

Palliative Care in the Home

A GUIDE TO PROGRAM DESIGN

Table of Contents

Section 1

Introduction

- A | Letter from Diane E. Meier, MD
- B | Key Principles of Community-Based Palliative Care
- C | Defining Home-Based Palliative Care

Section 2

Context for Program Design

- A | Needs Assessment
- B | Organizational Ownership
- C | Administrative Home
- D | Territory
- E | Community Characteristics

Section 3

Funding Sources and Payment Models

- A | Revenue for Services and Alternative Payment Models
- B | Other Funding Sources
- C | Impact of Payment Model on Program Design
- D | Billing and Reimbursement

Section 4

Program Design

- A | Foundational Concepts
- B | Patient Population
- C | Services
- D | Staffing

Section 5

Program Operations

- A | Central Office
- B | Using Technology
- C | Screening, Referrals and Initial Assessment
- D | Disenrollment
- E | Service Standards, Guidelines and Protocols
- F | Conducting a Home Visit
- G | Team Dynamics

Section 6

Metrics and Measurement

- A | The Importance of Measurement
- B | Deciding What to Measure
- C | Metrics Frequently Used by Home-Based Palliative Care Programs

Section 7

Branding and Marketing

Section 8

Developing A Business Plan

- A | Preparing the Budget
- B | Payment Structures
- C | Demonstrating Value
- D | Tools to Get Started

Section 9

Putting It Together

- A | Lessons Learned
- B | Next Steps

Section 10

Appendices

- Appendix A | Home-Based Palliative Care Workgroup Members
- Appendix B | Program Comparison Tables and Featured Program Profiles
- Appendix C | Supplemental Resources
- Appendix D | Acknowledgments

Section 1

Introduction

- A | Letter from Diane E. Meier, MD
- B | Key Principles of Community-Based Palliative Care
- C | Defining Home-Based Palliative Care



"We must start to think of the patient and the family as the sun, and the health care delivery system as one of the many planets that orbits around the sun. Home-based palliative care is the future of quality medical care for the sickest and most complex patients and their families."

Diane E. Meier, MD, FACP
Director, Center to Advance Palliative Care



Introduction

A | Letter from Diane E. Meier, MD

Palliative care is hitting its stride. Not so long ago palliative care was available only through the Medicare hospice benefit for the terminally ill. Now, hospital palliative care is a routine service, especially in larger hospitals that serve the sickest and most complex patients. While this is good news, we are far from securing reliable access to palliative care for our nation's seriously ill patients and their families because the great majority of them are neither dying nor in the hospital. In order to ensure access to palliative care where people need it, we must help communities build palliative care services that go to the patients and their families where they live—in their own homes.

I think of this turn as similar to the transition from pre-Copernican belief systems (when the sun was thought to orbit around the earth) to post-Copernican thinking, when realization slowly dawned that, in fact, the earth rotates around the sun. We have spent the last century building huge and costly hospital health systems to which patients must come for their care, even those who are most disabled and fragile. This has brought us health care that is too often of poor quality and that is bankrupting our society. As recognition grows that the most vulnerable and costly patients—the target population for palliative care services—do better when cared for in their own homes and communities, new models of care that orbit around the patient and the family are emerging.

We must start to think of the patient and the family as the sun, and the health care delivery system as one of the many planets that orbits around the sun. Home-based palliative care is the future of quality medical care for the sickest and most complex patients and their families. It is CAPC's goal to facilitate the building of capacity for palliative care in the community, and this *Guide* is a part of that effort. The *Guide* aims to shine a light on replicable principles and practices that characterize some of the most successful home-based palliative care programs already working in the U.S. We thank the CAPC Home-Based Palliative Care Workgroup for their enormous contributions to this document and we hope that others can learn from their experiences—both what works well and what doesn't work—in an effort to speed access to quality palliative care where it is most needed.



