



Advancing Palliative Care for Adults with Serious Illness: A National Review of State Palliative Care Policies and Programs

Rachel Donlon, Kitty Purington, and Natalie Williams

Executive Summary

Palliative care access remains a challenge across the country, despite its alignment with many states' goals to improve patients' health care experience and care quality, and reduce costs. Palliative care is interdisciplinary, patient-centered care for individuals with serious illness, provided in a hospital, in the community, or in the home, that can be delivered alongside curative treatment at any time following an individual's diagnosis.

States, as drivers of innovation in health policy, can influence how palliative care is perceived, accessed, and delivered. NASHP conducted a comprehensive review of how states are supporting the delivery of palliative care to adults. This report highlights major trends observed from all 50 states and Washington, DC, promising policy approaches, and key considerations for states to enhance palliative care access and quality across settings. While state engagement in palliative care varies across the country, many states have developed policies and initiatives to enhance access to and quality of palliative care services for individuals with serious illness using a variety of policy levers:

- Adopting regulations that define, standardize, and support palliative care delivery;
- Implementing palliative care reimbursement policies and quality measures within Medicaid and state employee health programs to promote high-value care;
- Incorporating palliative care into public health and public education strategies; and
- Convening stakeholders to inform policy and programmatic changes.

Introduction

An estimated 40 million adults in the United States are living with or have had a serious illness in the last three years.¹ Despite evidence that palliative care can improve patient's care experiences and reduce cost, access to quality palliative care for these individuals remains a challenge. Increasingly, states are showing interest in palliative care—a recognition of palliative care's potential to improve patient care and reduce costs as a component of patient-centered, high-value health care delivery systems.



The John A. Hartford Foundation
Dedicated to Improving the Care of Older Adults

This work is supported by a grant from The John A. Hartford Foundation, a national philanthropy based in New York City dedicated to improving the care of older adults.

Palliative care is interdisciplinary, patient-centered care for individuals with serious illness, provided in a hospital, community, or home. Palliative care can be delivered alongside curative treatment at any time following an individual's diagnosis with a serious illness.² This set of services, which can include advance care planning, counseling, and pain management, has been found to improve quality of life for individuals with serious illness by supporting autonomy, reducing symptom burden, providing support during treatment, and addressing the spiritual, emotional, and related needs that can accompany serious health conditions.³ While often used interchangeably with hospice, hospice programs serve individuals with a limited life expectancy who elect to forgo life-prolonging, curative treatments.⁴

A significant body of research supports the case for palliative care. By better managing symptoms and avoiding crises, palliative care has been shown to decrease utilization of unnecessary or unwanted services, reducing admissions, readmissions, and use of emergency department services.^{5,6} Notably, a 2016 study of Medicare Advantage enrollees found that despite added program costs, home-based palliative care generated a 4.2 to 6.6 return on investment for the payer.⁷ Another study focusing on state Medicaid enrollees diagnosed with serious illness and/or histories of hospitalizations similarly found that palliative care contributed to an average savings of almost \$7,000 per patient, compared to patients who did not receive palliative care.⁸

Factors such as inadequate workforce, stigma, and policies that limit services to those with a terminal illness deter people who could benefit from palliative care from receiving these services.⁹ A recent study found that 33 percent of hospitals with more than 50 beds did not have palliative care programs, most commonly in smaller facilities,¹⁰ and access varies across community settings.

States, as drivers of innovation in health policy, can influence how palliative care is perceived, accessed, and delivered. States across the country are advancing palliative care using a variety of policy levers:

- Adopting regulations that define, standardize, and support palliative care delivery;
- Implementing palliative care reimbursement policies and quality measures within Medicaid and state employee health programs to promote high-value care;
- Incorporating palliative care into public health and public education strategies; and
- Convening stakeholders to inform policy and programmatic changes.

NASHP conducted a comprehensive review of how states are supporting the delivery of palliative care to adults in hospital, community, and home settings. This report examines major trends observed from all 50 states and Washington, DC, highlights a variety of promising policy approaches, and offers key considerations for states to enhance palliative care access and quality across settings. The research creates a national baseline for understanding the current state policy landscape, and identifies opportunities for future state-driven policy efforts.

Research Methodology

In August and September 2018, NASHP conducted a comprehensive review of state palliative care policies and programs available to adults across hospital, community, and in-home settings. Staff reviewed publically available state regulations, legislation, model contracts, policy or program guidance documents, and other materials from all 50 states and Washington, DC. NASHP analyzed these documents to answer the following research questions:

1. Which states are supporting access to and quality of palliative care services through their roles as licensors, regulators, and payers of health care services?
2. Of states with evidence of some state-driven policies and/or programs to advance palliative care:
 - a. How do states define and regulate palliative care services/programs and/or palliative care providers?
 - b. How are state Medicaid and employee health programs promoting palliative care through coverage and reimbursement of palliative care services, quality incentives, or provider requirements?
 - c. How are state public health departments incorporating palliative care into their statewide initiatives, public awareness campaigns, or provider education efforts?
 - d. How are states engaging stakeholders to inform policy or program change?

For this scan, NASHP defined palliative care as interdisciplinary, patient- and family-centered health care that addresses the physical, mental, social, and spiritual well-being of seriously ill individuals. While often confused with hospice care, palliative care can be provided to seriously ill individuals at any disease stage and in conjunction with curative treatment. NASHP's analysis focused on state policies and programs that met this definition of palliative care and were applicable to adult populations. Pediatric-only palliative care programs were not included within the scope of this scan.

