In the late 20th Century, hospices represented a disruptive care model that recognized the holistic needs of patients and their caregivers. Today, modern trends are transforming end-of-life care once again and hospices and other palliative care providers are reimagining and expanding their roles in a new wave of care innovation for the 21st Century.

Transforming Serious Illness and End of Life Care in America
TRANSFORMING SERIOUS ILLNESS AND END OF LIFE CARE IN AMERICA

Executive Summary

When the modern hospice appeared in the United States in the 1970s and was subsequently incorporated into the Medicare benefit in the 1980s, it served as a radical innovation in care delivery—a model of care that not only treated the patient’s medical symptoms in their last months of life, but also addressed the mental, spiritual, and social needs of patients and their caregivers. Today, the confluence of technological, cultural, and demographic changes, chronic condition prevalence, and payment innovation portend a new future state for serious illness and end-of-life care as well as opportunities for those that provide that care. Change is on the horizon and is necessary.

The findings below reflect a series of interviews with serious illness and hospice community thought leaders. The report, commissioned by NHPCO, includes (1) how the holistic hospice model and palliative care has historically created value for public programs, private payers, patients, and their families; (2) challenges of providing hospice services more broadly and the ongoing trends reshaping the delivery of end-of-life care in the United States; (3) how innovators are translating the value of hospice’s holistic care outside the hospice benefit; and (4) recommendations for the hospice and palliative care community as a whole as well as specific sectors.

Key findings from this report include:

- The hospice model is valuable but needs to adapt to the diversifying needs of patients and caregivers.
  - The hospice Interdisciplinary Team, its members, and deep knowledge of a community are key values that are difficult for competitors to build independently.

- While the demand for serious illness and end-of-life care will grow, we do not see future growth in the traditional fee-for-service hospice model. A diversity of models will appear to serve patients and bring value to payers—well-positioned hospices and palliative care organizations can be valuable partners in these models.
  - Today’s successful models are looking for serious illness and end-of-life competencies that augment, rather than replace, a patient’s care team. There is an emphasis on reducing care transitions and handoffs between different programs.

- Providers that are competent in communicating value, especially through Key Performance Indicators, will be the best positioned to enter value-based arrangements, bear risk themselves, or partner with risk-bearing entities (see the reference section for some examples).
  - Care models and payment models in serious illness and end-of-life continue to evolve; we believe that providers should invest in general competencies like telehealth and data fluency rather than going “all in” on a particular value-based model.

- The time for hospice and palliative care providers to adapt is now.
  - Building value based and data sharing networks is imperative for the success of the hospice community in the future.
  - Future patient enrollment will be driven more by algorithms and networks than by provider relationships and marketing.
  - Different provider types have inherently different strengths, weaknesses, opportunities, and threats. These underlying traits as well as the dynamics of the provider’s local market should combine to create organization-specific strategies.
  - Adaptation will need a combination of building, buying, and partnering.
Hospice: A History of Care Innovation

Prior to the 20th century, it was very typical for people to die at home among family. Since that time, the growth of hospital care and changes in the underlying causes of death resulted in increasing numbers of individuals dying in institutional settings. By 1949 nearly half of deaths occurred in institutions and by 1980 that number had risen to nearly three-quarters (IOM, 1997). While the hospital setting provides access to the most sophisticated medical treatment, the reliance on the hospital setting at the end of life often creates gaps in non-medical social, emotional and spiritual care. End-of-life institutional care also creates barriers between patients and caregivers, increasing the trauma of loss on the patient’s family (Dobson & DaVanzo, 2018).

Hospice care was created to address these deficiencies in the institutional end-of-life care model. And nearly 50 years ago, hospice was the first healthcare program to integrate palliative and supportive care for terminally ill patients at the end of their lives. Rather than just treating the medical needs of the patient, it created a unit of care around the patient and family (Dobson & DaVanzo, 2018). As illustrated in Figure 1, the concept of the hospice model, as implemented through the Interdisciplinary team (IDT) was equally attuned to both the psychological/social/spiritual needs of the patients as well as the physical needs—this vision carries forward today in a hospice care model that addresses the breath of holistic needs faced by patients, caregivers, and family. Hospice also places a strong emphasis on palliative care: interventions that aim to lessen pain and suffering, improve quality and sometimes longevity (Temel et al, 2010). Evidence has shown that hospice’s holistic model provides patients a higher quality of life compared to relying solely on medical teams (Greer, 1988).

Hospice Basics

Today, when someone has a prognostic life expectancy of six months or less, a patient can elect the Medicare or Medicaid hospice benefit. When this election occurs, the hospice becomes responsible for the ongoing care of the patient related to their terminal illness and related conditions. Predominantly, hospices receive a fixed daily payment amount from Medicare or Medicaid for each day the patient is in the care of the hospice. During this time the interdisciplinary team focuses and delivers services that enhance, rather than prolong life, and supports the family and caregivers of the patient. Most individuals receive hospice services in their homes, but these services can be provided to individuals wherever they call home, including nursing facilities, assisted living facilities or other settings.

Beginning in 1982 hospice services were added to the Medicare program as a new and distinct benefit. As the Medicare hospice benefit gained acceptance, private payers added hospice benefits, generally mirroring the Medicare hospice benefit for those with commercial or Medicaid coverage. Rather than having a set fee schedule of services, the Medicare hospice benefit was designed to pay a per diem payment rate to hospices: a bundled payment. There are four per diem payment levels, based on the needs of the patient and their family, including routine home care, continuous home care, inpatient respite care and general inpatient care. Unlike traditional Medicare fee-for-service, because of the per diem payment, hospices don’t get paid more for providing more care at the end-of-life, but rather can focus on addressing the specific needs of individual patients and their family regardless of the itemized profitability, or cost, of those services.

This per diem payment approach was important because hospice care utilizes an interdisciplinary team to provide the full range of hospice services, including the important roles of social workers and chaplains, and non-clinical practitioners such as hospice aides and community volunteers. Although this payment approach for hospice is decades old, its innovative bundled/episode-based payment approach has commonalities with many of CMS’ new,
innovative payment models including the Bundled Payments for Care Improvement (BPCI), Comprehensive Care for Joint Replacement, and the Oncology Care Model.

