



# The Case

## for Community-Based Palliative Care

A New Paradigm for Improving  
the Care of Serious Illness

Center to  
Advance  
Palliative Care  
**capc**



**At least 12 million adults and 400,000 children in the United States are living with a serious illness—including metastatic cancer, advanced dementia, heart failure, and congenital illnesses—and this number is expected to increase significantly over the next two decades.**<sup>1-3</sup>

People living with serious illness make up the 5% of patients driving over half of all health care spending. They are disproportionate users of 911 calls, recurring emergency department (ED) visits, hospitalizations, and skilled nursing facility admissions. Yet despite high utilization of crisis care and high spending, this population often receives low-value, even distressing, service from our health care system.<sup>4,5</sup>

**It doesn't have to be this way.**

In the value-based environment, leaders need new strategies to identify and support patients *before* they end up back in the hospital. But with the “solution noise” bombardment, how can health care executives identify proven and effective strategies to improve value in the care of patients with serious illness?

Community-based palliative care *is* that strategy. Palliative care is medical care focused on relief of the symptoms and stress of serious illness. It is based on need, not prognosis. The goal is to improve quality of life for the patient and the family.

The evidence shows that reliable access to palliative care in clinics, long-term care facilities, and patient homes can ensure that our most complex patients receive high-quality, responsive care that prevents crises and the 911 calls that follow.

**As a case in point, consider Roseanne's story.**

## Palliative Care in Action

# A Case Study: Roseanne's Story

Roseanne is a 78-year-old woman with severe pulmonary hypertension and valvular heart disease. She has osteoporosis-related curvature of the spine, prior history of alcohol overuse, and a large hiatal hernia that further restricts her lung capacity. Surgery had been planned to repair her hernia but is now canceled due to her heart and lung impairment.

Roseanne lives alone in an apartment in a retirement community. She was widowed a year ago when her husband died of dementia. She was his primary caregiver during his illness—a situation that resulted in feelings of isolation and anxiety. Her two adopted sons live a day's drive away and visit infrequently.

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## Before Palliative Care

- Recently discharged after a hospitalization for respiratory distress, now on continuous oxygen
- Had trouble adjusting to the oxygen and had shortness of breath with anxiety or exertion, especially at night
- Severely fatigued and had no appetite
- Frustrated, confused, depressed, and anxious, particularly about losing her independence—and called 911 whenever she couldn't catch her breath

Roseanne's primary provider requested a palliative care consultation because of her repeated 911 calls for shortness of breath. The nurse practitioner/social worker team from a palliative care program run by a local hospice agency visited Roseanne at home regularly and offered 24/7 phone access.

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## During Palliative Care

- Discussed goals of care and clarified Roseanne's focus on maintaining independence at home
- Facilitated a video call with the primary physician and her sons to convey her wishes and the plan for addressing her shortness of breath
- Supported her ability to stay safely at home by engaging physical therapy to improve strength and balance, ordering a lighter-weight, longer-lasting portable oxygen concentrator to maximize independence, and educating on breathing techniques, including the use of a handheld fan, flutter valve, and incentive spirometer to maximize lung function

- Revised medications to improve dyspnea, mood, and appetite, and provided counseling for adjustment to illness
  - Developed a stepwise action plan for managing symptoms (handheld fan → spirometer → low-dose morphine → call to nurse help line) and avoiding visits to the ED
  - Collaborated and communicated with the primary medical team, frequently and routinely
  - Completed an advance directive (Physician's Orders for Life-Sustaining Treatment, or POLST) that is available to the health system should the need arise
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## After Palliative Care

- With ongoing involvement by the palliative care nurse practitioner and social worker, Roseanne's shortness of breath, anxiety, and appetite improved.
- She learned how to manage her own symptoms and when to call for help, and her confidence and quality of life improved as she resumed activities at her senior center and in her church.
- Roseanne reset her short- and long-term goals of care as her needs changed. Her family and medical team met the needs that she voiced and honored her wishes.
- These palliative care interventions helped her avoid hospitalization and long-term nursing home placement.
- Roseanne says, "Palliative care helped me live my life, so that I wasn't struggling just to get through the day."