Diane E. Meier, MD, FACP

DIRECTOR, CENTER TO ADVANCE PALLIATIVE CARE

B | Key Principles of Community-Based Palliative Care

Palliative Care in the Home: A Guide to Program Design is a reference for those who are planning and starting home-based palliative care programs. The *Guide* outlines a process for designing a home-based palliative care program that provides high quality care for patients and families, is responsive to stakeholder priorities and is financially and operationally sustainable. While program design in community settings is by nature heavily dependent upon local factors, the following principles provide a framework within which to make planning decisions.

KEY PRINCIPLES



ASSESS NEED

- Always assess stakeholder priorities and perspectives before designing a program.

UNDERSTAND THE LOCAL ENVIRONMENT

- Program design is dependent upon the needs of the patient population, availability of local resources and relationships with community partners.

PILOT THE PROGRAM

- Start small, monitor, evaluate and phase in growth over time.

ENSURE FINANCIAL SUPPORT

- Identify funding sources and the priorities of financial stakeholders to ensure sustainability.

COLLECT PROGRAM DATA

- Demonstrate the value of the program to key stakeholders and ensure quality.

COORDINATE CARE

- Safe care transitions and frequent communication between providers and settings are essential to quality palliative care.

ASSURE QUALITY

- Design the program to align with National Consensus Project *Clinical Practice Guidelines* including both medical and social supports for patients and families.

The *Guide* illustrates the application of these principles through case studies of ten home-based palliative care programs that represent a variety of patient populations, organizational structures, geographic settings and payment models. Representatives from these programs participated in CAPC’s Home-Based Palliative Care Workgroup, an interdisciplinary committee of advisors that represents medicine, nursing, social work, and administration. The Workgroup served as the key resource for the *Guide*, offering insights into the mechanics of their established programs and providing tips from the field that reflect real-world challenges and opportunities. Their input was gathered through telephonic meeting transcripts, interviews and audio recordings.

The *Guide* takes an in-depth look at three of the programs represented by the Workgroup: JourneyCare Palliative Care, OACIS/Palliative Care Home-Based Consult Service and ProHEALTH Care Support. These programs represent three different payment models and three different organizational platforms—a hospice organization, a health care system and a large multispecialty clinician group. The programs illustrate the impact of organizational sponsorship, payment structure and community partnership on program design and reinforce the importance of a customized response to the unique needs of the community in which care is provided.

The pioneering programs highlighted in this *Guide* demonstrate that there is no “perfect” model for home-based palliative care. Rather, the appropriate model for any program is the one that aligns closely with the needs and priorities of patients, families, community partners and program stakeholders.



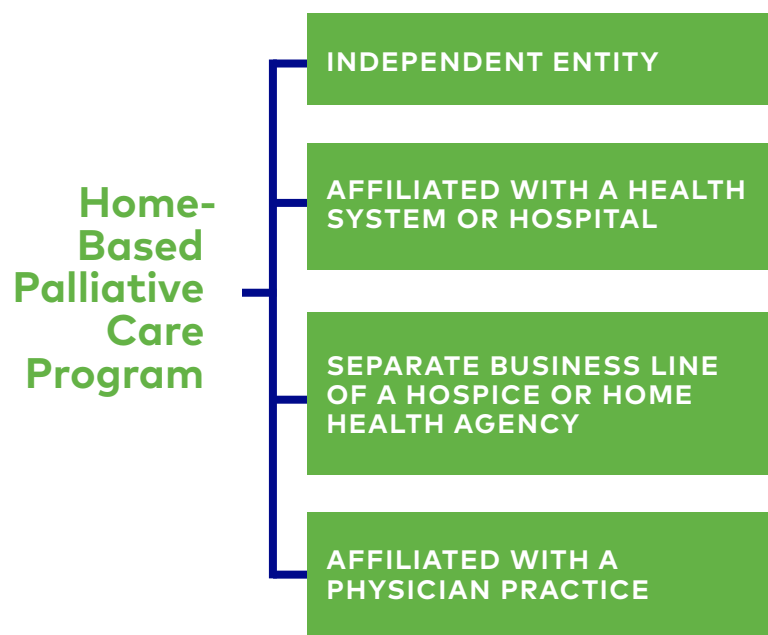
For a list of Workgroup members, see Appendix A of this *Guide*. Full program profiles and a table comparing delivery models for the ten programs represented by the Workgroup can be found in Appendix B.

