



# Palliative Care: A Primer for State Policymakers

Lyndsay Sanborn and Kitty Purington

## Introduction

Five percent of Medicaid beneficiaries account for more than 50 percent of the program's expenditures.<sup>1</sup> State policymakers are paying increased attention to better managing the health care needs of these individuals, many of whom have complex and serious illness, some of whom are near the end of life. When providing quality care to patients with complex needs, curative treatment is often not enough: palliative care – addressing the physical, emotional, and spiritual needs of individuals with serious illness – can offer additional tools to states seeking to promote high-value care for populations with complex needs.

Palliative care is patient-centered care for individuals with serious illness that focuses on providing relief from the symptoms and stressors of disease.<sup>2</sup> Unlike hospice, which is often limited to those at the very end of life, palliative care can be delivered alongside curative treatment at any stage of a serious illness. Adding palliative care to a treatment regimen has been shown to improve health outcomes and quality of life, while lowering costs for high-need, high-cost populations.<sup>3</sup> One study of Medicaid enrollees diagnosed with serious illness and/or a history of hospitalization found that palliative care contributed to an average savings of almost \$7,000 per person when compared to patients who did not receive palliative care.<sup>4</sup>

While substantial evidence indicates that palliative care improves patient experience and lowers cost by reducing avoidable utilization, access to and utilization of palliative care is lagging across the country. Reports estimate that fewer than 5 percent of patients who could benefit from palliative care receive it.<sup>5</sup> Lack of workforce capacity, stigma, and policies that prevent timely access to palliative care can contribute to limited utilization of these services.



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



*Monkey Business Images/Shutterstock*

### State Policy Levers to Improve Palliative Care

- Develop standards and definitions within state licensing and regulation;
- Measure and track the quality of palliative care;
- Articulate payment and policies within Medicaid;
- Build workforce capacity; and
- Educate patients, providers, and the public.

If states employ a range of policy strategies, they can play an important role in improving access to palliative care and the quality of services delivered. This brief provides resources for state policymakers interested in expanding palliative care, including:

- An outline of field-tested definitions and resources;
- Identification of key policy considerations; and
- Opportunities available to states to support their palliative care policies and programs.

“Serious illness is any condition that carries a high risk of mortality, negatively impacts quality of life and daily function, and/or is burdensome in symptoms, treatments, or caregiver stress.”

Kelley, Amy. (2014). *Defining "Serious Illness"*. *Journal of palliative medicine*. 17. 10.1089/jpm.2014.0164.

## Overview of Palliative Care

Palliative care addresses the “physical, functional, psychological, practical, and spiritual consequences of a serious illness.”<sup>6</sup> It is a team-based, interdisciplinary approach that includes services, such as advance care planning, pain management, counseling, care coordination, and addressing the needs of the family. Importantly, palliative care can be delivered alongside curative treatment and does not require an individual to forgo other interventions.<sup>7</sup>

Palliative care can be delivered by health care professionals with varying levels of expertise.<sup>8</sup> The National Academy of Medicine defines palliative care as either primary or specialty care: *primary palliative care* (or non-specialty palliative care) is provided by health care professionals who may not have specialty training or hold a certification in palliative health care. Internists, primary care physicians, nurse practitioners, and oncologists, for instance, may assess and manage symptoms, and provide information, referral, and support to patients with serious illness and their families. *Specialty palliative care* providers are trained in complex care and disease management, which includes the treatment of persistent and progressive symptoms, worsening of anxiety and depression in those with serious illness, end-of-life counseling, and documenting patient’s goals and desires surrounding the type of care they wish to receive during their illness and death.<sup>9</sup> Specialty palliative care is delivered by clinicians with advanced training and/or certification, often in conjunction with a multidisciplinary team that can include a nurse, social worker, physician, a chaplain, and other supports.

Palliative care can be delivered across a wide range of settings. Hospitals have been at the forefront of palliative care delivery: hospital certification was established by The Joint Commission in 2011, and as of 2016, 75 percent of hospitals with more than 50 beds provided access to a palliative care team.<sup>10</sup> While there has been a steady increase in the availability of hospital palliative care programs, this increase in capacity varies across regions and states, with fewer programs in rural, southern states and smaller hospitals.<sup>11</sup> Research shows that public and private insurance payment for palliative care in hospital settings varies as well, and may not cover all aspects of care.<sup>12</sup>

Increasingly, palliative care is being delivered in community settings, such as outpatient practices and clinics, homes, and residential care facilities.<sup>13</sup> The Joint Commission began certifying community palliative programs offered by home health and hospice programs in 2016.<sup>14</sup> Clinical Practice Guidelines for Quality Palliative Care, developed by the National Consensus Project, can also provide guidance on palliative care delivery in community settings.<sup>15</sup> Similar to palliative care within hospital settings, payment for palliative care services delivered outside of the hospital or hospice setting varies widely, depending on payer and other factors.<sup>16</sup>

# Key Considerations for State Policymakers

As explored in the National Academy for State Health Policy (NASHP) report, [\*Advancing Palliative Care for Adults with Serious Illness: A National Review of State Palliative Care Policies and Programs\*](#), states have a number of policy levers they can use to improve access to and quality of palliative care. Outlined below are some of the key considerations that state health policymakers may want to explore when crafting and implementing policies that support palliative care.