Figure 1: Interdisciplinary Team Overview

The Value of Hospice

Today there are more than 4,950 hospice organizations across the country serving 1.6 million Medicare beneficiaries every year (CMS, 2021). Furthermore, the share of Medicare decedents using hospice has risen to nearly 52% (MedPAC, 2021). Hospices are required to report several quality measures for Medicare. In 2019, the most recent year available, hospices scored exceptionally well on reported quality measures. For example, hospices documented a pain screening and assessment in over 98% of hospice admissions. Additionally, hospices documented at least one visit to a beneficiary in their last three days of life 90% of the time (Id.). Additionally, hospices received high marks on patient and caregiver satisfaction with an average of 84% of caregivers giving the highest hospice recommendation rating (Id.).
Another distinct value of hospice is its connection to a local community. While many aspects of health care delivery have local components, for hospices that local connection is essential to their work. Because most hospice care requires going into someone’s home, having a workforce that can gain the engagement and trust of a patient and their family is essential. This involves individuals that understand local cultures, customs and norms that vary between suburban Virginia, rural Michigan, or Denver’s city center. Additionally, hospices often serve as a link to other community resources—for example, gathering information about what transportation services are most reliable in a neighborhood or what person at a social services agency will be best able to assist a family. Even today, this knowledge is gained from experience living or working in a community rather than standardized data or directories.

**Serious Illness and End-of-Life Care Today**

It is accepted that the hospice benefit provides a high-quality, patient-centered experience for beneficiaries who elect hospice in their last six months of life, but today there is a growing realization that elements of the hospice benefit have great benefit for (1) those with advanced, but not terminal, illness, and (2) those with a presumptively terminal illness that would still like to receive some curative treatments.

Current regulations and reimbursement structures create barriers to access to hospice services for these patient populations. But new innovative models have begun to test ways to expand the hospice benefit. For example, the Medicare Care Choices Model (MCCM) tested a new option for Medicare beneficiaries to receive supportive care services from selected hospice providers, while continuing to receive services provided by other Medicare providers, including care for their terminal condition. CMS will complete the final evaluation in the first quarter of 2022, determining whether providing these supportive services can improve the quality of life and care received by Medicare beneficiaries, increase patient satisfaction, and reduce Medicare expenditures and will be used to model future innovative payment systems. The link to the third annual report can be found [here](https://www.cms.gov/Newsroom/MediaReleaseDatabase/Fact-sheets/2021-08-12). In addition, the Medicare Advantage (MA) Value-Based Insurance Design (VBID) Demonstration allows MA organizations to incorporate the hospice benefit into MA plans (hospice services are otherwise carved out of MA). Some MA plans have partnered with hospices in their service area to develop and offer palliative care services. In other areas, participating Medicare Advantage Organizations have developed their own robust palliative care programs to accompany hospice care, as well as engage their members in an advance care planning process.

CMMI has also recently launched another demonstration: The [Global and Professional Direct Contracting (GPDC) Model](https://www.cms.gov/Newsroom/MediaReleaseDatabase/Fact-sheets/2021-08-12). This model allows for Direct Contracting Entities (DCEs) that are specifically focused on the High Needs Population. This High Needs Population model targets providers that have experience service Medicare FFS beneficiaries with complex needs. To this end, many hospice and home health providers have become participant providers or preferred providers. This model has a risk assumption that approaches that of Medicare Advantage for the participant providers, but preferred providers can still accept a discounted FFS rate in exchange for the opportunity to participate in shared savings gains. While this model is not currently allowing new DCEs, existing providers can join those DCEs already approved to participate: [PY2021 Participant Public Announcement (cms.gov)](https://www.cms.gov/Newsroom/MediaReleaseDatabase/Fact-sheets/2021-08-12).

Outside of hospice there are also many companies developing products and care models to bridge the gap between chronic illness and end-of-life care. These include home-based primary care practices for those with advanced illness, home-based palliative care, advanced illness care coordination, and geriatric urgent care. These organizations are also partnering with a number of technology companies that are enabling telehealth, enhancing remote patient monitoring, developing advanced analytics and artificial intelligence (AI) to support the care team, and enhancing team communication and connectivity. Finally, work is also proceeding with organizations that are assembling advanced illness and palliative provider networks, creating value-based payment models, and creating interfaces with community-based organization to address social determinants of health.
In Figure 2 below we have illustrated the breadth of reimbursement opportunities. We have highlighted the four models that provide opportunity for serious illness and end-of-life care. CMS/CMMI will continue to move care models into full risk and integrated care that is reflected in the upper right quadrant.

*Figure 2: The Diversity of Payment Models in Serious Illness and End-of-Life Care*
Transforming Serious Illness and End of Life Care in America

External Trends Changing Serious Illness and End-of-Life Care

Back in the 1970s, hospice care served as a disruptive innovation to institutionalized end-of-life care. Today, changes to technology, social constructs, demographics, and epidemiology create an opportunity to re-examine if the hospice benefit created over four decades ago meets all the needs of the patient and their family today. Specifically, the major external drivers of change include:

- Changing family composition resulting in additional burdens on family caretakers;
- An increasing number of older Americans while the size of the working-age population remains stagnant;
- Rapid improvements in and adoption of telemedicine and telehealth;
- Changing profiles of the seriously ill and end-of-life populations with less terminal cancer and more progressive neurological disease;
- The continued growth of Medicare Advantage as a presence in Medicare, and
- Innovation models to enhance the value of serious illness and end-of-life care.

More details of these trends are discussed in the appendix.

Industry Trends

Responding to the external trends in serious illness and end-of-life care, models are emerging to extend the value of palliative and serious illness care to more people and populations. Many of these models target individuals who will benefit from hospice’s interdisciplinary, patient-centered model of care prior to a prognosis of less than six months. For example, many of the new innovations engage patients in the last one to two years of life. Other models integrate palliative services in conjunction with curative treatments independent of disease prognosis. Outlined below are examples of some of these models.

Palliative and Advanced Illness Care

There are significant social and emotional barriers to planning for and engaging in palliative and end-of-life care (Dobson & DaVanzo, 2018). Twenty five percent of patients in hospice in 2019 had a stay of five days or less (MedPAC, 2021) —and while during these short hospice stays patients derive some benefit from hospice services, they do not get the full benefit of the interdisciplinary team.

