



Palliative Care in the Outpatient Setting

Action Guide and Resource Compendium

April 2016

About this Guide & Table of Contents



This Action Guide and Resource Compendium provides a list of recommendations and resources to support clinicians, provider organizations, and policymakers in supporting palliative care in the outpatient setting. It is intended to serve as a companion document to policy recommendations presented in the ICER report, *Palliative Care in the Outpatient Setting*. The full report and additional materials are available on the [ICER website](#).

How to use this Action Guide: Each section contains one or more key recommendations from the report, accompanied by resources to provide further background and implementation support to help stakeholders translate and apply the guidance to practice and policy.

A more detailed explanation of the recommendations contained within this guide is presented in section 7 of the [ICER report](#).

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Implementing a Program

The materials at right provide information and resources useful to those implementing and maintaining palliative care programs.

Starting an Outpatient Palliative Care Program

CAPC Outpatient Palliative Care Resources (log-in required)	Resources from CAPC for starting and running an outpatient palliative care program
How to Start an Outpatient Palliative Care Program	A short article from the American Academy of Hospice and Palliative Medicine on starting up an outpatient program
Up Close: A Field Guide to Community-Based Palliative Care in California	A report on Community palliative care from the California HealthCare Foundation
11 Strategies to Help Sustain a Community-Based Palliative Care Program	An article from eHospice on sustaining community-based palliative care.
Next Generation of Palliative Care: Community Models Offer Services Outside the Hospital	A 2012 report from the California HealthCare Foundation on outpatient palliative care trends, models, and opportunities.
Improving Outpatient Palliative Care	Information from CAPC about improving palliative care services in the outpatient setting.

Developing Coverage Policies



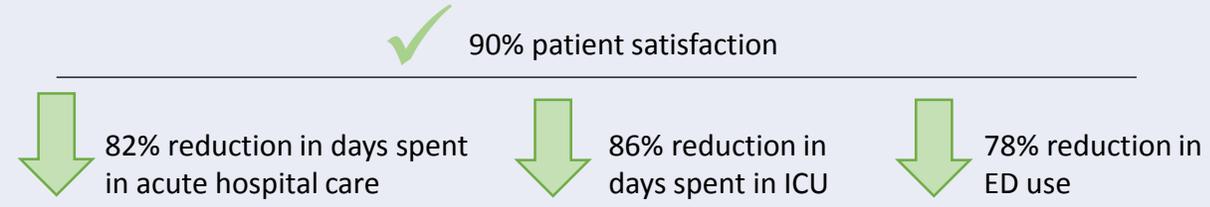
PAYER RECOMMENDATION: Design coverage policies that avoid creating artificial lines between palliative care and curative care.

Aetna’s Compassionate Care Program, summarized at right, allows patients to receive hospice services, typically reserved for patients in the last six months of life who have chosen to forgo curative therapies, to access services throughout the last 12 months of life, while still receiving curative therapies.

Compassionate Care Program (CCP), Aetna

- Key features:
- Loosened restrictions around hospice care. Patients are able to access hospice services earlier in their disease progression and are able to continue receiving curative treatments while using hospice services.
 - Telephonic Nurse Case Managers. Nurse case managers with specialized training in advanced illness and palliative care are available by phone for support and to help address concerns. Managers are able to develop relationships with members and families to better serve their needs.

Results
In Medicare Advantage members enrolled in the CCP, Aetna reports the following results:



On average, health care costs have fallen by \$12,000 per person in the program.

[Learn more about the program from Aetna.](#)

Developing Coverage Policies

PAYER RECOMMENDATION: Implement reimbursement policies that adequately reimburse the provision of outpatient palliative care services.

PAYER RECOMMENDATION: Expand the Medicare Care Choices Model demonstration project that allows curative treatment to be provided concurrently with hospice care.

By offering a per beneficiary per month capitated payment, the Medicare Care Choices Model allows for more flexibility in the palliative care services provided. Similar to Aetna's Compassionate Care Program, this model also allows patients to access services earlier in the course of a serious illness than typical hospice benefits, generally reserved for those patients with a life expectancy of six months or less.

Medicare Care Choices Model

What it is: A new Medicare pilot program allows Medicare beneficiaries to receive support services from hospice providers while concurrently receiving curative therapies. Previously, Medicare beneficiaries had to agree to forgo curative treatment in order to access hospice services.

The goals of the program are to:

- Increase access to currently underutilized supportive services that hospice offers
- Improve quality of life and patient satisfaction among beneficiaries
- Inform new payment systems for Medicare and Medicaid hospice programs

Payment: Medicare will pay participating hospices a fixed per beneficiary per month fee, ranging from \$200 to \$400, to provide services that previously could only be billed under the Medicare Hospice Benefit.