The *Guide*, a companion to CAPC's online course *503B: Designing Your Home-Based Palliative Care Program*, is one of several resources available to CAPC members who are planning and developing community-based palliative care programs. These resources are listed in Appendix C.

C | Defining Home-Based Palliative Care

Palliative care is the medical team-based specialty focused on providing relief from the symptoms and stress of serious illness. The goal is to improve quality of life for both the patient and the family. Palliative care is provided by a team of doctors, nurses, social workers and other specialists that works together with a patient's other doctors to provide an extra layer of support. It is appropriate at any age and at any stage in a serious illness and can be provided along with curative treatment.

Home-based palliative care is specialist palliative care delivered to seriously ill patients in the setting that a patient calls "home," whether that is a private residence, an assisted living facility, senior housing group home, skilled nursing facility, shelter or the street. Specialist palliative care delivered in the home is defined by the same national quality standards that guide delivery of care in inpatient palliative care programs. The following graphic summarizes the types of organizations that deliver home-based palliative care.





KEY PRINCIPLE

ASSURE
QUALITY

1. Standards and Certification

STANDARDS

Now overseen by the [National Coalition of Hospice and Palliative Care](#), The National Consensus Project for Quality Palliative Care (NCP) is a forum convened by the leading U.S. hospice and palliative care organizations in a collaborative process to improve the quality of palliative care practice. The NCP created quality guidelines for palliative care that were originally published in 2004. As part of its mission, the NCP regularly updates these practice guidelines to respond to the changing health care environment and reflect the maturation of the field. CAPC references the most recent 2013 edition, [Clinical Practice Guidelines for Quality Palliative Care 3rd Edition](#), when defining standards for home-based palliative care programs.

The NCP *Clinical Practice Guidelines* direct the development, structure and standardization of palliative care teams, outline the essential elements of high-quality palliative care and set national goals for access to palliative care.

The NCP Clinical Practice Guidelines articulate the highest standards for the delivery of palliative care. Achievement of these standards is a process, and requires program development and improvement over time.

The *Clinical Practice Guidelines* present a quality framework for patient- and family-centered palliative care. In the context of community settings, this includes:

- Comprehensive palliative care with continuity across health settings
- Early introduction of palliative care at diagnosis of a serious or life-threatening condition
- Interdisciplinary collaborative care
- Clinical and communication expertise across interdisciplinary teams
- Relief of physical, psychological, emotional and spiritual suffering and distress of patients and families
- A focus on quality
- Equitable access to palliative care services

PALLIATIVE CARE PROGRAM CERTIFICATION

As of the writing of this *Guide*, certification for home-based palliative care programs has been released by [The Joint Commission](#) (TJC) and is in development with [Community Health Accreditation Partner](#) (CHAP). CHAP published a draft of community-based standards for public comment in spring 2016. As of January 2016, TJC released prepublication information on certification eligibility for hospice and home care agencies as part of their Community-Based Palliative Care Certification Option for Home Care. CHAP and TJC entities accredit the majority of home care and hospice agencies in the United States and new palliative care certification options are primarily aimed at these organizations. It is unclear whether these certifications will apply to physician and advanced practice nursing group practices. When final, these certifications should be used in conjunction with NCP *Clinical Practice Guidelines* to guide home-based palliative care program design.

