

REFORMING THE MEDICARE HOSPICE BENEFIT

WHAT REALLY MATTERS

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PIONEERING HISTORY

Before 1980 hospice was not a business, it was a “social reform movement” as characterized by hospice pioneers Zelda Foster and Florence Wald. It began as a protest movement of sorts in living rooms and kitchens across the United States. People protested patients being lied to about the trajectory of their disease. They protested the undertreatment of pain and people ending their lives at the end of a hospital hallway—alone, isolated, hooked up to tubes and machines. However, most people in those days saw choosing the alternative of hospice as giving up the fight to live.

Mary Labyak, an early hospice pioneer, who founded Suncoast Hospice, taught that death is so much more than a medical event. As she said: “It is above all about human dignity, no matter how long life was. I think it has grown not so much because we were smart... but because we had the capacity to listen to what our patients and our communities needed, and to build that for them.”

Today, four decades later, everyone is familiar with hospice and insurance covers it. In the last two decades alone, the share of Medicare decedents who elected hospice has doubled – from less than a quarter to nearly half. The number of hospice providers has also more than doubled, from 2,334 in 2000 to 5,058 in 2020, with almost all of the provider increase coming from the entry of for-profit providers.

The word “hospice” today applies to a range of provider types and care models. The remaining community-based, mission-driven hospices adhere to the core model of hospice care as it was first conceived and practiced in the world’s most renowned hospice, St. Christophers, founded by Dame Cicely Saunders.

This core model is based on the belief that:

- Hospice is a concept, not a place
- The patient and the family are the unit of care
- The care of family after the death with bereavement care is as important as the care itself
- Care is wholistic: Mind, body, spirit in order to address Saunder's "total pain," which included the physical, emotional, social, and spiritual dimensions of distress.
- Care is provided by an interdisciplinary team of physicians, nurses, social workers, counselors, spiritual care providers, personal care providers and volunteers without a hierarchy—all team members equally contribute.
- Care is provided regardless of ability to pay.
- Research, and continuous learning must be applied to care well for patients and families.
- Care is driven by needs and includes inpatient care in a homelike atmosphere for acute symptom management, respite care, continuous care, and routine home care.
- Continuity of care across settings is a critical component of quality hospice care.
- Care is accessible 24 hours a day, seven days a week.
- "You matter because you are you", Saunders said. "This principle of respect goes to our deepest connections as human beings."

These core principles were embodied by the first regulations for the Medicare hospice benefit published by CMS (HCFA) in 1983. The regulations were drafted with the challenges of small rural hospices and larger urban hospices in mind based on learnings from a demonstration project. At the time, the program they defined was innovative and unique, utilizing newer payment methods such as capitation and per diem payment that covered the full scope of hospice activity rather than reimbursing separately for each distinct service. When the benefit was unveiled and implemented across the country, expectations were set for continued philanthropic support and the necessary role of volunteers. Most non-profit hospices today continue with their commitment to the idealism of hospice and the original model of care that is consistent with these core principles.

HOW HOSPICE IS CHANGING

"Hospice" is now applied to a wide range of programs, from those that adhere to the original comprehensive model of care to those that emphasize parts of the total hospice experience but not the whole. Hospices established in recent years have been almost exclusively for-profit entities, many backed by private equity funding.

Over the last 20 years, while the number of non-profit hospices increased by 12 percent, the number of for-profit hospices increased by 345 percent. Today, 73 percent of all hospice programs are operated by for-profit entities. While there are many more for-profit hospices, most of them are much smaller than their non-profit competitors – with an average daily census (ADC) of 58 compared to an ADC for non-profits of 68. NPHI member hospices are some of the most established and largest non-profit hospices, with an ADC of 329. While there are a number of fairly small, for-profit hospices today, many are part of larger national chains.

Unfortunately, hospice is rapidly becoming more of a “commodity” business than any kind of reform movement, as the major source of growth has come from substantial amounts of private equity capital attracted to the industry by the opportunity to achieve high profit margins by stripping down the care model. In 2019, the average aggregate margin of a for-profit hospice was 19.2 percent compared to 6.0 percent for non-profit providers. Non-profit hospices providing the full model of care today are operating on thin margins with the aid of generous philanthropic support.