# A New Paradigm for Improving Serious Illness Care

Palliative care works because it starts by determining what patients (and their families) actually need. In Roseanne's case, clear instructions were needed for what to do if she felt short of breath at night, so that she didn't automatically call 911. The palliative care team helped by giving her instructions to first use a handheld fan, try an extra puff of her bronchodilator, and—if those fail—take a very small dose of morphine to relieve air hunger. Roseanne also needed a 24/7 telephone number she can call at any time if she is afraid or anxious, to be reminded of the simple steps she can take to feel better and to hear a caring and concerned human voice at the other end of the line.

Because palliative care helps ensure that resources are matched to patient and family needs and priorities, it results in substantially lower costs. Roseanne now knows what to do if she has trouble catching her breath. If the well-trained nurse on the call line is concerned, she can arrange a next-day office visit to make sure there are no reversible contributors to Roseanne's symptoms.

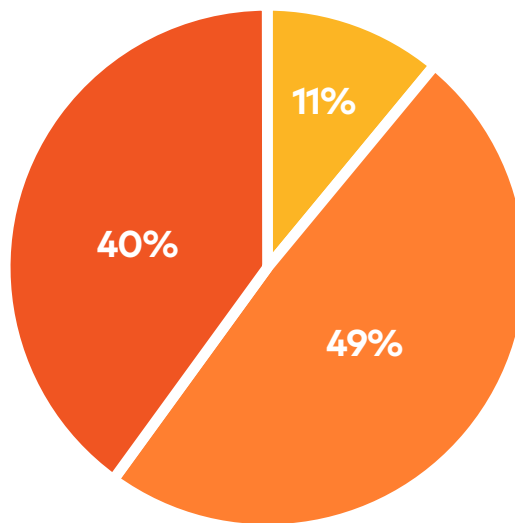
This is how palliative care reduces preventable crisis care. It is simple, but it does require elements that are not routinely available in our system: clinicians well trained in management of symptom distress like shortness of breath, and meaningful, responsive 24/7 telephone access when patients need help. This provides patients, hospitals, the health care system, and clinicians with a high-value solution to challenges associated with serious illness.<sup>6-8</sup>

# Palliative Care Focuses on the Highest-Need, Highest-Cost Patients

High spending in health care is not limited to those at the end of life. Palliative care is for all individuals with serious illness who face heightened risks of crisis hospitalization and preventable spending—often over years. Of the top 5% of health care utilizers in the United States, only 11% are in their last year of life, with a full 40% facing year after year of high utilization.<sup>9</sup>

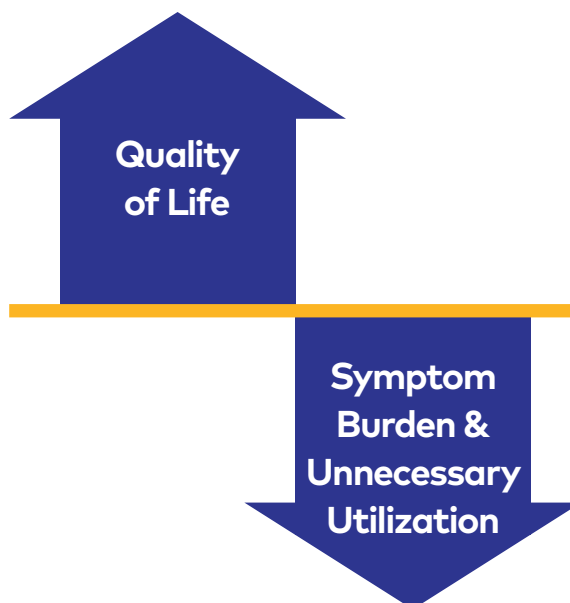
**FIGURE 1**  
**Costliest 5% of Health Spenders**

- Last 12 months of life
- Short-term high spend
- Persistent high spend



**FIGURE 2**  
**Improves Quality of Life and Reduces Symptom Burden**

Palliative care provides the care that patients want—and *because it meets their needs*, it reduces unnecessary utilization of crisis care. Its focus on the highest-need and highest-cost patient segment, accounting for the majority of spending, makes it an essential strategy for population health management.