Some specialties have guidelines specific to palliative care delivery in their fields. Such guidelines exist for oncology, cardiology, nephrology and neurology. Up-to-date standards can be accessed through the professional organizations of specialty fields. For example, Standard 2.4 of the Commission on Cancer's *Cancer Program Standards 2012: Ensuring Patient-Centered Care* states that at accredited programs: "Palliative care services are available to patients either on-site or by referral." The standard describes palliative care as "...an essential component of cancer care, beginning at the time of diagnosis and being 'continuously available' throughout treatment, surveillance and, when applicable, during bereavement."

Per the standard, Commission on Cancer-accredited cancer programs must provide the following palliative care services either on-site or off-site via referral:

- Team-based care planning that involves the patient and family
- Pain and non-pain symptom management
- Communication among patients, families and provider team
- Continuity of care across a range of clinical settings and services
- Attention to spiritual comfort
- Psychosocial support for patients and families
- Bereavement support for families of patients who die and team members who provided care to the deceased
- Hospice care when the patient's prognosis is limited and death would not be surprising

More information about Commission on Cancer accreditation and palliative care requirements can be found [online](#). A list of commonly used standards from other specialties is provided in Appendix C.3 of this *Guide*.

2. Unique Aspects of Specialist Home-Based Palliative Care

There are important differences between palliative care delivery in a home setting and palliative care delivered in inpatient or office settings:

- The palliative care clinician often works independently in the patient's home, without immediate access to team members or other resources.
- Patients at home with high-intensity palliative care needs are often unable to travel; the clinician travels to the seriously ill patient. Travel ("windshield") time may be significant, especially in rural areas.
- Palliative care team members are visitors in the patient's home; the patient is in control of home visits with respect to when they occur, who else is there and the living conditions/care environment.
- Home-based palliative care relies heavily on physical assessment and communication skills because laboratory, imaging and other diagnostics may not be readily available.

HOME-BASED PALLIATIVE CARE DIFFERS FROM OTHER HOME-BASED SERVICES

Specialist palliative care differs from other home-based services such as hospice and home health with regard to eligibility criteria, scope and type of services offered and the clinical expertise required. However, some house calls or home-based primary care medical programs deliver palliative care *services* to patients in their homes as part of their broader range of services.

Definitions:

Hospice: As defined by Medicare, hospice provides palliative care for terminally ill patients who choose to forego insurance coverage for curative or life-prolonging treatments and whose life expectancy is certified by two physicians to be six months or less if the disease follows its usual course. Hospice is a holistic approach integrating medical, physical, spiritual and psychosocial perspectives in an effort to support the best possible quality of life, symptom management and preparation for a peaceful and dignified dying process. Hospice care is covered by the Medicare Hospice Benefit and other payers. Hospice care can be delivered by an interdisciplinary team in any setting (home, nursing home, assisted living facility, hospice residence or hospital), but the great majority is provided at home.

Home Health: To qualify for a home health service under Medicare, a physician must certify that the patient needs intermittent skilled nursing care and/or physical therapy or speech-language pathology or has continuing need for occupational therapy services. Eligible patients need frequent re-evaluation. A patient must also be homebound (defined as a condition in which leaving the home isn't medically recommended; or a condition that keeps the patient at home without help; or leaving the home requires considerable effort by the patient). Under the Medicare statute, home health care is designated as either restorative (improvement can be measured) or maintenance

(home health services are necessary for a safe and effective maintenance plan). Home health patients and their caregivers may need education and training for care (such as wound care or administration of insulin); for procedures and equipment (such as bladder catheterization or drainage tubes); for rehabilitation (such as safe transfers and assisted mobility); or for management of uncontrolled symptoms (such as pain, shortness of breath or constipation). The focus of home health services is to achieve improved or stabilized clinical or functional status. A home health episode of care is 60 days; recertification for additional episodes is possible if criteria are met. Because reimbursement to home health agencies is episode-based, there are strong financial incentives to discharge patients once “skilled needs” have been addressed. Ongoing need for personal care supports (such as assistance with bathing or toileting), respite care for exhausted family caregivers and 24/7 phone access for emergencies are not covered by home health agencies.