**Review how palliative care is defined by state policies and programs.** The National Quality Forum identified five structural elements of high-value palliative care models. These models:

- Target services to the highest risk group;
- Include an interdisciplinary team of providers and social supports;
- Provide 24/7 access to clinical care;
- Integrate medical and social supports; and
- Provide services alongside and independent from curative care.

NASHP identified that approximately 50 percent of states define palliative care in some way, and/or incorporate standards for palliative care in regulation.<sup>18</sup> That said, how and where palliative care is defined matters – most states define palliative care within the context of hospice licensure or regulation, limiting the applicability of definitions or standards to services provided to those with a terminal illness. States can consider tying definitions and standards to a wider range of facilities and providers positioned to deliver this level of care. **Colorado** broadly defines palliative care within its health care facility licensing regulations to include team-based, specialized care for people with serious illness, with the goal of providing relief from symptoms regardless of diagnosis. The definition applies to services delivered within hospitals and nursing facilities.<sup>19</sup> **Maryland** defines palliative care in its hospital regulations and provides standards for palliative care service delivery that include staffing, education, and plan of care requirements.<sup>20</sup>

**Measure the quality of palliative care services.** The National Quality Forum's (NQF) portfolio for Palliative and End-of-Life Care includes measures that address the physical and social aspects of care, including pain management, dyspnea, and the spiritual, psychological, cultural, and legal aspects of care.<sup>21</sup> Five states, **Colorado, Illinois, New York, Rhode Island** and **Texas**, include palliative care-related quality metrics in their financial alignment demonstrations or Medicaid managed care long-term services and supports contracts. **Texas'** Delivery System Reform Incentive Payment (DSRIP) program has several health care transformation projects that include palliative care quality improvement. Texas DSRIP providers can elect to report on eight palliative care metrics to earn incentives.<sup>22</sup>

**Identify populations that can benefit most from palliative care services.** For specialty palliative care services, state Medicaid programs can identify populations that may benefit most from these services to help increase access and target scarce resources. States can identify priority populations based on factors such as functionality, diagnosis, or level of acuity. **California's** Medicaid program, Medi-Cal, designed its palliative care benefit to address the needs of individuals with congestive heart failure, chronic obstructive pulmonary disease, advanced cancer, and liver disease. Use of claims and clinical data can assist states in identifying patients who could benefit most from palliative care services. States can also consider bolstering access to palliative care in settings that serve complex patients, such as post-acute rehabilitation and skilled nursing facilities.

**Leverage continuing medical education requirements to build workforce capacity and increase access.** Access to palliative care can be limited due to a lack of trained providers, especially in rural or smaller hospitals.<sup>23</sup> States are increasingly including palliative care as a continuing medical education (CME) requirement, building capacity to manage lower-acuity patients in primary care or non-specialist practices. **Rhode Island** physicians are required to

complete a minimum of four hours of CME every two years on priority topics identified by the Rhode Island Department of Health, which has included end-of-life and palliative care.<sup>24</sup> Under its Medical Practice Act, **Vermont** requires physicians to have at least one qualifying hour of CME credits demonstrating competence in identifying and referring patients to hospice, palliative care, and pain management services in each renewal period.<sup>25</sup>

**Articulate policies and payment to support palliative care.** State Medicaid programs can pay for certain palliative care services using existing Current Procedural Terminology (CPT) or Healthcare Common Procedure Coding System (HCPCS) codes. However, states note that without using modifiers, existing CPT codes may not provide sufficient data to track utilization or evaluate the quality of services delivered. Moreover, states find that simply making the codes available does not necessarily improve access or uptake of the service.<sup>26</sup> Additional outreach and education to providers may be helpful. **California** developed a palliative care policy that outlined eligibility and available services within the state's managed care contracts. For fee-for-service (FFS) additional guidance included a description of how services mapped to specific billing codes within the state's existing fee schedule.<sup>27</sup>

**Consider incorporating palliative care into public health and public education strategies.** Stigma surrounding serious illness and end of life can limit public awareness about the benefits of palliative care and inhibit use of services. States can invest in public education efforts to address these barriers. In **Wisconsin**, the Division of Public Health works with the state's Aging and Disability Resource Centers to educate older adults and individuals with developmental or intellectual disabilities about palliative care and hospice.<sup>28</sup>

