 2017 when her mother was dying in agony in her suburban Texas home. After doctors advised against further treatments for the cancer in her spine and nervous system, a hospice company representative came to her mother's hospital room to admit her to home hospice care.

"In the past 7 days she's gone downhill VERY fast ... and now she's quickly losing speech, sight and lucidity," Wray wrote by email. She listed the medications prescribed to manage her mother's symptoms. "Despite all of the above, my mom is in utter misery." Wray and her family were at wit's end. "We just sit there, with our hearts shattering, trying to give her morphine, ice her head, and wait to repeat when she awakes."

At their insistence, a hospice nurse visited, yet told them to "Just keep doing what you're doing."

Wray and I spoke by phone. I was appalled by what she described and called a physician executive at the hospice's national corporate offices. The next day she texted me: "The doctor and lead nurse came and rectified the situation — they told us the drugs we had should only have been used for 'breakthroughs' after the baseline was established..." With the new pain regimen Wray's mother rapidly became more comfortable.

I asked her if the physician ever apologized for this serious medical error. He had not.

Hospice nurses routinely instruct patients and their families to call the hospice care company or organization instead of 911 if a crisis occurs. Unfortunately, what happens next varies widely and is often insufficient. Short staffing with reliance on less-experienced nurses is one trend that hobbles swift, effective responses. Another is the diminishing presence of physicians.

Elizabeth, a hospice nurse in New England, wrote me in distress. "I'm increasingly disheartened by the atmosphere in which I work." By phone, she explained that the hospice's single physician spent just half his time with this hospice, which cared for about 100 patients on any given day. He often left care planning meetings early and commonly prescribed medications, including morphine and fentanyl, by relying on nurses' recommendations. Seeing patients was not in his job description, Elizabeth told me, asking, "How can I continue to provide good hospice nursing care and avoid being burnt out?"

It is an existential question.

Early hospices ensured that people who were dying had access to physicians able to skillfully manage their pain and complex symptoms. It's a cruel irony that many American hospice programs have now become *barriers* to dying patients seeing physicians.

In 1983 when Medicare began [paying hospices a daily rate](#) (it was [\\$100](#) in 1983 and has grown to [\\$203.40](#) per patient per day in 2023), a lucrative business model emerged. In recent decades, an obsession with efficiency and productivity — a polite way of saying *with profit* — has afflicted hospice's vital functions.

The quest for margin at the expense of mission is hardly restricted to for-profit health care. That said, nonprofit and for-profit hospices perform differently in ways that affect quality. Nurses in for-profit hospice programs tend to carry higher caseloads — 15 to 18 dying people per nurse are not uncommon, as I've learned from talking with hospice nurses, doctors and administrators — and [visit patients less often](#).

[HealthPivots](#), a company that analyzes national hospice datasets, found that in 2021 nonprofit hospices provided substantially more physician visits, 92 visits per 100 patients, than for-profit programs, with 54 visits per 100 patients. Medicare requires every hospice program to be able to deliver four levels of care: routine home care, respite care, continuous care, and general inpatient care. Alarming, 53% of American hospices, including 61% of for-profits, provided no general inpatient care at all, depriving suffering patients of this "hospice ICU" level of care. Overall, nonprofits delivered general inpatient care [two and a half times](#) more often

than for-profits. And a [2019 study](#) by the Milliman consulting group found that nonprofit hospice programs spent more than twice as much on grief services for families than their for-profit counterparts.

For-profit programs consistently excel on one measure: making money. The Medicare Payment Advisory Committee reported that for-profit hospices achieved a [Medicare aggregate financial margin](#) of 19.2% in 2019 compared to 6.0% for nonprofit programs.

Hospices exist to provide the best, and most humane, care for dying people. Today's publicly traded and private equity-owned hospice companies have a competing priority: delivering a financial return on their shareholders' investments. This well-capitalized segment of the industry [has been growing](#) — from 6.3% in 2011 to 11.6% in 2019 — by acquiring small, mostly nonprofit programs. Their aggressive tactics for recruiting patients, the higher salaries they pay, and their bare bones "high efficiency" clinical practices influence the business environment for all hospice providers.

I and others who truly believe in the value of hospice can't give up. At its best, this kind of care is nearly magical in its ability to restore seriously ill people to a sense of living in the midst of dying. But for hospice to have any chance of surviving with its therapeutic potential intact, leaders in the field must confront their own denial. In this situation, we are either the solution to the problem or the problem itself.

Fixing the disaster that many hospice programs have become will require long-term updating of Medicare hospice certification, conditions of participation, and quality survey regulations, as well as strengthening the oversight and legal accountability of hospice programs.

But simple steps by the field itself can help right away. National organizations that are leaders in the field must immediately publish explicit operational and staffing standards. They should routinely post public-facing information detailing each program's ownership, nursing caseloads, nurse and doctor visits per patient, and more to empower people — all of us — to avoid low-performing hospice programs for our families' care.

The founder of hospice, Dame Cicely Saunders, [once observed](#), "How people die remains in the memory of those who live on." Her statement inspired a generation of hospice workers. It now reads as a warning about the hazards of commodified hospice care.

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