Hospices across the country that are “woven into their communities” and that remain focused on “the family” as the unit of care, honor the role of volunteers and interdisciplinary teams, and passionately stretch to fill gaps of care for the seriously ill and bereaved are being replaced by national hospice companies focused more on increasing productivity and market share, than changing the world “forever for the better”.

Tax status alone does not shape the hospice model of care, and there is a wide variation in practice among both non-profit and for-profit providers. Several studies, however, point to notable differences on



average between non-profit and for-profit hospices in who they serve, how they operate, and their outcomes and satisfaction.

A recent [article](#) by Melissa D. Aldridge, reported that when comparing for-profit and non-profit hospices, for-profit providers offer narrower ranges of services to patients, use less-skilled clinical staff, care for patients with less-intensive care needs over longer enrollment periods, have higher rates of complaint allegations and deficiencies, and provide fewer community benefits, including training, research, and charity care. For-profit hospices are more likely than non-profit hospices to discharge patients prior to death, to discharge patients with dementia, and to have higher rates of hospital and emergency department use.

The prevalence of bereavement care provided by today's hospice organizations has [waned](#) as the industry has become predominantly for-profit. Studies have demonstrated that non-profit hospices are more likely than for-profit hospices to provide certain bereavement services, such as support groups and workshops for families.

While the grief care of family members of hospice patients is not a "covered service" under the Medicare Benefit, [bereavement care](#) has been seen as an essential service, despite lack of payment by CMS, because the [family](#) rather than patient alone are the "unit of care". This support is particularly important when considering that [spousal bereavement](#) is associated with an elevated risk of morbidity and mortality for the surviving spouse.

SUMMARY OF EMERGING DIFFERENCES IN PRACTICE

Non-profit hospices across the U.S. share a common bond in their commitment to the idealism of hospice and the historical model of care. Most non-profit hospice programs have developed models of care that support the founding tenets listed above. Some of these tenets can only be adequately funded by philanthropy, unique to non-profit organizations.

Several the foundational principles have been challenged in the last decade with the rapid proliferation of multi-state, for-profit programs. Some practices of for-profit hospice programs erode integrity of the Medicare hospice benefit and the founding model, even when not an outright violation of the law.

Table 1 compares and contracts the practices of non-profit and for-profit providers

Table 1.

Principle	Non-Profit Best Practice	Common For-Profit Practices
Patient and family are the unit of care	Typically focus care on the well-being of caregivers and family members.	More often focus care on the patient and less on the family.
Site of care	Focus on making care known and accessible to all regions and individuals regardless of, age, diagnosis, or other personal characteristic.	Focus is always on whatever the most profitable site currently is, i.e., focus on providing care in nursing homes rather than cancer centers.
Bereavement care	Operate grief centers for adults and children that may include camps, groups, individual counseling, and family counseling; along with regular support groups for adults.	Often refer to the local non-profit hospice for bereavement care. Typically, do not offer comprehensive bereavement counseling for either adults or kids.



Principle	Non-Profit Best Practice	Common For-Profit Practices
Volunteers	Typically have volunteers perform more hours than the minimum requirement that is equal to 5% of the hospice's total paid patient hours. Data suggests that before COVID non-profit providers volunteer hours were equivalent to between 6% and 30% of their paid hours.	Typically use volunteers for less than the required minimum equal to 5% of paid hours.
24/7 availability	Provide 24/7 availability typically staffed by an RN. Often able to respond within 30 minutes or less, including going to the ER when helpful to sustain continuity of care. Can provide in-person visits around the clock.	Often provide telephone support and use an answering service after hours.
Respite care	Provide respite care in their own facilities or contract with nursing homes.	Provide very little to no respite level of care.
General inpatient care	Provide general inpatient care (GIP) primarily in owned facilities or leased hospital beds.	Often provide little to no GIP care at all.
Care regardless of ability to pay	Utilize philanthropic support to care for those not covered by Medicare or Medicaid.	Typically focus exclusively on Medicare beneficiaries.
Special population focused programs	Offer a range of dementia, ESRD, and other disease-specific hospice and palliative care programs.	Offer fewer disease-specific programs.
Covered services	Provide all drugs, supplies, DME, and treatments as required by Medicare.	Often limit offerings of drugs, supplies, DME, and treatments through restrictive formularies, declination of treatments or discharge, restrictions on medical supplies and durable medical equipment.