In recent years, many new models have emerged to engage patients prior to their last weeks and months of life, employing both advance care planning and goals of care conversations and holistic palliative medicine. These models, unlike hospice, do not require the patient to forgo any curative care. The ability to address pain along with social determinants of health and behavioral health needs has been shown to reduce crisis-oriented medical interventions such as hospital stays, emergency department visits, and readmissions (Martin, 2016) (Health Care Transformation Task Force, 2016) (CHCF, 2013). There is not a standardized model for these programs, but usually they are branded as home-based palliative care, serious illness, or advanced illness programs. Depending on the program, they target anywhere from sickest 1-5% of the population. Patients usually have a life-limiting (although not necessarily terminal) diagnosis and can also have signs of uncoordinated care or unmet needs (e.g., frequent ED use or recent inpatient admissions).

These models are most popular where providers or vendors of health plans are at full risk for medical care. Here the programs can demonstrate their savings through metrics such as reduced days in the hospital or increased days at
home. Those savings can then be used to justify payments to palliative care and serious illness providers beyond what can be charged using fee-for-service alone.

**Innovation Opportunity: Making Palliative Care and Serious Illness Care Work in Fee-for-Service**

“Palliative care is a great option for the patient of any age who wants that last round of chemo, who has debilitating pain, who has trouble navigating serious illness and just needs a bit more help to get through it. There is no single demographic that would solely benefit from palliative care—it can be a gift to people with illness from all communities and walks of life.” **Dr. Balu Natarajan**

While the market for risk-based palliative care and serious illness programs is well developed, the flexibilities such as payments for certain provider services, telehealth flexibilities, risk-adjustment, and value-based payments are limited in Medicare Fee-for-Service (FFS) outside of demonstration programs.

Often significant issues such as provider travel time between patients, care coordination time, and documentation challenges can quickly eat through revenue obtained from FFS reimbursement, limiting which team members can serve patients. Most respondents reported these limitations as the key barriers to building palliative services in a FFS environment. Lack of reimbursement for social workers or chaplains that are not traditional Medicare providers have also limited the spread of home-based palliative care—recognizing the value of these services, many hospices will provide these programs at a loss as a part of their community benefit.

Given these deficiencies, there is an opportunity for both innovative organizations and CMS to develop solutions so that the nearly 60% of beneficiaries outside of Medicare Advantage can realize the value of home-based palliative care and serious illness programs. Such innovation will also provide local providers, especially in rural and underserved communities, the opportunity to better utilize limited staffing. Delivering the best care should be payer agnostic and finding ways to have care models work in multiple payment arrangements will lead to the best use of limited community resources and improved access.

**Reaching Underserved Populations and Telehealth**

Necessity is the mother of invention, and during the ongoing COVID-19 Public Health Emergency, hospice and palliative care providers, like others in the health care system, rapidly adapted their processes to minimize risks to patients, caregivers, and the health care delivery workforce. Additionally, circumstances of many members of the health care workforce have changed because of their own personal caregiving and support demands.

While Medicare Advantage has, for several years, had broader flexibility to include an array of telemedicine services in benefit designs, FFS Medicare has been quite limited. Many telemedicine services had to be initiated from a clinic site and were further limited to mostly rural geographies. Since the COVID-19 pandemic, many more services can be provided via telemedicine with in-person reimbursement parity.

This has created a rush of innovation and new market entrants looking to seize on this opportunity. New telemedicine companies have been founded to provide patients with an array of services from the convenience of home or the office. However, for these businesses to ultimately succeed, they will need to show their value in terms of avoided in-person visits and acute care interventions as well as a creating a differentiated patient experience.
Innovation Opportunity: The Goldilocks of In-Person and Virtual Care

“Our experience during COVID demonstrated that meaningful impact could be made virtually, even with a population of patients with serious chronic or advanced illness. While there is nothing that completely replaces the multi-sensory experience of sitting with a patient on their couch or observing their ability to navigate in their home, it has become clear that not all interdisciplinary interactions require it. A skilled palliative care clinician can often build tremendous rapport with a patient and/or caregiver through telephone and/or video visits. And sometimes, the most effective intervention is the one that is the quickest or most convenient for the patient or family to access.” Tara Friedman, Aspire Health

Virtual care has proven its ability to deliver services efficiently and better utilize scarce workforce resources, yet personal interaction is essential to the hospice model for a vast majority of patients and their families. Also, while having 24-hour triage services can help to prevent some acute medical interventions, sometimes urgent in-home services are needed to avoid what would otherwise be a hospital admission.

Some hospice services can be accomplished virtually. For example, goals of care, care navigation, social assessments, medication management, crisis preparation, counseling, and even some clinical assessments and interventions can be done via telehealth or virtually. Other services such as personal care, wound care, medical device support, and urgent care and intervention may necessitate face to face involvement.

Across the industry, there is still significant experimentation around how to optimize the delivery of in-person versus virtual care. Some advanced illness providers are testing and finding success with all-virtual models for some patients; but these models are usually supplementing existing care relationships. Other industry participants have noted the increasing social isolation and loneliness in their patients, and how in-person connections are essential to gain engagement and acceptance with a provider.

Organizations that can determine what care model optimizes efficiency, engagement, and outcomes will be well-positioned to create value not just at the end-of-life, but with a variety of partners, programs, and patients.

Value-Based Payment and Medicare Advantage Carve-In

The CMS Innovations Center (CMMI) announced that, beginning in 2021, Medicare Advantage Organizations (MAOs) could add a Hospice Benefit Component to their Value Based Insurance Design (VBID) model to test offering hospice services as carved into MA. Until the development of this model, hospice services have always been excluded from MA, by statute, so when an MA enrollee elects hospice, the hospice is paid directly by Medicare rather than through a health plan. In 2021, nine MAOs offered the Hospice Benefit Component. In 2022, that number has risen to thirteen. CMMI will test this model for five years to determine how and if the Medicare hospice benefit can be offered through MAOs. While this current demonstration was put in place with many guardrails such as open out-of-network access and plan payments that support greater hospice use, a full carve-in will disrupt the business of hospice more significantly.

Because in the model, MAOs must offer all the benefits available to FFS beneficiaries, a hospice carve-in will not be the end of the hospice benefit. MAOs also have the option, outside the VBID model, to offer palliative care services to MA enrollees. While hospice is a defined provider in Medicare with a definition and a regulated set of services to Medicare beneficiaries, palliative care does not have a defined set of core services which must, at a minimum, be available to enrollees. While the lack of defined core services allows the MA flexibility to design services and a care plan that meets an individual enrollee’s needs, there is often confusion about the services offered and a concern about the integrity of the offerings when there is no standard. MA plans will weigh the value of hospice versus other
interventions at the end of life and encourage their networks to utilize the care that optimizes clinical, patient experience, and efficiency outcomes. In this environment, hospice and palliative providers have an opportunity to be the providers or choice for MA, but to do so they will need to prove their ability to provide value and share quality reports and patient information.