## The Pillars of Palliative Care

The goal of palliative care is to improve quality of life for both the patient and the caregiver. Its pillars are<sup>10</sup>:

- **Expert symptom management** to reduce both physical and emotional distress.
- **Consultation support** for primary care providers and specialists in caring for their most complex patients.
- **Skilled communication** and intensive patient/family/clinician decision-making discussions.
- **Clear patient and caregiver education** on what to expect in order to empower patients to handle symptoms at home, enable optimal shared decision making, and reduce anxiety.
- **Coordinated care and efficient transitions** across settings so that treatments match the changing needs and priorities of the patient and the family over the long course of a disease.

“To be competitive, health systems need to add quality and value to both the patient and provider experience. Palliative care allows us to do that. Investing in palliative care in the communities we serve has been a key differentiator for our health system.”

**James Clarke, MD**

**Senior Vice President, Primary and Specialty Care Services, Hackensack Meridian Health**

# Palliative Care Where It's Needed: In the Community

Availability of palliative care services has exploded in U.S. hospitals in the last decade. Palliative care teams are now the rule in U.S. hospitals, not the exception: services are available in 94% of hospitals with more than 300 beds, and in 72% percent of those with more than 50 beds.<sup>11</sup> Palliative care is increasingly recognized as the standard of practice, as evidenced by inclusion in major health plans' quality programs and licensure requirements in a growing number of states.

Palliative care is surging in hospitals because health care leaders recognize its impact on patients, clinicians, and their organizations. *But*, they also know that access to inpatient palliative care during a crisis is not enough. The overwhelming majority of people with serious illness are neither dying nor hospitalized. They and their families receive care over months or years while living in their communities, and that's where palliative care can have the biggest impact on averting crises and the 911 calls that typically follow.

**Palliative care needs to be available in all settings outside hospitals—in medical offices and clinics, in post-acute and long-term care facilities, and in patient homes.**

Data-driven models using diagnosis, utilization, and indicators of frailty (such as home durable medical equipment, or DME, requirements) combined with the referring clinician's opinion can help identify "impactable" patients early in their disease trajectory.

# Characteristics of High-Quality Community-Based Palliative Care<sup>12,13</sup>

## **Consistent Across Transitions**

Services are consistent across transitions as priorities, disease progression, and locations change.

## **Broadly Accessible**

Services are available for people regardless of where they live and receive health care.

## **Prognosis Independent**

Services are provided based on need and are independent of prognosis, diagnosis, or disease stage.

## **Collaborative and Coordinated**

Services are delivered by an interdisciplinary team that provides regular assessment and care planning over time, in collaboration with all other providers.

# The Value of Community-Based Palliative Care

There is strong evidence proving community-based palliative care's impact on quality, satisfaction, utilization, and costs across settings of care. Research shows community-based palliative care "results in more compassionate, affordable, and sustainable high-quality care."<sup>14</sup> *Because* it starts with assessing and meeting the needs of both the patient and the family, it yields unique value for health care organizations by:

- **Reducing ED utilization** by avoiding symptom crises—the leading reason for ED visits among those with serious illness<sup>15</sup>
- **Reducing costly and often harmful utilization of acute-care hospital services** for highly complex patients
- **Enabling success** in global budgeting and risk contracts through lower health care expenditures<sup>16,17</sup>
- **Reducing Centers for Medicare & Medicaid Services (CMS) penalties** for avoidable readmissions of patients with serious chronic illness such as heart failure or COPD
- **Differentiating the health care organization's reputation in the marketplace** as a provider of high-quality, comprehensive services for the community
- **Improving the overall health care experience** of patients and their family members, thereby extending positive word of mouth

"Expanding palliative care in the community is part of our health system's strategy; it adds value to our post-acute care platform and to the patients we touch."