THE IMPACT OF VARIATION

The care model makes a difference to beneficiaries and their families, who are attracted to hospice by the promise of comfort, amelioration of pain, spiritual and emotional support for the beneficiary and the family, and a peaceful transition. The better care experience and support provided by community-based, mission-driven hospices is apparent from the metrics on experience of care, satisfaction, and outcomes.

Table 2 highlights key difference in quality of care and care satisfaction between for-profit and non-profit providers.

Table 2.

<p>Caregivers more satisfied with the care their loved one received</p>	<ul style="list-style-type: none"> • Families of patients in for-profit hospices were more than 4 times as likely to report in satisfaction surveys that “promises were not kept” by their hospice than families of patients in non-profit hospices. (Brereton 2020) • A recent study of NPHI member hospice programs showed on average 88.6% of their caregivers would recommend their hospice compared to 82.6% of for-profit programs. (HealthPivots NPHI Study 2022)
<p>Care is more accessible</p>	<ul style="list-style-type: none"> • Non-profit programs are more likely to care for expensive, short-term length of stay cancer patients than their for-profit counterparts. Nearly a third (31%) of the patients of non-profit providers have a terminal diagnosis of cancer (despite their higher cost of care) compared to only 20% of patients in for-profit hospice programs. • Non-profit programs cover palliative chemo and radiation therapy 8 to 9 times more frequently than for-profit programs. (Milliman) • Non-profit hospices enroll a higher percentage (32%) of their patients from an inpatient hospital stay than for-profit hospices (22%).



<p>Clinical care provided at a higher level</p>	<ul style="list-style-type: none"> • Non-profit programs spend more on nursing level of care than for-profit programs (\$41.32 vs \$27.88). • Non-profit hospices provide patients with 10% more nursing visits, 35% more social worker visits and two times as many therapy visits as for-profit hospices. For-profits have more aide visits per patient day. (Milliman, Table 10) • Non-profit hospices report more than 3 times the number of physician or nurse practitioner visits per patient day as for-profit hospices. (Milliman, Table 10)
<p>Care at the end of life is more robust</p>	<ul style="list-style-type: none"> • 87.7% of NPHI-member hospice patients receive one or more visits in last 3 days compared to 83.6% of for-profit hospice patients. (Milliman)
<p>Greater continuity of care with fewer discharges prior to death</p>	<ul style="list-style-type: none"> • Beneficiaries in non-profit hospices revoke their hospice election at half the rate (4%) as for-profit hospices (8%). (Milliman, Figure 1) • Non-profit hospices are less likely to live discharge their patients prior to death without cause or for no reason (8%) than for-profit hospices (13%). (Health Pivots 2022 NPHI)
<p>Lower utilization of higher cost settings such as hospitals</p>	<ul style="list-style-type: none"> • Non-profit hospices have an average 30-day readmission rate that substantially lower than for-profit hospices (1.8% vs 2.6%). (HealthPivots 2022 NPHI) • Non-profit hospices provide inpatient care more than for-profits -- spending \$1.04 per patient day (ppd) compared with only \$0.14 by for-profit providers -- in order to avoid discharging a hospice patient to an acute care hospital. (Milliman) • Non-profit hospices live discharges generate far lower hospital costs for Medicare in the 7 days post discharge (\$180.12) than for-profit hospices (\$262.00). (Milliman, Table 14)

Philanthropy enables greater service

- Non-profit hospices spend more than twice as much on uncovered bereavement services and palliative care programs as for-profits. They spend ten times as much on fundraising as for-profits.
- For-profit hospices spend four times as much on advertising as non-profit hospices. (Milliman, Table 12)

THE STORIES - THE QUALITATIVE DIFFERENCE

Many tangible and intangible features of hospice care contribute to quality of the family and patient’s end-of-life experience. Some of the qualitative aspects of community-based, mission-driven hospice are described above. Many of them, though, are difficult to characterize and measure in a way that may be compelling to a payer or purchaser.