Innovation Opportunity: Thinking Beyond Per Diem and FFS

“The hospice industry has been the pioneer of a risk-based reimbursement model since its founders worked with CMS to design a high-quality, cost-effective care model for patients at their end of life. The leaders of our industry are excited to work with CMS and other payors to collaborate on ways we can continue to enhance patient and their family’s experiences through their journey of advanced illness. I’m very optimistic these efforts will dramatically improve the overall experience for every individual in this country for decades to come as the collective healthcare industry evolves towards value-based care.” Nick Westfall, VITAS Healthcare

The hospice level-of-care per diem payment rate has been successful in Medicare FFS by creating administrative simplicity and operational flexibility for hospice providers. Because this is the method used by Medicare, in the event of a carve-in, initially most MA plans will find it easiest to build their networks modeling the existing payment structure—perhaps adding on incentive payments for meeting certain performance metrics. Just like hospices, MAOs value simplicity and will be reluctant to invest in developing alternative payment models unless there is a substantial opportunity for a return (quality, cost, or both).

Nonetheless, as MA integration progresses, payers will also begin to realize that their incentives may not align with the current per diem payment structure. Especially related to long hospice stays, concurrent care and rural care, there will be opportunities for hospices to partner with plans to think differently about cost and value. Additionally, health plans will want to partner with providers to find a more appropriate care model and reimbursement for the current portion of hospice admissions that last only a few days.

In preparation for this, hospice and palliative providers will need to know exactly what their services cost to effectively negotiate reimbursement rates and apply their models to new financial spreadsheets that could be a blend of FFS, per diem, incentive reimbursement, per member per month and/or lump sum payments.

Data-Driven Decision Making

Traditionally, hospice and palliative care providers have maintained their census through a combination of relationships with local providers and hospitalists, building community brand awareness, and partnering with nursing facilities and assisted living facilities. These providers, thinking of their patients’ needs, often are how patients get connected to hospice care. Nonetheless, research has long documented this referral process as a barrier to access because medical providers consistently underestimate the prognosis of their patients (Christakis, 2000). As the number of serious illness and end-of-life care programs and services has increased in recent years, they have fueled a demand for predictive analytics and data-driven decision making that goes beyond provider prognosis.

Part of the data sophistication of these new models is that they are increasingly aware of the patients for whom their care model is most effective. Perhaps it is those with multiple chronic conditions, the home-bound population with Activities of Daily Living (ADL) deficiencies, or those with a serious illness that is not yet terminal. By using predictive analytics on a set of clinical or claims data, programs can identify a potential patient population. Many organizations have found that for some individuals, an expensive serious illness program does not produce a return on investment (e.g., if the enrollment in the program extends for more than two years, or costs are not driven by something that the model can improve: drug costs, dialysis, etc.).
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Generally, predictive algorithms are not used on their own. They are supplemented with information from a treating physician or an in-person assessment. Nonetheless, because the process starts with mining data and direct patient engagement, it can happen outside the traditional referral relationships many hospices have used as the source of their enrollment—a risk to referral-based enrollment.

Once a patient is enrolled in a program, there is also a substantial amount of data tracked and analyzed to optimize outcomes. One commonality is a dashboard of Key Performance Indicators (KPIs) that are tracked by these programs that allow them to demonstrate their value to payers or that feed into contractual incentives or shared savings calculations. More information on Key Performance Indicators can be found under References and Additional Reading.

Patient level data is used to adjust the care model once the patient is enrolled. For example, if a chronic condition is becoming more unstable, more frequent home-based visits occur. Many programs also use data-driven decision making to added supplemental palliative care. Here palliative services are integrated within a program that serves a chronic or serious illness population but can dynamically be added to or removed from the care team as the patient’s condition changes. In addition, the same data can be used by health plans to increase their own reimbursement through the Hierarchical Condition Categories (CMS-HCC) model, which includes diagnoses recorded on professional, inpatient, and outpatient claims.

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**Innovation Opportunity: Improving Data Fluency through Technology Investments or Partnerships**

“Hospices will need to have analytics to measure all costs of care, cost avoidance, days at home, emergency and inpatient utilization metrics. They prove their value by these measures and become worthy of participation based upon these specific measures.” **Jeremy Powell, Acclivity Health Solutions**

We see the market share of traditional Medicare FFS hospice decreasing over the coming decade. While the total number of individuals needing end of life care will grow, non-hospice end-of-life palliative, MA-driven value-based hospice, serious illness care, and palliative services integrated with at-risk primary care will siphon census away from hospices that choose to rely solely on community-based referrals into traditional hospice programs.

Nonetheless, hospice and palliative care providers that choose to embrace this multi-modality future will see increased growth and opportunity. But this engagement will require providers to learn the new language of value through data fluency. Specific competencies that must be developed include:

- Data driven enrollment risk stratification to assign different tiers of services
- Quality reporting on cost of care and quality of care
- Data sharing with referral sources and partners in care
- Processes created to measure and improve a differentiated patient and caregiver experience

Some hospice and palliative care providers will have the resources to develop these capabilities on their own, but smaller rural or regional hospices may need to partner with outside organizations that specialize in data and informatics platforms, jointly develop infrastructure with similarly situated providers, or create partnerships with local health systems or ACOs that could share expertise and resources to create joint value.

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**Joint Ventures and Partnerships**

Just as hospice creates an interdisciplinary team of professionals to serve a patient at the end of their life, new innovations in serious illness and end-of-life care require organizations and providers with different skill sets to come together to provider whole person care.
As the industry evolves, the need for comprehensive solutions that minimize care transitions and deliver the right care at the right time are emerging. This change is in response to some of the early specialized programs that relied on assigning patients to specific, siloed interventions. In many instances, the transitions into and out of these programs proved problematic and once enrolled, some patients were found to need different types and intensities of services than those programs could provide—compromising outcomes. New programs are building out longitudinal services that escalate or de-escalate based on patient and caregiver needs as well as health risk.