**Timothy Friel, MD, FIDSA**  
Chair, Department of Medicine, Lehigh Valley Health Network

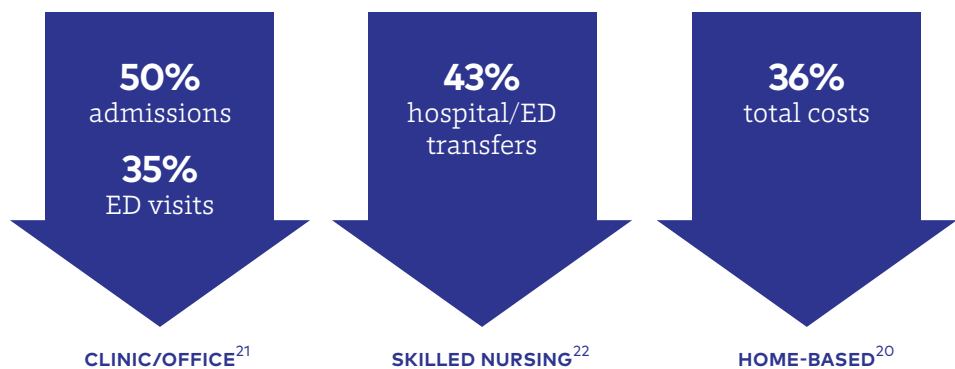
## Community-Based Palliative Care Improves Patient and Clinician Satisfaction

- Increases patient, caregiver, and clinician satisfaction scores<sup>18,19</sup>
- Family caregivers report satisfaction, decreased caregiver burden, and fewer unmet needs<sup>19</sup>

## Home-Based Palliative Care Improves Hospice Utilization<sup>20</sup>

- 35% increase in hospice enrollment
- 240% increase in median hospice length of stay (LOS)

## Palliative Care Reduces Avoidable Spending and Utilization in All Community Settings



## Health Care Innovators Recognize Community-Based Palliative Care as a Triple Win

Forward-thinking health care leaders are looking beyond hospital walls to wherever a patient needs care. They view palliative care as a “triple win”—equally beneficial to patients, to clinicians, and to health care organizations.

Based on the strong evidence of palliative care benefits, organizations are expanding the reach of community-based palliative care. In 2019, the Center to Advance Palliative Care (CAPC) released results of a three-year mapping project to identify community-based palliative care programs nationwide.

**CAPC's survey revealed more than 3,100 sites of community-based palliative care delivery across the country, provided by 890 programs.**

These data indicate that a growing number of hospitals, health systems, and community-based provider organizations understand the value case for community-based palliative care:

- **Hospitals and health systems** are extending palliative care services into ambulatory clinics, cancer centers, skilled nursing facilities, and patients' homes to ensure reliable access to needed care, reducing reliance on 911 calls.
- **Hospice organizations** are developing separate business lines to offer palliative care to people in their communities who are seriously ill but not eligible for, or do not elect, Medicare hospice services.
- **Home health agencies** enrich care for eligible patients by adding palliative care services to the home health episode.
- **Medical practices** are offering palliative care in their offices, as well as in their patients' homes when travel to the office becomes too difficult for patients.
- **Long-term care providers** are building palliative care capacity to prevent crises, avoid unnecessary admissions, and address the needs of not only their patients and patients' families, but also those of their referring hospitals.

# The Right Strategy in Any Payment Environment

## Program Profiles

**Health care organizations are building new population health and post-acute strategies that have community-based palliative care programs at the core, regardless of reimbursement method.**

**The following program profiles highlight good examples →**

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# OACIS Community Palliative Care: Impact in the Fee-for-Service Market

**Optimizing Advanced Complex Illness Supports (OACIS) is a community-based palliative care program established by Lehigh Valley Health Network (LVHN) in Allentown, Pennsylvania. This American Hospital Association Circle of Life Award–winning program is housed in the Lehigh Valley Physician Group and clinically aligned as the Section of Palliative Medicine and Hospice in Internal Medicine.**

**OACIS's community-based palliative care program is an investment that benefits LVHN by:**

- **Offering a continuum of palliative care that provides collaborative, proactive care and decision-making services, balancing avoidable and costly high-tech, reactive care**
- **Supporting LVHN's primary care providers: primary providers note an increase in confidence and effectiveness when they know their most complex, vulnerable patients are assessed and cared for in the home by palliative care specialists**
- **Coordinating with home health services and with hospice care as a clinical partner in the home to achieve smooth, timely transitions for seriously ill patients**
- **Assuring patients and caregivers that their wishes are understood, respected, and followed**