Aspects of hospice care practiced in the original care model that are difficult to measure are nonetheless important in defining the differences between the experience of care and the quality of care in the original care model adopted by the community-based, mission-driven non-profit providers, and the modified care model pursued by more-recently established for-profit companies. A few case studies convey these qualitative differences in the experience of care.



From a hospice nurse reporting a death:

"Peter was an avid birder, traveling across the world annually for a birding trip with one of his sons. We preserved some of his hair for her to give, at a later date, to her children and close friends with the purpose of letting them scatter this piece of him in a farewell ritual. It was especially meaningful for her to consider that perhaps some of the birds he loved to watch would use his hair in their future nests."

Despite all the strain of Peter's unexpected illness and rapid decline, his family was at peace with what was happening. His wife said that he was able to be present, in some manner, with her right up until this morning."

From a nurse practitioner, who worked as a hospice nurse with for-profit programs:

It was common practices of for-profit hospices to work in long term care facilities exclusively, refuse to care for complex, patients in "bad neighborhoods" or individuals experiencing homelessness, have a reduced formulary, and not cover medications appropriately.

From the daughter of two hospice patients:

One parent died under the care of a large non-profit hospice. Just weeks later another parent died in a Las Vegas for-profit hospice. She could not believe the difference. The patient being cared for by a for-profit program was told he could not have a hospital bed for comfort until he was "bedbound". When the daughter called saying he was in pain the hospice would not make a visit, and when he was dying, they said to call them when he passed and they would alert the funeral home.

THE HOSPICE "VALUE PROPOSITION"

What really matters to people – what is valued – in the end-of-life experience provided by a hospice? The answer varies, depending on who those people are. For convenience, we can group them into three categories:

- Beneficiaries and their families
- Payers: Medicare and health plans
- Providers: Non-hospice clinicians and other personnel who may be referral sources

Beneficiaries and their Families

Beneficiaries and their families, in making the choice for hospice, are seeking an alternative experience of care to intensive medical treatment that is focused on symptom relief and comfort and prepares them for a peaceful transition. What they value from the hospice in this experience is:

Access: Beneficiaries and their families want to know the hospice will accept them and continue caring for them through the end, regardless of their ability to pay.

Commitment: The election of hospice is viewed by the beneficiary and family as an implicit contract, with a commitment from the hospice to be present through the end of life. Beneficiaries do not want to be live discharged by the hospice later on and returned to a hospital ICU or SNF. If they need a more intensive level of care, they want to receive it in the hospice inpatient unit with as little disruption and dislocation as possible.

Comfort and Support: Beneficiaries and their families are drawn to hospice by the promise of an emphasis on providing palliative comfort care, relief from pain, and support in what is often one of the most difficult periods of their lives. This includes getting the drugs and treatment needed for symptom relief, care coordination and navigation of services and supplies, support for their caregivers, counseling for anxiety and depression, spiritual support, personal interaction from RNs, hospice aides, and volunteers, and grief and bereavement support for the family through and beyond the beneficiary's passing.

Available Responsive Care: One aspect of care that is particularly important to beneficiaries and families is the availability and frequency of in-home visits and the at-all-hours responsiveness of the interdisciplinary team in the event of a sudden change in the patient's condition.

Payers

Payers who will reimburse for hospice care or contract with a hospice as part of a network of service providers have the expectation that the hospice provider will be accredited, experienced in the community, employ a qualified staff, and be capable of providing high-quality care at a lower cost than continuing treatment in a hospital setting. With these stipulations in mind, they are looking for:

Savings: Hospice is a care model that has the potential to significantly reduce the cost of end-of-life care. Payors are looking for the return on investment (RoI) from this alternative. The hospice needs to demonstrate its ability to reduce expensive, avoidable treatments and hospitalizations for a substantial percentage of the enrolled population. In particular, payers expect to see a minimal number of live discharges back to intensive hospital care and high end-of-life medical costs.

