

# MAINE STATE LEGISLATURE

The following document is provided by the  
**LAW AND LEGISLATIVE DIGITAL LIBRARY**  
at the Maine State Law and Legislative Reference Library  
<http://legislature.maine.gov/lawlib>



Reproduced from electronic originals  
(may include minor formatting differences from printed original)



**Maine Hospice Council and Center for End-of-Life Care**  
*Where Change Happens*

December 14, 2020

130<sup>th</sup> Maine Legislature  
Committee On Health and Human Services

Dear Senator Ned Claxton and Representative Michele Meyer:

The Palliative Care and Quality of Life Interdisciplinary Advisory Council, established in statute in 2015, functions to make recommendations that would improve the quality of life of people living with serious medical illness.<sup>1</sup> **This letter is in response to a request by the Health and Human Services Committee in March 2020, to provide recommendations regarding models of palliative care delivery and sustainable methods of reimbursement.**

**Background:**

According to the National Academy for State Health Policy (NASHP), there is increasing awareness of the needs of seriously ill patients, many of whom may be in the final stages of life.<sup>2</sup> These are patients with complex medical, psychosocial and spiritual needs, who often die in hospitals or nursing homes, and consume significant amounts of health care resources. Consider that 5% of both Medicaid and Medicare beneficiaries account for 50% of total expenditures.<sup>3, 4</sup> Studies have shown that patients with serious illness experience pain and other symptoms, endure lengthy hospitalizations, receive futile and costly treatments, and make decisions about their care without a full understanding of their illness and what to expect.<sup>5, 6</sup>

Palliative care and palliative medicine are relatively new specialties in medicine. Palliative care is interdisciplinary, patient-centered care for individuals and their families living with serious illness. The cornerstones of palliative care are excellent pain and symptom management, the integration of psychosocial and spiritual supports, and the opportunity to engage in conversations regarding wishes for future care.<sup>7</sup> Patients with serious illness who receive palliative care are more likely to stay at home, because that's where they prefer to be. Integrating palliative care into the treatments of patients with serious illness has been shown to improve health outcomes and quality of life, while lowering costs for high-need, high-cost populations.<sup>8, 9</sup> One study of Medicaid beneficiaries with serious illness found that palliative care resulted in an average savings of almost \$7000 per person when compared to those patients who did not receive palliative care.<sup>10</sup>

Unfortunately, access to palliative care remains a challenge in various populations and geographies across Maine. Our own work, through the Palliative Care and Quality of Life Interdisciplinary Advisory Council, revealed that only 27% of Maine Hospitals provided access to inpatient palliative care consultation, and most of these services were restricted to the more urbanized and populated parts of the state. Access to palliative care in the most rural areas remains mostly unavailable. Further, there is very little palliative care delivered in community and home settings which is where most patients with palliative care needs can be found.<sup>11</sup> And of the programs that do exist in Maine, there is little evidence that there is adherence to [the Clinical Practice Guidelines for Quality Palliative Care, 4<sup>th</sup> Edition](#),<sup>12</sup> created and distributed by the National Consensus Project for Quality Palliative Care.

Since inception in 2016, the Palliative Care and Quality of Life Interdisciplinary Advisory Council has determined that the barriers to the further growth of palliative care are predominantly 4- fold:

1. Lack of awareness of the benefits and availability of palliative care on the part of the provider community;
2. Lack of awareness of benefits of palliative care on part of the consumer and patient community;<sup>13</sup>
3. Lack of workforce capacity. Maine has limited number of credentialed palliative care providers to provide specialty-level palliative care. Maine also lacks infrastructure to educate primary care providers in the skills and evidence of palliative care;
4. Lack of reliable and sustainable reimbursement for the interdisciplinary team-based palliative care, described in the *Clinical Practice Guidelines for Quality Palliative Care, 4<sup>th</sup> Edition*.

*The Maine Hospice Council is a 501(c)3 non-profit organization. All donation are tax-deductible.*





## Maine Hospice Council and Center for End-of-Life Care *Where Change Happens*

### **Moving Forward:**

Palliative care is patient-centered care for individuals and families living with serious medical illness. Most importantly, it is interdisciplinary care, delivered by a high-functioning, highly trained team of professionals, including physicians, advanced practice practitioners, nurses, social workers, pharmacists, therapists and chaplains. The goal of palliative care is the best possible quality of life for patients and families, with ongoing assessments and interventions to manage physical, emotional, social, and spiritual distress related to serious medical illness. These are the core elements of standards written into the *Clinical Practice Guidelines for Quality Palliative Care, 4<sup>th</sup> Edition*. Further, the care embodies ethical and informed decision-making that ensures that all patients receive the type of care that meets their goals, values and overall wishes.

While the early structure of most palliative care programs was hospital-based inpatient consultation, the recent trends in program development have been in community and home-based settings. The goal is to identify and engage patients further “upstream,” in hopes of mitigating suffering and relieving unmet needs “downstream.”<sup>14</sup> Earlier engagement with patients and families allows greater opportunity to avoid crisis, direct patients away from unhelpful emergency room visits and hospital stays, and ultimately avoid the costs associated with inefficiencies and lack of preparation.