<b>Patients</b>	<ul style="list-style-type: none"> <li>→ Seriously ill adult patients with multiple hospitalizations and/or complex medical and social needs</li> <li>→ Serves patients in their homes, office settings, assisted living facilities and skilled nursing facilities as part of the network's palliative care continuum</li> </ul>
<b>Team</b>	<ul style="list-style-type: none"> <li>→ Business and clinical leadership dyad</li> <li>→ Nurse practitioner–led interdisciplinary care teams</li> </ul>
<b>Services</b>	<ul style="list-style-type: none"> <li>→ In consultation with a patient's primary care clinician and specialists, OACIS teams focus on pain and symptom management, advance care planning, case management, and patient and caregiver education. The team actively engages patients and family members to develop plans to avert crises that result in unnecessary ED and hospital visits.</li> </ul>
<b>Financing</b>	<ul style="list-style-type: none"> <li>→ Primarily fee-for-service reimbursement through Medicare, Medicaid, and commercial insurers</li> </ul>
<b>Outcomes</b>	<ul style="list-style-type: none"> <li>→ Improves quality: OACIS consistently receives "Max" Highmark Quality Blue ratings for its continuum of palliative care services</li> <li>→ Decreases direct inpatient costs: OACIS documented a 30–50% reduction in direct inpatient costs<sup>23</sup></li> <li>→ Increases appropriate use of LVHN's resources</li> </ul>

"I do a better job as a primary care physician by having a more complete, holistic understanding from the palliative care team about my most medically and socially complicated patients, their health, their family, and their goals. My patient care and my workflow improve thanks to community palliative care services... and that results in a benefit to LVHN."

**Kevin McNeill, MD**  
**Primary Care Physician, Lehigh Valley Health Network**  
**Associate Medical Director, Valley Preferred**

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# Banner Health System's Home-Based Palliative Care: Reduced Utilization and Costs for ACO Patients

Banner Health System's accountable care organization (ACO) aimed to use a population health strategy to improve quality outcomes for high-cost, high-intensity Medicare Advantage (MA) members managed under risk.

"We showed that when palliative care programs align with health system priorities, they can successfully expand outside hospital walls to serve a high-need/high-cost population in the community."

**Stacie Pinderhughes, MD**

**Chief Medical Officer, UnitedHealth Medicare and Retirement, AZ, CO, MN**

**Former System Medical Director of Palliative Care, Banner Health**

<b>Patients</b>	→ High-cost, high-intensity MA members identified via utilization rates
<b>Team</b>	→ Interdisciplinary care team, including nurse practitioners (NPs), registered nurse (RN) case managers, and social workers
<b>Services</b>	<p>→ NPs focus on refractory symptom management, physical assessment, goals-of-care discussions, and coordinating care with patients' primary care providers and specialists.</p> <p>→ RN case managers provide patient education, reconcile medications, and develop care plans with patients and their families.</p> <p>→ Social workers assist with garnering needed resources in the home.</p>
<b>Financing</b>	→ Banner's home-based palliative care service contracts with the system's ACO to fund services.
<b>Outcomes</b>	<p>A retrospective cost analysis (analyzing claims data supplied by the ACO for members enrolled in the home-based palliative care program and those not enrolled) showed that home-based palliative care patients demonstrated significantly less service utilization and cost in the months leading up to death.</p> <p>→ Cost divergences were seen most clearly in the last three months of life: \$9,843 for palliative care patients vs. \$27,530 in the control group.</p> <p>→ Reduction in claims was driven by significantly lower:</p> <ul style="list-style-type: none"> <li>→ Cost per inpatient visit (\$1,137 for palliative care patients vs. \$5,946 for patients in the control group)</li> <li>→ Instances of readmission (7.7% for palliative care patients vs. 22.6% for nonpalliative care patients)</li> </ul> <p>→ Patients with specific complex chronic diseases demonstrated a \$1,148 per member per month cost savings above nonpalliative care patients across all 21 months prior to death.</p> <p>→ Cancer patients showed total expense differences in the last three months of life: \$10,950 (palliative care) vs. \$28,676 (control).</p>

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# Home Connections: A Partnership between a Not-for-Profit Hospice Organization and Private Payers

Home Connections is a home-based palliative care program implemented in 2007 as a partnership between Hospice & Palliative Care Buffalo (a not-for-profit hospice in New York State) and three private insurers. Positive results from early studies of the program's clinical impact, health care savings, and utilization reinforced the value of community-based palliative care and catalyzed program expansion.