Expertise: Payers value hospice providers that can demonstrate expertise in cost-effective management of patients with advanced illness and complex care needs and can stand up services beyond hospice that support more dimensions of advanced illness care management, including palliative care and home-based primary care.

Quality of Care: Payers value the ability of a hospice to reduce costs without compromising quality of care. Payers value a hospice that can provide quality metrics demonstrating that it implements critical components of hospice processes, achieves a comparatively high rate of desired outcomes, and receives high marks for patient and family satisfaction with the experience of care.

Executional Excellence: Payers value demonstrated capability and experience in contracting to provide services and in meeting payer expectations for data reporting and performance requirements. Payers also value providers who have experience in the community working with other network providers and community partners.

Providers

Physicians and hospital discharge teams play a major role in helping patients and families make the decision to elect hospice and select a particular hospice organization. These recommendations are often influenced by long-standing relationships with leading community hospice providers. What providers value in establishing these relationships are:

History of Community Engagement: Providers often turn first to established hospice providers with a history of community engagement and long-term relationships with local health care institutions and practitioners. Medical providers who are established in the community often have direct experience through family members who have gone through hospice or through community events involving the hospice. Long-standing hospices may also have agreements with hospitals and physicians in the community that include commitment to making referrals.

Expertise and Quality of Care - Some physicians prefer to make a handoff from curative care to hospice, without continuing to consult or provide non-hospice care. In that case, providers will have an interest in seeing that their patient has comprehensive end-of-life care that they would not be able to provide, and that they have the best experience of care possible once they enter hospice. Other physicians will want to retain their attending relationship with their patient and continue primary care visits and non-hospice treatment. In this case, the ability to work with the hospice to coordinate hospice and non-hospice care is important.

CONCLUSION

As hospices communicate their value to their various audiences, what comes through as important in decisions to select a hospice are often elements that are difficult to measure and effectively communicate. These are the “intangibles” that can greatly affect a patient’s and their family’s experience of care.

There are hospices – mostly non-profit hospices – that continue to provide the holistic, person and family-centered, community-based model of care in the U.S., that incorporates these intangibles leading to a better experience of care for patients and families at the end-of-life. At the same time, these hospices deliver substantial savings for payers compared to the alternative of intensive ICU care, largely because they do pay attention to these intangibles, and they do not seek cost minimization as the primary strategy to achieving profits.

Given the current pressures in the rapidly evolving health care market, it is essential that providers, policy makers, and other relevant stakeholders work together to preserve and perfect this unique, holistic, and historically successful model of hospice and advanced illness care.

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Christy Whitney, RN, MS served as the founding CEO of HopeWest for 29 years. She has Master's Degree from the University of Colorado in Community Health Nursing. She was founding director of an "all volunteer" hospice in Durango, Colorado in 1979. She later served as Vice President of Mercy Medical Center, and CEO of Hospice Northern Virginia, now Capital Caring.

She is a co-founder of The National Partnership for Hospice Innovation (NPHI), was an appointed member of the National Rural Advisory Committee for HHS, served on the Caring for Colorado Foundation, National Hospice & Palliative Care Organization, Hospice in Sub-Saharan Africa Boards of Directors. She co-authored the American Nurses' Association Standards of Hospice Nursing, and wrote chapters for the A.H.A. publication "Hospital Hospice Management Models" and the V.A. Hospice Manual. She was the principal author of the National Hospice Organization's first Service Guidelines for Hospice Care. She completed a brief internship in the office of Congressman Bill Gradison in 1998.

ABOUT NPHI

The National Partnership for Healthcare and Hospice Innovation (NPHI) is a collaborative of 80+ not-for-profit, community-integrated hospice and palliative care providers dedicated to ensuring patients and their families have access to care that reflects their individual goals, values and preferences. Representing providers from 34 states and the District of Columbia, NPHI and its members help design more innovative and effective models of care, advocate for comprehensive and community-integrated care customized to meet each person's unique needs, and build collaboration between national thought leaders, decision-makers, and other healthcare stakeholders to improve hospice care. www.nphi.info