Once NASHP completed its review of publically available state regulations, legislation, model contracts, policy and program guidance documents, and other materials, NASHP contacted the following officials from all 50 states and Washington, DC to review the data for accuracy and/or provide any additional relevant information:

- Medicaid directors
- State employee health plan administrators
- Insurance commissioners
- State public health officials
- Board of medicine directors
- State health care licensing and certification directors

Key findings from this analysis are included in this issue brief and highlighted in Appendix A and B.

Findings: State Regulation of Palliative Care Services

States regulate how institutions such as hospitals, long-term care facilities, and home health agencies deliver care. State licensing and other regulations can define the types of services delivered, staff composition and training, and other core features. States also license physicians and other care providers and oversee state professional boards that determine minimum educational standards and continuing professional education requirements. Through these and other regulatory strategies, states can promote patient and provider awareness of palliative care, and encourage the delivery of high-quality services.

NASHP compiled and analyzed state statutes, licensing requirements, and other state regulations pertaining to how and whether facilities and providers are required to deliver palliative care, and if so, how these services are defined and delivered. NASHP's scan found that almost half of states have incorporated reference to palliative care into facility or provider licensing regulations or statutes. The following are some of the key findings of this analysis:

The majority of states define palliative care within their state hospice regulations. Because the majority of these definitions are embedded within hospice regulations, they describe services that may only be available to individuals with terminal illness. Three states — Colorado, Maryland, and New York — define palliative care as part of their health care facility licensing. Texas defines the service in the context of its home and community-based services regulations. Four states — Florida, Massachusetts, New York, and Tennessee — define palliative care within statutes that promote advance care planning and/or information sharing.

While the purpose of states' palliative care definitions varies, the definitions themselves share common features. Notably, definitions for palliative care in five states — California, Connecticut, Oklahoma, Rhode Island, and Texas — are nearly identical, adapted from a definition endorsed by the National Quality Forum that includes the following components:

- Ensures all care is patient- and family-centered;
- Optimizes quality of life by anticipating, preventing, and alleviating suffering;
- Serves patients' needs throughout the continuum of a person's illness;
- Addresses physical, intellectual, emotional, social, and spiritual needs; and
- Facilitates patient autonomy, access to information, and choice.¹¹

Colorado has opted for a more expansive definition of palliative care, defining the service as team-based, specialized care for people with serious illnesses, with the goal of providing relief from symptoms regardless of diagnosis. The language states that palliative care “is appropriate at any age and at any stage in a serious illness and can be provided together with curative treatment.” The state applies this definition to services delivered within hospitals and nursing facilities.¹²

Because many states define palliative care within their hospice regulations, the definitions found in several states, including Minnesota, North Carolina, North Dakota, and Virginia, reference care for patients at the end-of-life or with a terminal illness.

States promote the delivery of palliative care within hospitals, nursing homes, and long-term care facilities in various ways. Only one state, Maryland, explicitly mandates that hospitals with more than 50 beds have a palliative care program. Maryland's regulations require programs to be marketed to patients and families, meet specific staffing and training requirements, develop inter-disciplinary care plans for each patient, and complete Medical Orders for Life-Sustaining Treatment (MOLST) forms in accordance with state law.¹³ Other states have taken varying approaches:

- While providing palliative is not a requirement in Colorado, hospitals and facilities that choose to provide these services must have written policies and procedures in place to ensure that patients receive an assessment, care to manage their symptoms, advance care planning, services to address psychosocial and spiritual needs, access to family supports, and bereavement counseling.¹⁴
- Massachusetts, New York, Oregon, and Rhode Island all require hospitals, nursing homes, and long-term care facilities to provide information to patients about palliative care. Oregon, for example, requires licensed health care facilities to have procedures in place to identify patients who could benefit from palliative care, provide education to patients, and refer to available palliative care services, as needed.¹⁵
- In Florida, hospitals, nursing homes, and assisted care facilities must honor physician orders for pain medication and palliative care services.¹⁶

In addition to regulating facilities, several states require primary care providers to share palliative care information with patients. In Massachusetts, Michigan, and New York, primary care providers are required to provide information about options related to pain management and palliative care. However, in each of these states, the requirement applies to patients with terminal illness. In Florida, health care providers must share information and comply with requests for pain management or palliative care from patients.

States use continuing medical education requirements to build provider capacity in palliative care. The medical boards and/or licensing authorities in six states — California, Massachusetts, New Jersey, Oregon, Rhode Island, and Vermont — require continuing medical education (CME) in end-of-life care, palliative care and/or pain management. Vermont, under its Medical Practice Act, requires physicians to demonstrate competence in identifying and referring patients to hospice, palliative care, and pain management services by completing at least one hour of qualifying CME credits on these topics.¹⁷ In Georgia, physicians working in pain management clinics are required to demonstrate coursework in palliative care.¹⁸

Findings: State Reimbursement Strategies

Across the country, state Medicaid programs cover approximately 68.2 million people,¹⁹ including 7.4 million older adults and more than 11 million people with disabilities,²⁰ and state employee health programs (SEHP) serve over 5 million employees and their families.²¹ States have significant leverage to shape how services are delivered and accessed through their roles as purchasers for Medicaid and SEHPs.