Participation: Over 140 hospices are now participating in the model, and the model is expected to allow up to 150,000 Medicare beneficiaries to access services. The model began in January of 2016 and will run for three to five years.

[Learn more about the program from CMS.](#)

Alternative Delivery Options: Payers



PAYER RECOMMENDATION: Reimburse for alternative delivery methods, including remote access to care, such as telehealth.

Experts identified workforce shortages and geographic access challenges as key barriers to accessing palliative care. New technologies, such as telehealth/telemedicine, have the potential to meet the palliative needs of seriously ill patients, and payers could improve patient access and outcomes by providing reimbursement for these alternative care delivery options.

The resources at right provide some examples of innovative payer programs that support the provision of palliative care.

Payer Resources	
Aetna’s Compassionate Care Program	Aetna’s program relies on telephonic support from nurse case managers.
Blue Cross Blue Shield of Massachusetts: Complete Care for Advanced Illness Program	In January of 2016, BCBSMA launched a new palliative care initiative aimed at increasing education and training around serious illness and end-of-life for patients, clinicians, and families. The program also includes efforts to encourage earlier and expanded use of hospice benefits.
Improving the Care of Serious Illness Through Innovative Payer-Provider Partnerships: A Palliative Care Toolkit and Resource Guide	The toolkit to support payer and provider collaboration in caring for patients with complex needs.

Alternative Delivery Options: Providers

PROVIDER RECOMMENDATION: Be flexible in how palliative care is delivered.

As new technologies arise to help reach patients in rural areas, those with limited mobility, or those with increasing frailty, providers should evaluate the utility of telehealth/telemedicine to improve patient outcomes. Experts also noted the important role community health workers, who often see patients in the home, are increasingly playing in delivering high quality palliative care.

The resources at right highlight how some physicians are using telehealth to reach more patients.

Telehealth Program Examples

[When patients live far from care, video conferencing can be a palliative support lifeline](#) (PBS Video)

One example of using video conferencing in palliative care.

[Symptom Control & Palliative Care Telehealth Program, Alberta Hospice Palliative Care Association](#)

A clinic in Canada relies on telehealth to provide real-time consultation support for physicians treating patients with cancer in rural communities.

[Pediatric Palliative Care Telehealth Initiative](#)

The Center for Connected Health Policy is piloting a program to understand how telehealth can improve pediatric palliative care.

Incorporating Palliative Care into PCMH

PAYER RECOMMENDATION: Consider outpatient palliative care services a key component of high quality patient-centered medical homes (PCMH).

One model for the delivery of palliative care could involve training primary care teams in PCMHs on the core components of palliative care, while supporting clinicians in identifying complex patients in need of specialized palliative care. By incentivizing PCMHs to deliver supportive services to those with serious illness alongside curative treatments, e.g. through supplemental reimbursements tied to demonstrating the ability to deliver palliative care in the outpatient setting, payer policies could support improved access and outcomes for seriously ill patients.

Integrating Primary Care and Palliative Care

[A More Cohesive Home: Integrating Primary and Palliative Care for Seriously Ill Patients](#)

A Health Affairs blog piece on integrating palliative care services into primary care settings.

Developing Quality Measures

PAYER RECOMMENDATION: Collaborate with policymakers to take on the challenge of designing quality measures that foster high quality care without incentivizing one-size-fits all approaches to palliative care.

A partnership with palliative care experts is needed for payers and other stakeholders to determine the appropriate set of quality measures to ensure the delivery of high quality palliative care in the outpatient setting. Experts agreed that there is a balance to strike when implementing new quality guidelines – the metrics should be tied to improved patient outcomes while giving providers the flexibility to deliver palliative care to varied, complex patient populations.

The resources at right highlight examples of existing standards for certification and quality measurement.

Quality Measures for Palliative Care

[Certification for Palliative Care Programs](#)

The Joint Commission’s requirements for certification of inpatient, hospital-based palliative care services.

[Clinical Practice Guidelines for Quality Palliative Care](#), 3rd edition

Quality guidelines from the National Consensus Project for Quality Palliative Care (2013).

[A National Framework and Preferred Practices for Palliative and Hospice Care Quality: A Consensus Report](#)

A framework for hospice and palliative care, intended for use in developing a foundation for quality measurement and reporting, from the National Quality Forum (2006).

Building Provider Awareness

PROVIDER RECOMMENDATION: Build awareness with PCPs, oncologists, cardiologists and other specialists about the availability of palliative care services in the outpatient setting.

The resources at right provide resources and tips for physicians discussing palliative care with patients.