Furthermore, industry leaders are adapting by creating comprehensive post-acute and serious illness services to meet patient and caregiver needs across the longitudinal continuum. Hospice and palliative care providers can and are playing a key role in supporting these new innovations as the industry workforce and interdisciplinary product has high value to those rewarded on total cost of care.

Still other organizations are pursing formal partnerships in this space through mergers, acquisitions, or joint ventures. Some recent examples include:

- Ascension’s purchase of Compassus and partnership with Dispatch
- Amedysis purchase of Asera Care, Personal Care and Contessa
- Private Equity aggregators of small hospices
- LHC purchase of Heart of Hospice and others

We are seeing similar integration movement on the data and utilization management side of the industry, including companies that take EMR and claims data to track and provide artificial intelligence to the providers. For example, companies like Medalogix (home health) and Muse (hospice) are coming together to build a better continuum of data share and value to their clients. Like Medalogix, WellSky is another example of a data and technology organization that has grown through multiple strategic horizontal and vertical mergers and acquisitions to serve a broader range of post-acute, serious illness and end-of-life providers.

Model Examples
There are an array of care and product models being used in serious illness and end-of-life care. Many of these models do not operate in a FFS (Fee-for-Service) framework but instead use a variety of alternative payment model approaches. The following figure shows common programs where hospice and palliative care providers may operate or partner with programs. We also included what we have observed as the most common payment models between the payer and the service provider. For reference, the chart includes the following terms:

- PACE: Program for All-Inclusive Care for the Elderly
- PEPM/D: Per Enrollee Per Month (or Per Day) payment
- PMPM: Per Member Per Month payment
Figure 3: Care and Payment Model Map

- Direct Primary Care
- Multispecialty Practices
- Care Coordination
- Carve-Out Network Administration (e.g. Behavioral)
- Utilization Management and Network Management

- Focused Specialty Practice
- Serious Illness Practice
- Serious Illness Care Augmentation
- Care Management

- Palliative Care
- Palliative Care Consultation
- Advanced Illness Care Coordination
- End-of-Life Network Aggregators

- Hospice + PACE

Common Payment Models:
- Full Risk
- PEPM/D
- PMPM
- FFS
- FFS + Incentive

Where Hospice and Palliative Care Providers are Operating
Working Toward the Future

Hospices, palliative care providers, and other health care stakeholders know the time to innovate their approaches is now. The environmental and market trends along with new technologies necessitate change. We believe there are a series of steps that can be taken by those interested in preparing for the future. Specifically, this involves (1) defining the value of serious illness and end-of-life care through metrics; (2) evaluating the opportunities available in a local market and how to benefit from those opportunities; and (3) evolving operations and business models to be a dynamic partner and innovator.

**Figure 4: Framework for the Future**

- **Define Value**
- **Evaluate the Local Market**
- **Evolve Operations**

Hospice and palliative providers interested in capitalizing on the future opportunities in serious illness and end-of-life care come in all shapes and sizes. Many hospices are small and serve a limited or isolated geographic area, others have already invested in sophisticated informatics, have co-managed home-health practices, or participate in value-based arrangements. No matter what the size or sophistication, the desired competencies are going to be the same; but the path to develop these competencies will be organization specific.

Depending on existing scale, capital, culture and human resources, organizations will need to determine what part of this work they can do themselves, what needs to be bought, or where a coordination with an aligned partner may be the most efficient path. We recommend at least some strategic planning work so that organizations can articulate key decision-making inputs including:

- What are my organization’s core competencies and capabilities?
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- Who in my market is taking risk and what is the addressable market?
- How much performance-based financial risk am I willing to take?
- What needs of my community are not being met? Who shares concern for the unmet need?
- What are the greatest impediments to my organization’s vision?

An organization that understands its own strengths, weaknesses, opportunities, and threats will be better positioned to make decisions about where it needs to focus internal resources, buy external solutions, or collaboratively leverage the competencies of others. We have outlined some high-level ideas for organization to get started with in Table 1.

Define Value

As hospices look to translate the value of their work beyond FFS Medicare into areas such as Medicare Advantage, home-based palliative care, and serious illness programs, the language of the conversation will be metrics. These metrics must align with the values of potential purchasers and partners. Metrics are also necessary for aligning reimbursement and performance guarantees.

Quantifying the value of hospice care is not meant to replace the soft value of hospice—the aspects of personal interaction and care that cannot sometimes be quantified. Throughout our process of interviewing hospice organizations and palliative care providers we were struck by the stories of patients who, through their engagement with the Interdisciplinary Team, were able to realize a better life overall in their last years, months or weeks. These stories, and the personalized, caring support that leads to them is essential to the model at the core of palliative and hospice providers. The metrics are the “what”, not the “how” and “why”—all of these are essential for a compelling value discussion.

Key Finding: Communicating System-Level Value Metrics through KPIs

“As a palliative care organization scaling our services for patients with serious illness nationally, it is vital that we have standardized KPIs by which to measure our success. We consider our programs successful if we are positively impacting the outcomes that have been shown to affect the quality of life of patients and their caregivers, such as increased days at home and health care that aligns with their goals and values.” Karen Hyden, Amedisys

The metrics of success for the serious illness and end-of-life provider of the future is different from those most are tracking today. These include:

- Hospital Admissions
- Hospital Re-Admissions
- Emergency Department Visits
- Days at Home
- Total Cost of Medical Care
- Goals of Care Documentation and Achievement
- Net Promoter Score
- Enrollment Success Percentage
- Discharge Status

Organizations that are not familiar with these metrics, or how to track and report them, should engage outside expertise such as consultants, vendors, professional associations, analytic organization, or their trade associations.
Evaluate the Local Market

Because local markets vary, a component of this framework for the future is the evaluation of the local health care market. We have observed that serious illness and palliative care services have already entered most urban markets where Medicare Advantage plans are more prevalent. In these saturated markets, opportunities look different than in more rural areas or in metro areas where traditional FFS Medicare still dominates.

Additionally, while Medicare Advantage is an obvious partner because of the number of beneficiaries served and their flexibility to test and innovate clinical and reimbursement models, MA plans may not always be the optimal partner. Below we have shown the array of potential purchasers for the services of palliative and hospice care providers.

Figure 5: Potential Purchasers of Palliative and Serious Illness Services

Additionally, hospices and palliative care providers should augment their own capabilities through partnerships with community resources. For example, EMTs (Emergency Medical Technicians) can improve access to in-home care in rural areas, or social service organizations can aid with instability in utilities or housing that contribute to frequent emergency room visits or other avoidable medical costs.