NASHP compiled and analyzed Medicaid state plans and waivers, managed care model contracts, and other policy guidance. NASHP's scan found that while there were few examples of states that had a specific palliative care benefit in their Medicaid programs, many states did incorporate palliative care into one or more of their Medicaid policies. NASHP found limited explicit coverage of palliative care benefits within SEHPs. The following are some of the key findings of this analysis:

Eight states have specific palliative care benefits available to at least a portion of their Medicaid beneficiaries. Two states — Arizona and California — have implemented their respective palliative care benefits for a wide range of Medicaid beneficiaries. Arizona's palliative care benefit is available to the majority of its Medicaid population, including those enrolled in fee-for-service (FFS), managed care, and managed long-term services and supports (MLTSS) plans. Beneficiaries may receive palliative care services such as pain management, counseling, personal care services, and advanced care planning in conjunction with curative treatment.²² California implemented its palliative care benefit within Medi-Cal (Medicaid) managed care plans and FFS providers.²³ Washington incorporated palliative care into Apple Health — the state's managed care program — although the benefit is limited to individuals with a life-limiting illness.²⁴

Other states include palliative care benefits as part of a specialized managed care program, such as Programs of All-Inclusive Care for the Elderly (Florida and Iowa) or financial alignment demonstrations for individuals dually eligible for Medicare and Medicaid (Florida, Michigan, New York, and South Carolina). South Carolina's financial alignment demonstration, for example, includes palliative care services for enrollees that have a serious, chronic, or life-limiting illness but do not qualify for or desire to enroll in hospice.²⁵

State Medicaid programs vary in how they cover palliative care benefits. In states with a specific Medicaid palliative care benefit, the descriptions of these services, settings where they can be delivered, and patient eligibility varies. The table below summarizes the palliative care benefits across the eight states.

Table 1. Eight States' Medicaid Palliative Care Benefits

State Programs	Eligibility Criteria	Available Services	Available Delivery Settings
Arizona Managed care, managed long-term services and supports (MLTSS), and fee-for-service (FFS) ²⁶	Individual at any age who is currently or is expected to experience declining health, or is diagnosed with a chronic, complex, or terminal illness.	Suggested services: <ul style="list-style-type: none"> • Physical and/or behavioral health medical treatment • Pain and stress relief • Referrals to community resources (e.g., counseling) • Practical supports (non-billable services provided by a family member or caregiver to assist or perform functions) 	Not addressed in policy guidance
California Managed care and FFS ²⁷	Individuals of any age who meet the general eligibility criteria, in addition to having a qualifying condition (advanced cancer, congestive heart failure, chronic obstructive pulmonary disease, and liver disease).	<ul style="list-style-type: none"> • Advanced care planning • Assessment/consult • Care planning • Pain management • Mental health services • Care coordination 	Inpatient, outpatient, and community settings
Florida Program of All-Inclusive Care for the Elderly (PACE) ²⁸	Not addressed in program manual		
Iowa PACE ²⁹	Not addressed in program manual		
Michigan Financial Alignment Demonstration ³⁰	Not addressed in model contract		
New York Financial Alignment Demonstration ³¹	Not addressed in model contract	<ul style="list-style-type: none"> • Family palliative care education • Pain and symptom management • Bereavement services • Massage therapy • Expressive therapies 	Not addressed in model contract
South Carolina Financial Alignment Demonstration ³²	Individual with serious, chronic, or life-limiting illness and having a history of hospitalizations, a history of acute care utilization for pain and/or symptom management, or based on the referral of a provider.	Focus on pain management and comfort care	Not addressed in model contract
Washington Managed care ³³	Life-limiting condition	Skilled care services and care coordination	Services can be provided in hospitals, clinics, the home, hospice care centers

Medicaid programs may use existing billing codes to reimburse for palliative care services. California uses existing codes in its physician fee schedule to allow providers to bill for services under its palliative care benefit, avoiding the need to amend its state plan or apply for a waiver.³⁴ California Medicaid issued guidance to providers, which mapped the palliative care services to existing billing codes. For example, California providers can use the community-based interdisciplinary care team consult Current Procedural Terminology (CPT) code series (99341-99350) to bill for palliative care services, including care coordination, care plan development, patient assessment, and provider-to-provider consultations.³⁵

NASHP reviewed CPT and Healthcare Common Procedure Coding System (HCPCS) codes that California and other states use to pay for individual palliative care services in inpatient, outpatient, or community settings. Some codes are associated with specific services (e.g., advanced care planning), while others (e.g., interdisciplinary team consultation) are more general and may be used in a variety of clinical situations. NASHP's findings below highlight how state Medicaid agencies reimburse for these codes, but it is difficult to draw further conclusions about how or whether these state Medicaid programs specifically support palliative care.

The most commonly reimbursed billing code is home or community-based interdisciplinary care team consultations (CPT code series 99341-99350). Forty-two states reimburse for one or more codes in this series. Reimbursement for other related billing codes is more variable:

- Nineteen states reimburse for interdisciplinary care team consultations in inpatient or outpatient settings (CPT 99366 and/or 99368);
- Seventeen states reimburse for advanced care planning (CPT 99497 and/or 99498);
- Fourteen states reimburse for respite care services (HCPCS T1005);
- Six states reimburse for in-home individual, family, marriage counseling (CPT 99510); and
- Five states reimburse for end-of-life counseling (HCPCS S0257).