Talking to Patients About Palliative Care

[Talking About Treatment Options and Palliative Care: A Guide for Clinicians](#)

A guide for speaking to patients about palliative care options.

[Ten Steps for What to Say and Do \(Video\)](#)

Guidance from Diane Meier, MD on discussing palliative care with patients and families.

[Palliative Doctors: FAQ](#)

Establishes what palliative care is, and explores the differences between palliative care and hospice.

[Communication and Palliative Care](#)

Clinician resources for improving communication skills from CAPC.

2011 Public Opinion Research on Palliative Care, CAPC

A [2011 report](#) assessed attitudes and perceptions of both consumers and physicians toward palliative care. The report's findings provide useful information for communicating about palliative care. Some highlights of the report are included below.

Patient Priorities: Consumers were asked which elements of palliative care were most important to them. The top four choices are were:

- It helps give patients and families the best quality of life possible.
- It helps patients and families manage pain, symptoms, and stress associated with serious illness.
- It is a partnership of the patient, medical team, and family.
- It is appropriate at any age and any stage of serious illness.

Terminology: Participants in the qualitative analysis were more likely to associate the terminology of “Advanced Illness” with terminal illness and end of life than “Serious Illness.” Palliative care should be positioned for patients with “Serious Illness.”

Physician Perceptions: Physicians often view palliative care as synonymous with hospice or end of life care. Physicians may be hesitant to refer patients for services as a result.

Provider Training



PROVIDER RECOMMENDATION: Train non-palliative care specialists, especially PCPs and other clinicians, on the core principles of palliative care.

Fully acknowledging the increasing burdens on PCPs and other clinicians delivering primary care (nurse practitioners, physician assistants, etc.), experts on the panel noted that for non-complex, seriously ill patients, many of the principles of palliative care mirror high quality, integrated primary care. Efforts to educate PCPs and other clinicians, such as nurse practitioners and physician assistants, on core principles of palliative care would increase patient access and could improve outcomes.

The resources at right provide opportunities for education of physicians and other clinicians.

Training Opportunities for Physicians and Other Clinicians	
CAPC Online Curriculum (log-in required)	A list of CME eligible online training courses from CAPC.
AAHPM Education On the Go	Educational recordings on hospice and palliative medicine from the AAPHM.
VitalTalk®	Patient-provider communication training courses.
End-of-Life Nursing Education Consortium	ELNEC aims to equip a variety of providers and practitioners essential to the practice of palliative care with training opportunities that that the information can be taught to nursing students and practicing nurses. Trainings are offered for providers, staff development educators, nurses in a variety of specialties, graduate and undergraduate nursing faculty, other nurses with a background in palliative care.
Education in Palliative and End of Life Care	EPEC aims to educate health care professionals in the core clinical competencies of palliative care in an effort to expand primary palliative care to all patients in need. EPEC provides training opportunities for a variety of health care providers and offers distance learning modules.
Harvard Medical School Center for Palliative Care: Palliative Care Education and Practice	PCEP is a comprehensive course intended for physicians, nurses, and social workers to gain skills in palliative care services. PCEP consists of a 7 day intensive learning period, 6 months of independent project work and participating in online discussions, and an additional 6 day period of intensive learning to conclude.

Provider Training (continued)

Additional Training Resources	
Clinical Training in Hospice and Palliative Medicine	Information about Training from AAHPM
Certification and Licensing	Information on certification and licensing for palliative care providers and practitioners from CAPC.
Primer of Palliative Care, 6th Edition	Order the American Academy of Hospice and Palliative Medicine's palliative care primer.
Clinical Site Visit Directory	CAPC's list of hospital sites with established palliative care programs that are willing to host clinicians interested in on-site training in palliative care.
Evolving the Palliative Care Workforce to Provide Responsive Serious Illness Care (log-in required)	An article published in the Annals of Internal Medicine detailing the workforce shortage and possible solutions.

Mid-Career Training

POLICYMAKER RECOMMENDATION:

Expand the number of specialist palliative care providers by adjusting the certification process.

Because the certification program for specialist palliative care only began in 2008, many professionals who have practiced specialist palliative care lack the certification, since mid-career professionals are less likely to enroll in a fellowship program. Accreditation bodies should consider standards for awarding the certification to those with demonstrated proficiency in the principles of palliative care without requiring the fellowship.

Mid-Career Graduate Training

In response to the shortage of palliative care physicians and the lack of training opportunities for mid-career professionals, new graduate training options have begun to emerge:

University of Washington: Graduate Certificate in Palliative Care

The interprofessional Graduate Certificate in Palliative Care offers training for providers currently working in nursing, medicine, social work, spiritual care, and other disciplines. The program is geared towards both specialty providers offering consultative services, as well as primary palliative care providers for patients with serious illness. Members of currently practicing palliative care teams applying together are given admission priority.