“Social Workers and Community Health partners have expert understanding of the patient and family experience of their health in the context of their socioeconomic situation, environment, culture, beliefs and
values. With this understanding, these team members are uniquely positioned to partner with patients and their caregivers to identify and address their individual needs that will afford them the opportunity to safely age in place” — Jennifer Booker, Contessa Health

Figure 6: Potential Partners for Palliative and Serious Illness Services

We have also observed that the in many areas of serious illness and end-of-life care, the industry cycle has reached maturity in some segments. An industry cycle usually progresses from an emergence phase where innovators are developing the products and business strategies. Next, the industry cycle enters a growth phase where the market expands, and new participants emerge. After the growth phase comes a phase of industry consolidation. Here the addressable markets have all been introduced to the product and market share is gained either by building a better or cheaper version of the product or acquiring smaller players. This is sometimes referred to as a “shakeout” phase. This generic industry cycle is illustrated in Figure 7 below.

From our conversations, the market for value-based serious illness/palliative products in Medicare Advantage has reached this shakeout phase in most metropolitan areas. In these areas MA plans either have a solution, are choosing among multiple solutions, or actively developing their own solution. Any organization that is looking to develop a value-based product in this area would need to have a differentiator that would set it apart from the existing participants in the market.
On the other hand, the market is less competitive for programs that cater to more suburban or rural areas or that can operate simultaneously in both a FFS and value-based environment. Organizations that can develop solutions for these markets are primed for rapid growth.

*Figure 7: Industry Cycle*
Evolve Operations

Industry change generally happens slowly, and then all at once. It is often difficult to predict exactly what the “all at once” will be, but those who refuse to prepare or believe they are the exception to change often face a series of bad choices when the world around them has unsympathetically moved on.

The change in how serious illness and end-of-life care is delivered has begun. The promise of telehealth and telemedicine is more widely understood than just two years ago. The push to be able to share digitized health information across the care continuum is reaching more and more providers. Workforce availability is forcing many organizations to think about efficiency and effectiveness in ways they have not done before.

Providers need to have their plan to prepare and respond to a future where algorithms are the main source of referrals, and the IDT is more connected to the patient and caregiver through digital monitoring and communication. The flexibility and problem-solving innovation that regularly occurs on the ground in care delivery will also need to find its way into operations: flexibilities to serve as a vendor, provider, consultant, or coordinator. There will be less space for organizations that make other industry players fit their processes and more space for organizations that seek to engage in collaborative problem solving to improve care and the patient experience.

We believe that serious illness and end-of-life care providers should have a plan in place to transform their operations over the next three to five years (and how to change more quickly in the event of “all at once”).

Key Finding: Home-Based Palliative Care as a Product or a Service or both?

Over the course of our industry interviews, we talked with many organizations that are looking to advance home-based palliative care. One of the early approaches in this area was the development of products for Medicare Advantage plans and other full-risk insurance products (e.g., managed Medicaid) based on alternative payment models. This approach saw the emergence and rapid growth of several companies.

As providers tried to follow these early adopter companies and develop their own serious illness and palliative care products (i.e., a set of services delivered to a patient population for a fixed charge), they have faced barriers related to service area limitations, lack of standardization that made plan interaction difficult, and cost structures that were sometimes uncompetitive with national vendors.

Additionally, more stakeholders are beginning to see limitations with creating discrete products along the care continuum leading to multiple providers, poor care transitions and patient resistance as care teams and services change. Many non-provider vendors have also been limited in their growth by how quickly they can develop their workforces and the limitations of these models in areas where the patient population is lower in density, resulting in increased travel time between patients.

One emerging market trend in this area is integration of home-based palliative care services with at-risk primary care (i.e., augmentation of an existing care team with on-demand expertise and services and reimbursement is more tied to volume with accompanying KPIs). These models have allowed palliative care providers to be better integrated in a care team, allow interventions to be more individualized, and enable smoother transitions to the end-of-life. These models can also allow for more reimbursement flexibility, more geographic flexibility, and more efficient use of scarce workforce resources. In this circumstance, the relationship would be as a service to at risk groups.
To adapt and find growth in the changing landscape of serious illness and end-of-life care, organizations will need to assess their current strengths, weaknesses, opportunities, and threats. At a high-level, we generally see differing approaches to market success depending on whether the provider is a small rural hospice, regional hospice, national hospice, integrated hospice, fee-for-service based palliative care practice, or risk-based palliative care practice. Each individual organization should make their own specific assessment, or partner with outside experts to help them make this determination; however, the below table identifies some generalities for each applicable provider type.

**Table 1: Generalized Market Analysis by Provider Type**

<table>
<thead>
<tr>
<th>Provider Type</th>
<th>General Strengths</th>
<th>General Weaknesses</th>
<th>Current Opportunities</th>
<th>Threats on the Horizon</th>
</tr>
</thead>
</table>
| Small Rural Hospice    | - Less competition from national or value-based entities  
- Best community knowledge and resource roldex  
- Workforce is trusted and has more cultural competence  
- Current business valuations are high by historical comparisons | - Limited resources for infrastructure like data analytics, technology, and administrative supports  
- Less trusted to have the capacity to scale outside of current market  
- Less likely to have upstream palliative care support services for those that don’t meet hospice eligibility | - Partnering with local and regional delivery systems and providers:  
  - Home health agencies to identify upstream patients  
  - Primary care at risk groups  
  - Health system transition to home programs  
  - At-risk palliative providers who do not have a business model that scales easily in rural markets. | - Workforce shortages  
- Inability to demonstrate value-based outcomes  
- Competition from larger national entities |
## Transforming Serious Illness and End of Life Care in America

<table>
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<tr>
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<td></td>
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<td>patients served and demonstrate value</td>
<td>- Larger national payer contracts taking controlling referrals and or end of life utilization.</td>
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<td>- CON states allowing new entrants (both threat and opportunity)</td>
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**National Hospice**

- Experience using electronic documentation and reporting outcomes
- Strong preferred relationships and partners with health systems and primary practice groups (both FFS and at risk)
- Patients served and demonstrate value
- Preferred partner to national health systems, senior communities, and payers
- Acquisition and merger with at-risk companies that are potential referral sources.
- Acquisition, merger, and partnerships with health system and LTC referral sources
- Direct contracting with Medicare
- Merger and acquisition of upstream referral sources by health systems, sending care to their integrated network
- MA referring to palliative care and decreasing hospice benefit utilization with or without carve-in
- Potential for health plans to build competing end of life services.