Five states include palliative care-related metrics or quality improvement requirements in their Medicaid programs. Colorado, Illinois, New York, and Rhode Island include at least one palliative care-related quality metric in their financial alignment demonstration or MLTSS contracts. These metrics are often linked to financial incentives for managed care plans. The most common metric is the Healthcare Effectiveness Data and Information Set (HEDIS) Care for Older Adults,³⁶ which measures the percentage of beneficiaries 66 years and older who have the following four services in one measurement year:

- Advanced care planning;
- Medication review;
- Functional status assessment; and
- Pain screening.

Two states — New York and Texas — incorporate palliative care into the quality improvement strategies included in their Delivery System Reform Incentive Payment (DSRIP) programs. Table 2 highlights each state's palliative care quality improvement strategy and associated metrics.

Table 2. Medicaid Quality Improvement Strategies in Texas and New York's Delivery System Reform Incentive Payment (DSRIP) Programs

State	Description	Quality Metrics
New York ³⁷	New York's DSRIP waiver established Performing Provider Systems (PPS). These networks must include a minimum of five transformation projects, with at least two focusing on clinical improvement. Palliative care is one of eight clinical improvement project options. There are five associated metrics related to integrating palliative care into the broader health care continuum.	DSRIP palliative care metrics: percentage of patients indicating need who were offered or provided: <ul style="list-style-type: none"> • An intervention for pain symptoms experienced during the past week • An intervention for physical symptoms (other than pain) experienced during the past week • An intervention for not feeling at peace during the past week • Intervention for depressive feelings experienced during the past week • An intervention when there was no advance directive in place
Texas ³⁸	Palliative care is one of several health system transformation projects that regional health care partnerships — regional groups of providers and a public hospital — are responsible for under Texas' DSRIP waiver. Each project has a quality improvement component. Additionally, Texas DSRIP providers can elect to report on a series of palliative care metrics, where they can earn incentives by reporting on quality metrics and demonstrating improvement.	DSRIP palliative care metrics: <ul style="list-style-type: none"> • Pain assessment • Documentation of treatment preferences • Documentation of discussion on spiritual/religious concerns • Bowel regimen for patients treated with an opioid • Dyspnea screening • Dyspnea treatment • Hospice admissions of less than three days • Patients who died from cancer not admitted to hospice

Other state Medicaid activity indicates the range of potential policy levers available to improve access to and quality of palliative care. Medicaid managed care plan or provider requirements related to palliative care were limited at the time of the scan, but wide ranging:

- **Managed care provider networks:** Two states — Arizona and California — require managed care plans to contract with networks of qualified providers for advanced care planning and palliative care, respectively.
- **Provider training:** While not a requirement, California recommends its managed care plans contract with Medicaid providers who have received palliative care training. Medicaid is utilizing a combination of state and federal administrative matching funds to contract with [California State University's Institute for Palliative Care](#) to offer palliative training to Medicaid providers and practice staff. The state reports it is now focusing on increasing primary care providers' participation in these trainings.³⁹
- **Opportunities in MLTSS contracting:** Arizona MLTSS plans and their care managers must educate beneficiaries on end of life care and advanced care planning, and assist beneficiaries in accessing those services as appropriate.⁴⁰ Florida MLTSS plans must implement disease management programs specific to end-of-life care.⁴¹

Few state employee health programs offer a specific palliative care benefit. Seven states (Illinois, Minnesota, North Dakota, South Carolina, Utah, Virginia, and West Virginia) report their SEHP plans offer a palliative care benefit to members. For example, the Minnesota State Employee Group Insurance Program defines available

palliative care services and associated cost sharing with its members. Plans offer palliative care services, such as advance care planning, accompaniment to office visits, pediatric and adolescent anticipatory grief support counseling, home health aide and respite care services, and bereavement supports, when ordered in writing by a physician and included in the written home care plan. Palliative care services are available to most members at no cost, but palliative care is subject to the deductible for members enrolled in the program's high-deductible plan.⁴²

Findings: Advancing Public Awareness and Stakeholder Engagement

States can foster public awareness and acceptance of palliative care, build consumer and provider buy-in, and support activities that build service capacity. This work may be shared across various agencies or sectors of state government. For this review, NASHP compiled and analyzed public health agency rules and regulations, state palliative care task force legislation, and other materials pertaining to palliative care.

NASHP's analysis found that state public health agencies are often the lead agency promoting awareness of palliative care, and that model legislation has been an effective policy tool for a number of states to adopt palliative care policies. The following are some of the key findings of this analysis:

Recent legislation related to public awareness and stakeholder engagement builds on common themes and resources. Twenty-seven states have a palliative care council or taskforce, ten of which require one or more state officials to serve as members. In many states, the authorizing legislation features common themes, suggesting states may have adapted the [American Cancer Society's \(ACS\) Cancer Action Network](#) model legislation as the basis for their work. The responsibilities of these councils and taskforces vary across states, they:

- Commonly serve a consultative role;
- Report to the governor, legislature, or state public health agency on the status of palliative care in the state; and
- Develop recommendations to promote palliative care.