## Looking Forward: State Palliative Care Policy Opportunities

NASHP research into state palliative care policies found that most states are just beginning to explore how palliative care can support existing health reform efforts. Certain state health policies and programs may be of particular interest as states explore the value of these services:

- **Home and Community-Based Services (HCBS) benefits:** State Medicaid HCBS waivers are designed to support individuals with complex needs to live in the community and avoid more costly institutional levels of care. Both primary and specialty palliative care services align well with their emphasis on person-centered planning required by recent changes to HCBS regulations.
- **Medicaid managed care contracts for complex populations:** States are increasingly contracting with managed care organizations to oversee Medicaid long-term services and supports benefits. Incorporating palliative care service definitions and/or measures into managed care contract language offers states an opportunity to target these services to populations with complex and serious illnesses. Similarly, Medicare Dual Eligible Special Needs Plans (D-SNPs) are required to contract with states and serve some of Medicaid's most complex and highest-cost beneficiaries. These contracts may provide another policy lever for states wanting to target palliative care to higher-need Medicaid beneficiaries.
- **Delivery system reforms:** States have made significant investments in patient-centered medical homes, health homes for individuals with chronic conditions, collaborative care, and other models that support team-based, person-centered, and coordinated care. States may want to explore how this existing infrastructure can be leveraged to educate providers, enhance access to primary palliative care, and facilitate referral to specialty services when needed.
- **Opioid prescribing limits:** State legislative and regulatory initiatives that establish limitations on opioid prescribing can have the unintended consequence of limiting necessary and critical medications for people receiving palliative care. Many states have taken steps to mitigate this unintended consequence by carving out prescribing exceptions for palliative care from these prescribing limitations.

# Conclusion

Palliative care is good care, a person-centered approach that can ease the burden of disease for individuals with serious illness while reducing avoidable spending. The approach aligns well with states' interests in supporting value-driven care, particularly for individuals with complex needs. Recent research suggests that states are just beginning to explore how palliative can support other state health reform goals and initiatives. As more people live longer with complex, serious conditions, approaches to care that support the quality of life – while honoring individual needs and preferences – will become increasingly important. For more information and resources to support states in these efforts, visit NASHP's [Palliative Care Hub](#).