**Integrated Hospice**

- Resources to support diversified products and palliative care upstream services
- Data reporting on quality outcomes
- Ability to build, buy or partner with needed resources
- More competitive pay and benefits and ability to retain qualified workforce
- Well-positioned for MA carve-in because of ability to standardize and scale
- Less initial trust from communities
- Larger target for legal threats and compliance actions
- Most profitable patients will be the first target for MA plans carving in hospice
- Preferred partner to national health systems, senior communities, and payers
- Acquisition and merger with at-risk companies that are potential referral sources.
- Acquisition, merger, and partnerships with health system and LTC referral sources
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- MA referring to palliative care and decreasing hospice benefit utilization with or without carve-in
- Potential for health plans to build competing end of life services.

**FFS Palliative**

- Flexibility to treat patients largely independent of payer
- Home-based programs can create substantial driving down-time
- Optimizing the appropriate use of telemedicine
- Workforce competition and shortages
- Divided markets create barriers to reaching scale
- Similar to regional hospice
- Also, embedded referral relationships and data sharing and quality reporting
- Also, affiliation may make referrals from competing delivery systems difficult to obtain
- Also, opportunities to support transition programs or hospital-at-home initiatives
- Also, danger of being forced away from value-based initiatives if owners are financially struggling

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<th><strong>Threats on the Horizon</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>- Easy to scale if providers are available</td>
<td>- Many provider types cannot directly bill on their own</td>
<td>- Providing wrap-around services to at-risk primary care</td>
<td>- Lack of sufficient referrals because awareness, algorithmic selection, and existing referral relationships</td>
</tr>
<tr>
<td>- Less policy risk if underlying value-based payment models or MA payment is changed</td>
<td>- Additional engagement barriers if closely aligned with hospice</td>
<td>- Serving communities with a larger density of potential patients (e.g., CCRC, LTC or SNFs)</td>
<td>- Return to pre-pandemic telemedicine restrictions</td>
</tr>
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**Risk-Based Palliative**

<table>
<thead>
<tr>
<th><strong>General Strengths</strong></th>
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<th><strong>Threats on the Horizon</strong></th>
</tr>
</thead>
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<tr>
<td>- Ability to set a price that is reflective of the cost to treat patients</td>
<td>- MA-only addressable population can be quite small in many markets</td>
<td>- Better identify the subset of a population that is best able to realize and ROI for these programs</td>
<td>- Consolidation of risk-based palliative care providers</td>
</tr>
<tr>
<td>- Can utilize data and AI to identify and enroll a population of eligible patients</td>
<td>- MA plans are more interested in full-risk arrangements than designing partial risk value-based payment models</td>
<td>- Designing a care model that can be profitable in rural or underserved areas</td>
<td>- MA risk-adjustment reform if models are over-reliant on diagnosis capture</td>
</tr>
<tr>
<td></td>
<td>- Often misalignment between health plan and provider service areas</td>
<td></td>
<td>- Risk-based primary care internalizing palliative</td>
</tr>
<tr>
<td></td>
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<td>- Pricing is undercut by models that promise similar results with a more judicious use of resources</td>
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Appendix: Drivers of Change

Back in the 1970s hospice care served as a disruptive innovation to traditional institutionalized end-of-life care. Today, changes to technology, social constructs, demographics, and epidemiology create an opportunity to re-examine if the hospice benefit created over four decades ago meets all the needs of patient today and whether these changes necessitate using hospice-like care models outside the last six-months of life.

Demographics and Workforce

The size of families in the United States continues to decrease, with 2020 seeing a record low birthrate in the United States (CDC, 2021). Smaller families mean that in the future, fewer workers and family members are going to be available to care for older individuals in their last years of life—increasing the relative burden on caregivers and care professionals. Specifically, Figure 8 below illustrates how the number individuals over 70 will nearly double from 2010 to 2030, while the number of working age individuals remains stagnant.

Additionally, more older individuals and smaller families supporting them should increase the prevalence of social isolation and loneliness—changing the types of social services needed by individuals in their last years of life. These changes will lead to a dynamic where patients will need more interpersonal care in the last years of life, but the resources available to provide that care will be reduced. Solving this imbalance will require increasing the workforce of caregivers relative to other industries, dramatically increasing the efficiency of the existing workforce, or both.

The Hospice Workforce

“With so much focus from providers and payors on caring for chronically ill patients ‘upstream’ from hospice, it is imperative that hospice organizations prepare in a thoughtful and thorough manner. By this I mean, appropriately educating and supporting the entire Interdisciplinary team to provide high quality ‘patient-centered’ care as these patients progress through the continuum of care.” Dr. Keith Lagnese, Prospero

The hospice workforce is unique in its skills and capabilities. The team is used to meeting with people who are in crisis clinically, spiritually, emotionally, and financially. They understand what it takes to keep people at home and know the local resources more deeply than most community based clinical providers. More importantly, the hospice workforce is trained to take care of patients as a team and provide consistent communication to the primary care provider and others involved in the care of the patient. The hospice provider skillsets are uniquely positioned to bring direct care to communities and achieve the triple aim but there are significant concerns about having enough people to care for the masses of aging Americans. In addition, if we expand the model to more who are living longer, the hospice workforce will need both training, education, tools, and partners who are good at providing chronic disease management and urgent care for those seeking curative therapies.

COVID-19 has exacerbated a workforce shortage in all of health care and hospice is no exception. Data currently available on healthcare workforce shortages are pre-COVID-19 and do not represent the current reality of shortages of nurses, physicians, aides, and others that work in hospice.