Similarly, 15 states have legislation requiring public health agencies to develop and disseminate resources about palliative care, many of which have very similar requirements and build on the American Cancer Society materials. Public health agencies in these states are typically required to disseminate information about palliative care to the public, patients living with serious illnesses and their families, and/or providers. Their content often includes information detailing how to access palliative care services, links to providers and programs, and continuing education opportunities for providers.

Vermont and Wisconsin take alternative approaches to fostering public awareness. Vermont's Patient's Bill of Rights for Palliative Care and Pain Management requires that patients with serious illnesses be made aware of palliative care in order to make informed decisions about their treatment.⁴³ In Wisconsin, the state's Department of Health Services' Division of Public Health contracts with Aging and Disability Resource Centers in the state to educate older adults and individuals with developmental or intellectual disabilities about palliative and hospice care.⁴⁴

Thirty-nine states include palliative care in their cancer control plans. State public health agencies, often in conjunction with community-based coalitions, develop five-year cancer control plans as part of the Centers for Disease Control and Prevention's [National Comprehensive Cancer Control Program](#). Palliative care is a common feature in these plans. States typically include objectives to increase public awareness about palliative care and/or increase access to palliative care services. For example:

- Georgia's current Cancer Control Plan seeks to increase the percentage of cancer patients who receive palliative care. The plan identifies strategies to achieve this goal, such as developing a palliative care provider network

- and increasing the number of cancer centers in the state with a palliative care program.⁴⁵
- Massachusetts' Cancer Control Plan focuses on increasing access to palliative care services by expanding clinician capacity to provide palliative care, particularly for rural and/or underserved populations, and increasing public awareness about what palliative care is and how it can be accessed.⁴⁶

Key Considerations

NASHP's research reveals a great deal of state activity to support palliative care across a number of policy domains. Moreover, state policymaker review of and engagement in this research indicates a high level of interest, and in many instances, strong commitment on the part of state policy leaders to expand access to high-quality palliative care. However, this research also indicates that state engagement in palliative care varies greatly and that many states have not begun to use state policies to shape or strengthen this area of health care. As a result, many opportunities remain for states to enhance access to and quality of palliative care services for individuals with serious illness. The following section highlights emerging promising practices, as well as policy areas that may hold promise for future state activity, in the areas of access, reimbursement, and quality.

Improve Access to Palliative Care

States can take a multi-faceted approach to improving access to palliative care, such as targeting education to families and patients who could benefit from these services, increasing the availability of trained professionals who can deliver quality care, and engaging other policy sectors, such as state insurance regulators and public health officials. Key opportunities for states include:

- *Requiring education, outreach, and referral in inpatient and long-term care settings:* NASHP's research indicates that building palliative care requirements into hospital and/or long-term care facility licensing may be an underutilized policy lever. Individuals with serious illness often require inpatient and/or nursing home level care, and may use other long-term services and supports, such in-home nursing care. Current state activity offers examples of state policy strategies, such as requiring that hospitals have palliative care programs that meet certain standards (Maryland) and strategies that ensure patients and families understand the benefits of palliative care and how they can access it (New York and Massachusetts). States can also revisit regulatory or statutory definitions that limit palliative care service to those with a terminal condition, and consider using language that promotes access to palliative care at any stage of illness and differentiates palliative care from hospice.
- *Building workforce capacity:* Provider discomfort or lack of knowledge can be a significant barrier to palliative care access. States can collaborate with professional associations and other stakeholders to identify effective strategies to promote professional capacity. As NASHP's findings indicate, requiring a certain number of CME credits be dedicated to palliative care is one strategy, offering free or subsidized training is another. Engaging physician champions on state taskforces or councils is another opportunity for states to raise awareness among providers.
- *Insurance regulation:* States can use their capacity as health insurance regulators to advance palliative care. For example, within its statute governing disability insurance plans, Washington State requires disability plans to offer optional coverage of palliative care services without the need for beneficiaries to demonstrate that they are homebound.
- *Engaging public health:* State public health agencies can facilitate access by heightening awareness of palliative on state websites and at local public health offices, developing referral resources for patients and families, and developing and disseminating educational materials, and, potentially, delivering these services directly. [Massachusetts](#) and [Vermont](#) public health agencies house pediatric palliative care programs that may serve as models for adult palliative care programs.
- *"Carving out" palliative care from opioid prescribing rules:* In an effort to curb the rising rates of opioid addiction, many states are enacting new prescribing regulations that limit access to opioids. To ensure these limitations do not impede access to palliative care services, states such as [Vermont](#) and [Indiana](#) provide an exception for palliative care patients within their states' opioid prescribing rules.

Strengthen the Role of Medicaid Reimbursement

Care for individuals with serious illness is a major cost driver for state Medicaid programs. State health reform efforts increasingly focus on providing comprehensive and well-coordinated care to these high-need populations as a way to improve quality of care and drive down costs. Palliative care can align with this work, as a strategy that has been shown to improve care while reducing costs for individuals with serious illness. However, few states are fully utilizing Medicaid policies to support palliative care. Key opportunities for states include:

- *Developing a clear payment mechanism:* As discussed in the scan findings, states may implement a distinct Medicaid palliative care benefit, as modeled by Arizona and California. This strategy can help raise awareness of the service, enable states to shape and track how the service is delivered, and may allow for analysis of its effectiveness over time. Other states may want to support palliative care through existing billing codes without creating a distinct benefit or adding services to the state Medicaid plan. States using existing billing codes may want to develop guidance for providers on how to use these codes, to better track uptake of these services, and to support best clinical practices.
- *Building palliative care into existing Medicaid programs that support people with serious illness:* States already have programs within Medicaid that provide comprehensive services to populations with serious illness, such as home- and community-based services (HCBS) waivers and state plan options, MLTSS, health homes, Dual Eligible Special Needs Plans, and PACE. Palliative care aligns well with the goals of these initiatives and states may be able to take advantage of the more flexible Medicaid reimbursement strategies found in these models (e.g., per member per month or enhanced primary care payments) to support the delivery of comprehensive, team-based palliative care.