## Notes

1. Medicaid: A Small Share of Enrollees Consistently Accounted for a Large Share of Expenditures, Report to Congressional Requesters, United States Government Accountability Office, May 2015, <https://www.gao.gov/assets/680/670112.pdf>
2. About Palliative Care, Center to Advance Palliative Care, Accessed on April 16, 2019, <https://www.capc.org/about/palliative-care/>
3. 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.
4. R. Sean Morrison, et al., "Palliative Care Consultation Teams Cut Hospital Costs For Medicaid Beneficiaries," *Health Affairs* 30, no. 3 (Mar. 2011).
5. Kumar, P., Casarett, D., Corcoran, A., Desai, K., Li, Q., Chen, J., ... Mao, J. J. (2012). Utilization of supportive and palliative care services among oncology outpatients at one academic cancer center: determinants of use and barriers to access. *Journal of palliative medicine*, 15(8), 923–930. doi:10.1089/jpm.2011.0217 <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3396135/>
6. National Voluntary Consensus Standards for Palliative Care and End-of-Life Care, National Quality Forum, Accessed on April 6, 2019 [https://www.qualityforum.org/Projects/Palliative\\_Care\\_and\\_End-of-Life\\_Care.aspx](https://www.qualityforum.org/Projects/Palliative_Care_and_End-of-Life_Care.aspx)
7. Mellar 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).
8. Clinical Practice Guidelines for Quality Palliative Care, 4th Edition, National Consensus Project for Quality Palliative Care, Accessed on April 6, 2019, [https://www.nationalcoalitionhpc.org/wp-content/uploads/2018/10/NCHPC-NCPGuidelines\\_4thED\\_web\\_FINAL.pdf](https://www.nationalcoalitionhpc.org/wp-content/uploads/2018/10/NCHPC-NCPGuidelines_4thED_web_FINAL.pdf)
9. Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life, Institute of Medicine of the National Academies, Released September 14, 2015. <http://www.nationalacademies.org/hmd/Reports/2014/Dying-In-America-Improving-Quality-and-Honoring-Individual-Preferences-Near-the-End-of-Life.aspx>
10. Growth of Palliative Care in U.S. Hospitals 2016 Snapshot, New York: Center to Advance Palliative Care, 2018.
11. R. Sean Morrison and Diane E. Meier, *America's Care of Serious Illness: 2015 State-by-State Report Card on Access to Palliative Care in our Nation's Hospitals* (New York, NY: Center to Advance Palliative Care, 2015).
12. Sullender RT, Selenich SA. Financial Considerations of Hospital-Based Palliative Care [Internet]. Research Triangle Park (NC): RTI Press; 2016 Mar. Available from: <https://www.ncbi.nlm.nih.gov/books/NBK532652/ doi: 10.3768/rtipress.2016.rr.0027.1603>
13. Palliative Care in the Outpatient Setting A Comparative Effectiveness Report Revised Draft Report. Institute for Clinical and Economic Review, published on March 9, 2016, <https://icer-review.org/wp-content/uploads/2016/03/Palliative-Care-Revised-Draft-Report-030916.pdf>
14. Community-Based Palliative Care Certification Option for Home Health & Hospice, The Joint Commission, Accessed on April 16, 2019, [https://www.jointcommission.org/community-based\\_palliative\\_care\\_certification\\_option\\_july\\_1\\_2016/](https://www.jointcommission.org/community-based_palliative_care_certification_option_july_1_2016/)
15. Clinical Practice Guidelines for Quality Palliative Care, 4th Edition, National Consensus Project for Quality Palliative Care, Accessed on April 6, 2019, [https://www.nationalcoalitionhpc.org/wp-content/uploads/2018/10/NCHPC-NCPGuidelines\\_4thED\\_web\\_FINAL.pdf](https://www.nationalcoalitionhpc.org/wp-content/uploads/2018/10/NCHPC-NCPGuidelines_4thED_web_FINAL.pdf)
16. Why Some Patients Aren't Getting Palliative Care, The Pew Charitable Trust, July 10, 2017, <https://www.pewtrusts.org/en/research-and-analysis/blogs/stateline/2017/07/10/why-some-patients-arent-getting-palliative-care>
17. National Voluntary Consensus Standards for Palliative Care and End-of-Life Care, National Quality Forum, Accessed on April 6, 2019, [https://www.qualityforum.org/Projects/Palliative\\_Care\\_and\\_End-of-Life\\_Care.aspx](https://www.qualityforum.org/Projects/Palliative_Care_and_End-of-Life_Care.aspx)
18. Rachel Donlon, Kitty Purington, Natalie Williams, *Advancing Palliative Care for Adults with Serious Illness: A National Review of State Palliative Care Policies and Programs*, National academy for State Health Policy, Published December 2018, <https://nashp.org/wp-content/uploads/2018/12/Palliative-Care-Brief-Final.pdf>
19. #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>
20. Code of Maryland Regulations (COMAR) 10.07.01.01.
21. Palliative and End-of-Life Care 2015–2016 Technical Report, National Quality Forum, December 23, 2016, [https://www.qualityforum.org/Publications/2016/12/Palliative\\_and\\_End-of-Life\\_Care\\_2015-2016.aspx](https://www.qualityforum.org/Publications/2016/12/Palliative_and_End-of-Life_Care_2015-2016.aspx)
22. Texas DSRIP Measure Bundle Protocol, Texas Department of Health and Human Services, June 6, 2017, <https://hhs.texas.gov/sites/default/files/documents/laws-regulations/policies-rules/1115-waiver/waiver-renewal/1115-waiver-draft-measure-bundle-protocol.pdf>
23. R. Sean Morrison and Diane E. Meier, *America's Care of Serious Illness: 2015 State-by-State Report Card on Access to Palliative Care in our Nation's Hospitals* (New York, NY: Center to Advance Palliative Care, 2015).
24. 216-RICR-40-05-1.5.5; and State of Rhode Island Department of Health, "Physician Licensing," accessed December 6, 2018. <http://health.ri.gov/licenses/detail.php?id=200/>.
25. 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](#).

26. State-Only Roundtable: State Strategies to Address Palliative Care, Facilitated Conversation, National Academy for State Health Policy Annual Conference, August 16, 2018.
27. Letter to All Managed Health Care Plans, Re: Palliative Care, State of California, Health and Human Services Agency Department of Health Care Services, Dec. 7, 2018, <https://www.dhcs.ca.gov/formsandpubs/Documents/MMCDAPLsandPolicyLetters/APL2018/APL18-020.pdf>
28. 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>.

#### **Acknowledgements:**

The National Academy for State Health Policy (NASHP) wishes to thank Stacie Sinclair at the Center to Advance Palliative Care, Rachel Donlon, and Trish Riley for their input and additions to this brief. The authors also wish to thank Amy Berman, Scott Bane, and Rani Snyder of The John A. Hartford Foundation for their input and generous support of this work. This state scan was supported by a grant from 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](http://www.nashp.org).