Furthermore, the issue of the hospice workforce intersects with issues of equity and inclusion. The community-based nature of hospices usually translates into familiarity with varying attitudes, preferences, and religious traditions related to end-of-life care. For example, hospices’ current six-month prognosis eligibility criteria requires that both the patient and the family acknowledge impending death, “a concept that often runs counter” to the spiritual beliefs of people of color (Yancu, 2019).
“The bedrock of the interdisciplinary team are non-clinical aides and community health workers. These team members tend to be more diverse and better able to build a rapport with traditionally underserved communities.” Edo Banach, NHPCO

Figure 8: 2010 and 2030 (Estimated) Demographic Pyramids for the United States

*Data from PopulationPyramid.net derived from the United Nations, Department of Economic and Social Affairs (2019 estimates)

Data and Technology
Technology will also provide both challenges and opportunities for serious illness providers. Positively, there is greater ability to provide more advanced monitoring, artificial intelligence, and interventional services in a home-based setting. And the crucible of the COVID-19 pandemic has forged the rapid adoption of telemedicine, remote-patient monitoring, and hospital-at-home services in contexts not previously contemplated.

The ability to capture, store and utilize data is also undergoing a dramatic transformation. Hospitals and physicians have transitioned to electronic medical records and new government requirements are demanding that the information in electronic medical records can be easily transferred and utilized across the health care system. Hospice and palliative care providers realize the value of digitization of their work and new electronic platforms are improving the efficiency and capacity for data-driven decision making. For example, providers could use real-time information to assist with identifying the highest need patients, appropriate interventions, and labor allocation to support them.

Nonetheless, data and technology competencies are not universal. In some parts of the country data remains siloed, providers have been slow to invest in real-time data accessibility, and vital parts of the care plan remain stored in analog formats. These remaining gaps must be addressed both at a system and provider level, otherwise missed care opportunities and inefficiencies will persist.
Value-Driven Care

Public stakeholders and private market participants have become aware of the extraordinary costs and inefficiencies that have historically occur in serious illness and end-of-life care. The government and private payers are investing substantial time and resources to create new care pathways, integrate new technologies, evolve informatics and data analytics, and create payment models that better align the value of these new models with payers.

These incentives are especially strong in Medicare Advantage (MA) that now covers over 26 million Medicare members (CMS Monthly Summary, 2021). MA plans are paid a risk-adjusted capitated payment so there are strong incentives to provide the highest value care. Hospice remains outside of MA with a narrow exception of the Value-Based Insurance Design (VBID) demonstration. This carve-out serves to create stability for hospice organizations, but also creates a barrier to end-of-life care innovation.

Figure 9: Growth in Medicare Advantage over Time

CMS is testing model innovations related to hospice in FFS, but these models are also quite limited in their reach. The results of these tests will create an evidence base for alternative approaches to care in the final years of life, but their innovative changes will need to be incorporated beyond the demonstration phase to have a broader transformational effect. The private sector sometimes will mimic the CMS payment trends with their own innovations and seek
partnerships with Medicare advantage companies simultaneously, uniquely positioning them to be prepared to take on larger populations.

Epidemiology
Lastly, the causes of death and the experience with illness in our last years of life continues to evolve. For example, many cancers that were once mainstays of hospice admissions have become more treatable, while conditions that lead to long-term decline on less certain timelines are increasing. As illustrated in Figure 10, the percentage of Medicare decedents with cancer has decreased appreciably since 2002, while those with neurological conditions has grown substantially.

Figure 10: Changes in the Primary Medicare Hospice Diagnoses from 2002 to 2019 (NHPCO 2021 Facts and Figures)

The trend away from cancer as a primary hospice diagnosis means hospices will face more varied disease progressions and greater variety of patient needs. For example, neurological or cardiac admissions often experience intermittent acute declines interspersed with incomplete recoveries and periods of stability. This means that the palliative and social supports related to hospice need to adapt to this more variable disease progression path. An example of this is risk stratification of patients who have higher needs and acuity of illness. Having the ability to escalate services and deescalate based on changes in condition will be imperative for clinical teams in the future.
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Key Performance Indicators References


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Founder and Principal at ZAHealth, for over fifteen years Adam Zavadil has been helping clients at the intersection of health care delivery, regulation, and financing. Adam has developed deep expertise and substantial technical knowledge in Medicare Advantage and other public healthcare programs. Since its inception in 2019, ZAHealth has partnered to serve over a dozen organizations involved health care finance, delivery, and technology—from Fortune 50 companies to innovative start-ups.

In recent years, Adam has partnered with many organizations that are developing and implementing serious illness and palliative care products including hospices, MA plans, states, physician practices, and home health agencies. Here he has specialized in market research, financial modeling, alternative payment model design, quality measurement, regulatory compliance, and risk mitigation.

Adam received a Bachelor of Science from the University of Notre Dame in biochemistry and a MPH in Health Management and Policy from the University of Michigan School of Public Health. Adam also received his Juris Doctorate with honors from The George Washington University Law School.

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Dr. Katy Lanz currently serves Personal Care Medical Associates (PCMA) as Chief Strategy Officer and is the Founder and Principal at TopSight Partners. She is a healthcare executive with two decades of clinical and operational successes who recently led as Chief Clinical Officer for Aspire Health from start up to a multi-hundred million acquisition as the largest palliative practice in the country. She spent over a decade of the first part of her career at the bedside at a not-for-profit hospice.

Prior to Aspire, Katy served as the Executive Director for Geriatric Services at UPMC, where she was also the founding Director in the Palliative Care Institute. While in this role, she designed and implemented value based models in collaboration with payers and led a cooperative demonstration with the Center for Medicaid and Medicare Innovation that remains funded today.

Katy is a nationally awarded clinical expert and mentor, fellow in palliative care, board certified in adult, geriatric and palliative advanced practice nursing and leadership/business trained through Vanderbilt’s Inaugural DNP program and Duke Johnson & Johnson Leadership Fellowship. She currently serves as National Board Director for National Hospice and Palliative Care Organization and Board Member and Strategic Advisor for the Duke Johnson and Johnson leadership program.
Industry Background Interviews
We would like to thank the following individuals for proving invaluable background information and insights about the hospice and palliative care community and current trends in serious illness and end-of-life care.

Brian Bertram, Infinity Hospice
Jennifer Booker, Contessa Health
Liz Fowler, Bluegrass Navigators
Tara Friedman, Aspire
Karen Hyden, Amedisys
Dr. Keith R. Lagnese, Prospero
Terri Maxwell, TurnKey
Sara McBride, Wellbe
Dr. Balu Natarajan, Seasons Healthcare Management, Inc.
Jeremy Powell, Acclivity
Angie Sells, Amedisys
Chris Strayhorn, Concerto
Tina Taylor, Compassus
Dr. David Thimons, Personal Care Medical Associates
Nick Westfall, VITAS Healthcare
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