“Our hospice/payer partnership proved the value equation for community-based palliative care: remarkable clinical outcomes and significant cost savings. This is true in a fee-for-service structure and in a value-based environment.”

**Christopher Kerr, MD, PhD**  
Chief Executive Officer and Chief Medical Officer, Hospice & Palliative Care Buffalo

<b>Patients</b>	→ Adult and pediatric patients with serious illness
<b>Team</b>	→ Palliative care-trained RNs, social workers, and physicians
<b>Services</b>	→ Symptom management, care coordination, patient and caregiver education, supportive discussions about health care decisions and goals, social work visits to facilitate access to community services, respite care, and 24/7 on-call support
<b>Financing</b>	→ Contractual relationships with private insurers, ACOs, large medical practice groups, and hospital systems
<b>Outcomes</b>	<p>When Home Connections palliative care patients were matched with a control group with similar clinical and demographic characteristics to compare cost and utilization, the impact of palliative care was as follows:</p> <ul style="list-style-type: none"> <li>→ Cost savings achieved for patients in the last three months of life was \$6,804 per member per month for palliative care participants vs. \$13,846 for usual care.</li> <li>→ Actionable advance directives were completed by 71% of participants.</li> <li>→ Six of eight symptom domains improved (anxiety, appetite, dyspnea, nausea, well-being, and depression).</li> <li>→ More palliative care patients transitioned to hospice care: 70% vs. 25% for those receiving usual care.</li> <li>→ Palliative care patients enrolled in hospice had longer lengths of stay (with average LOS of 77.9 days compared to 56.5 days).</li> <li>→ Patients, caregivers, and physicians gave high program-satisfaction scores ranging between 93–96%.</li> </ul>

# A Call to Action

Organizations considering community-based palliative care don't need to start from scratch. Lessons learned from well-established programs can jump-start success and sustainability. A host of resources are available to help identify the target patient population, assess for gaps in care and opportunities to improve outcomes, select appropriate care settings, and build a high-quality, sustainable community-based palliative care service.

## 1. Assess the need [↗](#)

Gather information on existing community services, care management and transition services, and post-acute resources and capacity, as well as community demographics and patient characteristics. Use CAPC's Needs Assessment tool [↗](#) to design a high-impact community-based palliative care strategy.

## 2. Design the program [↗](#)

Online courses and downloadable technical assistance help organizations determine patient eligibility criteria, develop a business plan, and design staffing and services.

## 3. Consult with the experts [↗](#)

Leverage the experience of national community-based palliative care leaders by dialing in to CAPC Virtual Office Hours to get insights on building a community-based palliative care program.

## 4. Receive customized training and a full year of mentoring for community-based palliative care program design [↗](#)

Training and mentoring are provided by the national centers of excellence, the Palliative Care Leadership Centers (PCLC).

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# About the Center to Advance Palliative Care

## capc.org

The **Center to Advance Palliative Care (CAPC)**, established in 1999, is a national organization dedicated to increasing the availability of quality, equitable health care for people living with a serious illness. As the nation's leading resource in its field, CAPC provides health care professionals and organizations with the training, tools, and technical assistance necessary to effectively redesign care systems that meet this need. CAPC is funded through organizational membership and the generous support of foundations and private philanthropy. It is part of the Icahn School of Medicine at Mount Sinai, in New York City. Visit **capc.org**.



“In the new value-based health care environment where patient satisfaction drives five-star ratings, palliative care is improving our patients’ experience. And, our primary care clinicians report that availability of palliative care adds value to their practice and increases their effectiveness. More clinicians are interested in joining Hackensack Meridian Health because it offers community palliative care.”

**James Clarke, MD**

**Senior Vice President, Primary and Specialty Care Services, Hackensack Meridian Health**

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