House Calls: Primary or specialist medical care is delivered in the home by physicians and advanced practice providers (APPs)—nurse practitioners (NPs), clinical nurse specialists (CNSs), advanced practice registered nurses (APRNs) and physician assistants (PAs)— who make house calls when patients are unable to travel to their primary care clinic or physician practice. House calls programs typically serve frail older persons with multiple chronic conditions, functional impairments and cognitive decline, and provide primary care, including assessing and addressing need for medical, social, psychological and family caregiver supports.

Independence at Home: Independence at Home is a Centers for Medicare and Medicaid Services (CMS) demonstration project to evaluate a medical service delivery and payment incentive model to improve health outcomes and reduce expenditures for Medicare beneficiaries with multiple chronic conditions through the use of primary care house calls teams. Eligibility requirements for enrollees include two or more chronic conditions; coverage under traditional, fee-for-service Medicare; need for assistance with two or more functional dependencies (e.g., walking or feeding); a non-elective hospital admission within the last 12 months; and acute or subacute rehabilitation services in the last 12 months.

Comparison of Features of Specialist Palliative Care Services and Services Provided by Medicare Hospice and Home Health Agencies

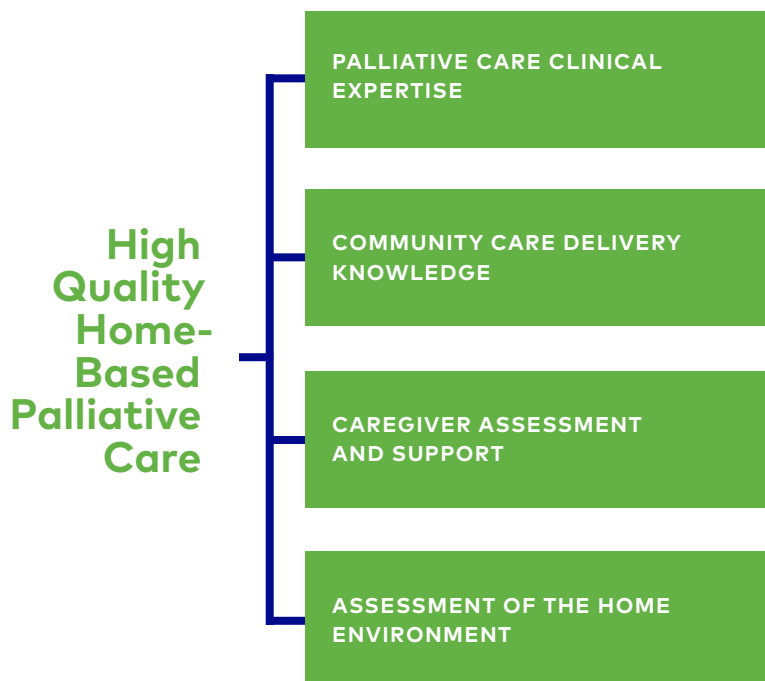
	Specialist Palliative Care in the Home	Hospice	Home Health
Population	Patient has serious or medically complex illness with functional impairments preventing clinic visits	Patient has a 'terminal' illness	Patient is homebound and needs intermittent skilled nursing care and/or physical or speech-language therapy, or has continuing need for occupational therapy services
Eligibility	Eligibility is determined by need, not by prognosis	To enroll, a patient must have a life expectancy of six or fewer months if his or her disease follows the usual course (as certified by two physicians)	There is no limit on life expectancy, but treatment must be either restorative or maintenance and an episode of care is limited to 60 days
Concurrent Care	Patient may continue with curative or life-prolonging treatment	Patient must decline curative/life-prolonging treatment	Patient needs short-term, skilled services (no solely personal or custodial care needs)
Clinical Team	Services are provided by an interdisciplinary team—core disciplines are nursing, medicine, chaplaincy and social work, along with other therapies based on patient need	Services are provided through an interdisciplinary team—core disciplines are nursing, medicine, chaplaincy and social work, along with other therapies based on patient need	Services are provided by registered nurses, and physical, speech and occupational therapists
Services	Core services are pain and symptom management and psychosocial and decision-making support (care may be both life-sustaining and palliative); in some cases, the palliative care team may assume primary medical care for the patient	Core services are pain and symptom management, psychosocial support (especially during the active dying process) and bereavement services	Skilled nursing care, physical therapy and speech therapy as primary need; occupational therapy as secondary need; and patient/family education for procedures, equipment or rehabilitation
Visit Frequency	Frequency of services varies based on patient need	Frequency of services varies based on patient need	Patient requires frequent re-evaluation of care
Reimbursement	Services are reimbursed through Fee-For-Service (FFS) billing under Medicare or by other payers or by risk-bearing entities	Patient elects the hospice benefit which is reimbursed on a per diem basis by Medicare, Medicaid or commercial insurance	Services are reimbursed through Medicare, Medicaid or commercial insurance