Ensure Quality and Oversight

Quality improvement and program oversight are important features of any state insurance program, and states can use these tools to improve the quality of palliative care services. States may want to take advantage of existing national palliative care quality resources as a starting point. The [National Quality Forum](#), the Center to Advance Palliative Care's [Serious Illness Framework](#), and the [Convening on Quality Measures for Serious Illness Care](#) have developed robust resources that can help states define evidence-based standards of care and quality metrics. Key opportunities for states include:

- *Implementing practice standards.* States can incorporate palliative care standards into hospital, nursing facility, and other long-term care regulations. Maryland and Colorado, for example, have developed specific standards describing how hospitals and other facilities must deliver palliative care.
- *Incorporating quality measurement and reporting requirements:* States can monitor access to and quality of palliative care by requiring providers, accountable care organizations, and/or managed care plans to report on related metrics, or include palliative care in performance improvement projects. NASHP's scan found relatively few states using these types of strategies. Given the growth of state value-based payment approaches, this may be an area of opportunity. States may want to start by tracking process metrics that are mapped to specific palliative care services. [New York](#) and [Texas](#) DSRIP programs offer examples of this approach.

Conclusion

Palliative care can improve patients' experience, while also reducing health care costs. As regulators, purchasers, and conveners, state policymakers are uniquely positioned to improve access to and quality of palliative care services provided to individuals with serious illness. As this baseline research indicates, interest in palliative care at the state policy level is emerging and likely to grow as state policymakers continue to shape and invest in delivery systems that provide high-value care to complex and aging populations. At least half of all states have one or more policies or programs in place to advance palliative care, laying the foundation for future innovation. Strategies and approaches from leading states help point toward the next steps in this work. NASHP will work with state policymakers to identify areas that are ripe for state action to expand access, improve quality, and elevate public awareness of the value of palliative care.

Appendix

[Appendix A: Scan of State Regulations for Adult Palliative Care Activity](#)

[Appendix B: Scan of State Medicaid Programs for Adult Palliative Care Activity](#)