University of Colorado: Interprofessional Master of Science in Palliative Care and Palliative Care Certificate Programs

Both the Master of Science in Palliative Care and the certificate program are offered in an online or hybrid online and in-person format. The courses, designed for working professionals, are intended to allow palliative care providers, including nurses, physicians, physician assistants, and pharmacists, to develop their skills and knowledge in palliative care.

Involving Caregivers in Advanced Care Planning

PROVIDER RECOMMENDATION: Involve patients and family caregivers in advanced care planning.

The evidence is clear on the benefits to patients who are involved in advanced care planning, but when family caregivers are included as the second locus of care, outcomes may improve for both the patient and the caregiver. When appropriate, providers should involve family caregivers and patients in care planning and care execution.

The resources at right can help to guide conversations with caregivers and offer caregiver support.

Resources for Caregivers	
The Conversation Project	Resources to support conversations about advanced care planning.
Caregivers Corner	Personal accounts of how palliative care helped caregivers caring for loved ones receiving palliative care services during treatment for an illness.
Caregiving	Resources for caregivers from AARP.
Family Caregiver Toolbox	A toolbox of helpful information for family caregivers from the Caregiver Action Network.
National Alliance for Caregiving	Learn more about the research and advocacy efforts of the National Alliance for Caregiving.
Resources from Get Palliative Care	Information for caregivers from Get Palliative Care.

Building Awareness for Patients

PATIENT RECOMMENDATION: Build awareness among patients to help dispel myths about palliative care.

Many patients may feel that discussions of palliative care are analogous to discussions of “giving up.” Providers and patients must build mutual trust to dispel commonly-held myths about the goals of palliative care. In addition, patients and families should be aware that palliative care also focuses on the needs of caregivers and can provide an additional layer of support for those caring for individuals with serious illness.

The resources at right can help educate patients about what palliative care is and how it can help.

Patient Education

Palliative Care: What You Should Know	A printable handout on palliative care.
A Quality Life (Video Series)	Personal accounts of how palliative care helped patients with cancer, diabetes, arthritis, heart failure, and other conditions during their treatments.
What is Palliative Care?	A brief video explaining palliative care, featuring Dr. Diane Meier from the Center to Advance Palliative Care.
Myths and Facts About Palliative Care	Common misconceptions about palliative care, and an explanation of the facts.
GetPalliativeCare.org	GetPalliativeCare.org offers resources for patients looking to learn more about what palliative care is, whether it’s right for their needs, and how and where they can find services.

Developing a National Education Campaign

POLICYMAKERS: Deploy a national educational campaign on the role of palliative care.

A national organization or federal agency such as the Office of the Surgeon General could undertake a national education campaign to help both patients and providers understand the role of palliative care in the care continuum.

The resources at right provide examples of existing educational campaigns in the US and abroad.

Hospice and Palliative Care Awareness Campaign Examples

All Ireland Institute of Hospice and Palliative Care	A report from Cavanaugh Communications includes an overview of a campaign to increase public awareness of palliative care services in Ireland. Additional resources and materials are provided on the Palliative Hub .
GetPalliativeCare.org	GetPalliativeCare.org, run by CAPC, offers numerous resources and consumer-focused information for educating about palliative care.
Moments of Life Awareness Campaign	The National Hospice and Palliative Care Organization launched a campaign in May 2014 to promote positive messages about hospice services.

Balancing Pain Management with Opioid Addiction



POLICYMAKER RECOMMENDATION: Balance needs of patients in pain with the goal of reducing opioid addiction.

Policymakers should consider policies that balance the need to reduce addiction while offering symptom relief to those who need it.

The resources at right provide more information about the appropriate use of opioids in palliative care.

Prescribing Opioids

[CDC Prescribing Guidelines](#)

Guidelines from March 2016 for prescribing opioids in chronic pain cases.

[Pain Management and Opioid Management in Palliative Care](#)

A CAPC course in pain management and opioid prescribing in palliative care.

Future Research Needs

Experts in palliative care and New England CEPAC members identified the following areas as key priorities for further research in the palliative care field:

Identify the components of palliative care that lead to success, in order to support efforts to implement effective palliative care programs.

Encourage research that focuses on the impact of palliative care on families and caregivers, especially their psychosocial and economic outcomes.

Study outpatient palliative care in varied clinical settings and diverse patient populations – not just in academic medical centers.

Add to the limited but promising research base examining a potential survival benefit for patients receiving palliative care.

Allocate resources to help thought leaders track and analyze the current provision of palliative care to identify additional research needs.

Study barriers to implementing high quality palliative care.