A more detailed explanation of Medicare reimbursement is included in Appendix C.1. Medicare hospice regulations can be found on [Medicare's website](#). Information about home health regulations can be found on the [CMS website](#).

Specialist home-based palliative care shares features with—but is distinct from—a primary medical house calls program and requires different staff expertise. Home-based palliative care programs employ palliative care specialists to deliver care in the home (on a consultative, co-management or primary care basis) for patients with serious illness. Primary care house calls programs typically serve patients with acute or chronic conditions or significant disability who are not able to travel easily to a clinic, and assume a primary care role for patients. Many house calls programs also provide elements of palliative care including family and social support, communication about patient and family priorities, symptom management and when the time comes, support for a peaceful death at home.

EXPERTISE NEEDED TO DELIVER HOME-BASED PALLIATIVE CARE

In addition to specialist clinical skills, home-based palliative care teams need expertise in health care delivery in the patient's own home, and in assessment of the home and of the patient's community.



Palliative Care Clinical Expertise

Specialist-level palliative care requires a trained interdisciplinary team focused on the patient's physical, psychological, social and spiritual needs, with specific skills that include:

- Expertise and training in complex pain and symptom management for seriously ill patients and patients who are at the end of life
- Expertise in evidence-based management of a broad range of chronic and serious illnesses
- Communication skills, including listening and therapeutic presence
- Assessment and management of psychological, social, practical and spiritual needs

Community Care Delivery Knowledge

The skills required to provide care in the community differ from those needed to provide care within the walls of an inpatient facility. Expertise in community care delivery is demonstrated by:

- Experience in a community-based health care organization such as a hospice, home health agency or house calls program
- Knowledge of available community resources and how they are accessed
- Capacity to work independently in the home without immediate access to team members
- Skills in communication and care coordination

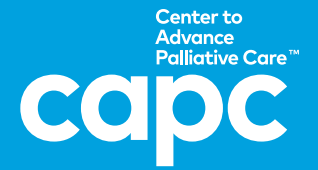
Caregiver Assessment and Support

Assessment of the willingness and capacities of family caregivers and provision of training, coaching, emotional support and 24/7 telephone access is a core function of specialty palliative care.

Assessment of the Home Environment

Home-based palliative care incorporates an environmental assessment of the living conditions, including access to food, cleanliness, heat, water, electricity and telephone, identification of safety risks and availability of adaptive equipment. Environmental assessment requires skills in cultural awareness and sensitivity.

More detail about assessing the patient's home environment can be found in Section 5F of this *Guide*, *Conducting A Home Visit*.



Center to Advance Palliative Care

55 West 125th Street, 13th Floor | New York, NY 10027 | 212.201.2670 | www.capc.org