Endnotes

1. Eric Schneider, et. al., *Health Care in America: The Experience of People with Serious Illness* (New York, NY: The Commonwealth Fund, October 2018). <http://features.commonwealthfund.org/health-care-in-america>.
2. "About Palliative Care," Center to Advance Palliative Care, accessed November 26, 2018. <https://www.capc.org/about/palliative-care/>.
3. Melliar P. Davis, et al., "A review of the trials which examine early integration of outpatient and home palliative care for patients with serious illnesses," *Annals of Palliative Medicine* 4, no. 3 (July 2015).
4. Centers for Medicare and Medicaid Services, "Palliative Care vs. Hospice Care: Similar But Different," accessed December 5, 2018. [https://www.cms.gov/Medicare-Medicaid-Coordination/Fraud-Prevention/Medicaid-Integrity-Education/Downloads/infograph-PalliativeCare-\[June-2015\].pdf](https://www.cms.gov/Medicare-Medicaid-Coordination/Fraud-Prevention/Medicaid-Integrity-Education/Downloads/infograph-PalliativeCare-[June-2015].pdf).
5. Samantha Smith, et al., "Evidence on the cost and cost-effectiveness of palliative care: A literature review," *Palliative Medicine* 28, no. 2 (July 2013): 130-150.
6. Barbara Gomes, et al., "Effectiveness and cost-effectiveness of home palliative care services for adults with advanced illness and their caregivers," *Cochrane Database of Systematic Reviews*, no. 6 (June 2013).
7. J. Brian Cassel, et al., "Effect of a Home-Based Palliative Care Program on Healthcare Use and Costs," *Journal of the American Geriatrics Society* 64, no. 11 (Nov. 2016): 2288-2295.
8. R. Sean Morrison, et al., "Palliative Care Consultation Teams Cut Hospital Costs For Medicaid Beneficiaries," *Health Affairs* 30, no. 3 (Mar. 2011).
9. Michael Ollove, "Why Some Patients Aren't Getting Palliative Care," *The Pew Charitable Trusts*, July 10, 2017. <https://www.pewtrusts.org/en/research-and-analysis/blogs/stateline/2017/07/10/why-some-patients-arent-getting-palliative-care>.
10. Tamara Dumanovsky, et al., "The Growth of Palliative Care in U.S. Hospitals: A Status Report," *Journal of Palliative Medicine* 19, no. 1 (Jan. 2016): 8-15.
11. National Quality Forum, *Palliative and End-of-Life Care Off-Cycle Measure Review 2017* (Washington, DC: National Quality Forum, September 2017). https://www.qualityforum.org/Publications/2017/09/Palliative_and_End-of-Life_Care_Off-Cycle_Measure_Review_2017.aspx
12. 6 Colorado Code of Regulations 1011-1 Chap 02. <https://www.sos.state.co.us/CCR/GenerateRulePdf.do?ruleVersionId=5623&fileName=6%20CCR%201011-1%20Chap%2002>.
13. Maryland Code 10.07.01.01. https://health.maryland.gov/ohcq/Documents/Palliative%20Care_10.07.01.31_5_18_2016.pdf
14. 6 Colorado Code of Regulations 1011-1 Chap 02. <https://www.sos.state.co.us/CCR/GenerateRulePdf.do?ruleVersionId=5623&fileName=6%20CCR%201011-1%20Chap%2002>.
15. 2017 ORS 413.273. <https://www.oregonlaws.org/ors/413.273>.
16. Florida Statutes Title XLIV Chapter 765.1103. http://www.leg.state.fl.us/STATUTES/index.cfm?App_mode=Display_Statute&URL=0700-0799/0765/0765.html
17. Vermont Department of Health Board of Medical Practice, "Rule of the Board of Medical Practice," effective October 15, 2017. http://www.healthvermont.gov/sites/default/files/documents/pdf/BMP_Board%20Rules%20Effective%202017.pdf.
18. "Chapter 360-8 Pain Management Clinics," Rules of the Georgia Composite Medical Board. <http://rules.sos.state.ga.us/gac/360-8?urlRedirected=yes&data=admin&lookingfor=360-8>.
19. "November 2017 Medicaid and CHIP Enrollment Data Highlights," Centers for Medicare & Medicaid Services, accessed February 27, 2018. <https://www.medicaid.gov/medicaid/program-information/medicaid-and-chip-enrollment-data/report-highlights/index.html>.
20. "Medicaid Enrollees by Enrollment Group," The Henry J. Kaiser Family Foundation, accessed November 8, 2017. <https://www.kff.org/medicaid/state-indicator/distribution-of-medicaid-enrollees-by-enrollment-group/?dataView=0¤tTimeframe=0&selectedDistributions=aged&sortModel=%7B%22collid%22:%22Lcation%22,%22sort%22:%22asc%22%7D>
21. "State Employee Health Benefits, Insurance, and Costs," National Conference of State Legislatures, accessed November 26, 2018. <http://www.ncsl.org/research/health/state-employee-health-benefits-ncsl.aspx>.
22. Arizona Health Care Cost Containment System, *AHCCCS Medical Policy Manual 310-HH-End of Life Care and Advanced Care Planning*, 2017. <https://www.azahcccs.gov/shared/Downloads/AMPMApproved/300/310-HH.pdf>.
23. California Department of Health Care Services, "All Plan Letter 17-015," October 19, 2017. <https://www.dhcs.ca.gov/formsandpubs/Documents/MMCDAPsandPolicyLetters/APL2017/APL17-015.pdf>; and "New Policy Guidance for Palliative Care," California Department of Health Care Services, accessed November 26, 2018. http://files.medi-cal.ca.gov/pubdoco/newsroom/newsroom_26508.asp.
24. Washington State Health Care Authority, Washington Apple Health – Fully Integrated Managed Care Contract, effective July 1, 2018. https://www.hca.wa.gov/assets/billers-and-providers/ipbh_fullyintegratedcare_medicaid.pdf.
25. Contract Between United States Department of Health and Human Services Centers for Medicare & Medicaid Services in Partnership with the State of South Carolina Department of Health and Human Services and the Coordinated and Integrated Care Organization, effective November 2017. <https://www.cms.gov/Medicare-Medicaid-Coordination/Medicare-and-Medicaid-Coordination/Medicare-Medicaid-Coordination-Office/FinancialAlignmentInitiative/Downloads/SCContract11012017.pdf>.
26. Arizona Health Care Cost Containment System, *AHCCCS Medical Policy Manual 310-HH-End of Life Care and Advanced Care Planning*, 2017. <https://www.azahcccs.gov/shared/Downloads/AMPMApproved/300/310-HH.pdf>.
27. "Palliative Care and SB 1004," California Department of Health Care Services, accessed November 26, 2018. <https://www.dhcs.ca.gov/provgovpart/Pages/Palliative-Care-and-SB-1004.aspx>.
28. "Program of All-Inclusive Care for the Elderly (PACE)," Florida Department of Elder Affairs, accessed November 26, 2018. <http://elderaffairs.state.fl.us/does/pace.php>.
29. Iowa Department of Human Services, PACE Program of All-Inclusive Care for the Elderly, revised 2018, <https://dhs.iowa.gov/sites/default/files/Comm316.pdf>.
30. Contract Between United States Department of Health and Human Services Centers for Medicare and Medicaid Services in Partnership with the State of Michigan, effective January 1, 2018. <https://www.cms.gov/Medicare-Medicaid-Coordination/Medicare-and-Medicaid-Coordination/Medicare-Medicaid->

- [Coordination-Office/FinancialAlignmentInitiative/Downloads/MIContract01012018.pdf](#)
31. Contract Between United States Department of Health and Human Services Centers for Medicare & Medicaid Services in Partnership with the State of New York Department of Health, issued July 3, 2014. <https://www.cms.gov/Medicare-Medicaid-Coordination/Medicare-and-Medicaid-Coordination/Medicare-Medicaid-Coordination-Office/FinancialAlignmentInitiative/Downloads/NewYorkContract.pdf>.
 32. Contract Between United States Department of Health and Human Services Centers for Medicare & Medicaid Services in Partnership with the State of South Carolina Department of Health and Human Services and the Coordinated and Integrated Care Organization, effective November 1, 2017. <https://www.cms.gov/Medicare-Medicaid-Coordination/Medicare-and-Medicaid-Coordination/Medicare-Medicaid-Coordination-Office/FinancialAlignmentInitiative/Downloads/SCContract11012017.pdf>.
 33. Washington State Health Care Authority, Washington Apple Health – Fully Integrated Managed Care Contract, effective July 1, 2018. https://www.hca.wa.gov/assets/billers-and-providers/ipbh_fullyintegratedcare_medicaid.pdf.
 34. Personal communication with Rene Mollow, California Department of Health Care Services, August 16, 2018.
 35. “New Policy Guidance for Palliative Care,” California Department of Health Care Services, accessed November 26, 2018. http://files.medi-cal.ca.gov/pubsdoco/newsroom/newsroom_26508.asp.
 36. “Care for Older Adults (COA),” National Committee for Quality Assurance, accessed November 26, 2018. <https://www.ncqa.org/hedis/measures/care-for-older-adults/>.
 37. Centers for Medicare & Medicaid Services, technical correction letter, New York Medicaid Redesign Team Section 1115 Waiver Number 11-W-00114/2, Jan. 19, 2017. <https://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Waivers/1115/downloads/ny/ny-medicaid-rdsgn-team-ca.pdf>.
 38. Centers for Medicare & Medicaid Services, approval letter, Texas Healthcare Transformation and Quality Improvement Program Number 11-W-00278/6, Aug. 24, 2017. <https://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Waivers/1115/downloads/tx/Healthcare-Transformation-and-Quality-Improvement-Program/tx-healthcare-transformation-stcs-082417.pdf>.
 39. “Palliative Care and SB 1004,” California Department of Health Care Services, accessed November 26, 2018. <https://www.dhcs.ca.gov/provgovpart/Pages/Palliative-Care-and-SB-1004.aspx>.
 40. Arizona Health Care Cost Containment System, Managed Long Term Care Contract Amendment, effective January 1, 2018. https://www.azahcccs.gov/Resources/Downloads/ContractAmendments/ALTCS/ALTCS2017/ALTCS_EPD_Contract_Amendment_Number2_YH18-0001.pdf.
 41. Florida Agency for Health Care Administration, Long-Term Care (LTC) Managed Care Program, effective February 1, 2018. [http://ahca.myflorida.com/medicaid/statewide_mc/pdf/Contracts/2018-02-01/EXHIBIT_II-B_Long_term_Care_\(LTC\)_Managed_Care_Program_Feb_1_2018.pdf](http://ahca.myflorida.com/medicaid/statewide_mc/pdf/Contracts/2018-02-01/EXHIBIT_II-B_Long_term_Care_(LTC)_Managed_Care_Program_Feb_1_2018.pdf).
 42. Minnesota Management and Budget State Employee Group Insurance Program, Summary of Benefits 2018-2019, effective January 1, 2018. https://mn.gov/mmb-stat/documents/segip/medical/SoB_current_AHP.pdf; and personal communication with Galen Benschhoff, Assistant Director, State Employee Group Insurance Program, October 18, 2018.
 43. 18 V.S.A. § 1871. <https://legislature.vermont.gov/statutes/section/18/042A/01871>.
 44. Wisconsin Department of Health Services Division of Public Health, Aging and Disability Resource Center Grant Agreement, January 1, 2018–December 31, 2018. <https://www.dhs.wisconsin.gov/adrc/pros/2018scopeofservicesfinal.pdf>.
 45. Georgia Cancer Control Consortium, Georgia Cancer Plan 2014-2019 (Atlanta, GA: Georgia Department of Health, 2014). ftp://ftp.cdc.gov/pub/Publications/Cancer/ccc/georgia_ccc_plan.pdf.
 46. The Massachusetts Comprehensive Cancer Prevention and Control Network, Massachusetts Statewide 2017-2021 Cancer Plan (Boston, MA: Massachusetts Department of Public Health, 2017). ftp://ftp.cdc.gov/pub/Publications/Cancer/ccc/massachusetts_ccc_plan-508.pdf.

Acknowledgements:

The National Academy for State Health Policy (NASHP) wishes to thank the members of the State Leadership Council on Palliative Care, as well as the state officials who reviewed its 50-state scan of palliative care activity, for their contributions. The authors also wish to thank Trish Riley and Lyndsay Sanborn for their input and support. Finally, the authors would like to thank Amy Berman, Scott Bane, and Rani Snyder of The John A. Hartford Foundation for their input on and generous support of this work. This state scan was supported through a grant with The John A. Hartford Foundation.

About the National Academy for State Health Policy:

The National Academy for State Health Policy (NASHP) is an independent academy of state health policymakers working together to identify emerging issues, develop policy solutions, and improve state health policy and practice. As a non-profit, nonpartisan organization dedicated to helping states achieve excellence in health policy and practice, NASHP provides a forum on critical health issues across branches and agencies of state government. NASHP resources are available at: www.nashp.org.