A study published in the *Journal of Palliative Medicine* in 2017 by Lustbader and colleagues described the impact of a home-based palliative care program within a large urban ACO. Patients were living at home with congestive heart failure, COPD (Chronic Obstructive Pulmonary Disease), metastatic cancer and dementia. Care delivered by a home-based palliative care team, when compared to usual care provided a 34% decrease in hospital admissions, a 35% increase in hospice enrollment, and an increase hospice length of stay of 240%. This amounted to an overall cost savings of \$12,000 per patient in the last 3 months of life.<sup>15</sup>

We have explored opportunities, at both various state and federal levels, for best practices in program structure and affordable models of reimbursement. We have researched materials published the National Academy for State Health Policy (NASHP) and the Center to Advance Palliative Care (CAPC). In terms of palliative care advocacy, these are 2 organizations that provide national and state-wide leadership in the policies and practices that best serve patients with unmet needs.

NASHP, through funding from the John A. Hartford Foundation, has spent the past 2 years exploring state and Medicaid initiatives across the country. It is necessary to make note of several documents that they have produced, including [Palliative Care: A Primer for State Policymakers](#), and [Advancing Palliative Care for Adults with Serious Illness: A National Review of State Palliative Care Policies and Programs](#).<sup>16</sup> These documents are comprehensive and informative. They have identified particular policy levers implemented by other states advance palliative care. These include:

1. Adopting regulations that define, standardize and support palliative care delivery;
2. Implementing palliative care reimbursement policies and quality measures within Medicaid and state employee health programs to promote high-value care;
3. Including palliative care into public health and public education strategies; and convening stakeholders to inform policy and programmatic changes.<sup>17</sup>

In addition, the states of California, Arizona and Colorado have taken meaningful steps in the creation of a Medicaid palliative care benefit. Specifically, in 2014, California passed SB 1004, requiring that the Department of Health and Human Services “establish standards and provide technical assistance for Medi-Cal managed care plans to ensure delivery of palliative care services.”<sup>18</sup> Medi-Cal providers are now required to contract with outside community palliative care programs, and deliver high-quality palliative care services to qualified patients. As a result of this bill all Medi-Cal beneficiaries in all of the state’s 58 counties now have access to palliative care. Equally exciting is the fact that established palliative care programs can depend on consistent and fair reimbursement for their services.

There are ongoing efforts to understand the complexities of ideal and fair reimbursement for both high-quality fee-for-service palliative care, with flexibility to be delivered across various settings, including home, ambulatory and long-term care. It is clear that the fee-for service model, that only rewards the physician and nurse practitioner contributions, is

*The Maine Hospice Council is a 501(c)3 non-profit organization. All donation are tax-deductible.*





## Maine Hospice Council and Center for End-of-Life Care *Where Change Happens*

highly inadequate, and does not support the way palliative care *should* be delivered. A more innovative model that rewards the value-added elements of palliative care is required.

Many of the proposed **value-based reimbursement models** in discussion today use a monthly case rate, or per member per month (PMPM) “bundled” approach for payments to a palliative care program, in exchange for all components and contributions to a patient’s care.<sup>19</sup> We support this, and feel the need to draw attention to the precedent provided by the MaineCare Hospice Benefit, as well as that provided by Medicare, in its reimbursement for hospice services since 1984.<sup>20, 21</sup>

An exciting example of a **value-based reimbursement model for palliative care** can be explored in the Primary Care First/Seriously Ill Population initiative, first introduced by the **Center for Medicare and Medicaid Innovation (CMMI)** in spring 2019, scheduled for roll out in late 2020.<sup>22</sup> Twenty-six geographic regions – including Maine – have the opportunity to participate in an innovative palliative care delivery model through a value-based reimbursement lens, either in collaboration with primary care practices, or as independent palliative care providers. This initiative is built on the work and recommendations of some of our nation’s most prominent innovators and experts in palliative care. In particular, California’s Sutter Health provided home-based coordinated care to more than 2000 seriously ill patients in 19 urban, suburban and rural counties in California. In the last month of life, enrolled patients saw decreased hospital days by 1361 per 1000 beneficiaries, decreased hospital deaths by 8.2 percent, decreased inpatient payments by \$6127, and decreased total cost by \$5657 per beneficiary.<sup>23</sup>

We would like to acknowledge the unusual and challenging times we are all living through. COVID-19 has impacted every aspect of our professional and personal lives. It is affecting every single patient and family who we hold close, in spite of the forced distance between us all. As healthcare organizations develop strategies to provide the best possible care during these uncertain times, palliative care has a critical role to play. Symptom management, skilled communication and care coordination are the cornerstones of high-quality palliative care. There has never been a more defining moment in our health care system. There has never been a more critical time for palliative care.<sup>24, 25</sup>

### **Summary and Recommendations:**

Palliative care is a standard of care for all patients and families living with a serious medical illness. Access to high quality palliative care in Maine is challenged by lack of awareness by both providers and community members, a lack of adequate clinicians trained in palliative care, and lack of adequate reimbursement for palliative care providers striving to deliver the highest quality of palliative care services. Therefore, we make the following recommendations for your consideration:

1. Endorse and adopt a definition of palliative care that recognizes the valuable contributions of multiple members of an interdisciplinary team, providing care to patients with serious illness, of all ages, in all settings, and meeting the standards for palliative care outlined in the National Consensus Project’s Clinical Practice Guidelines for Quality Palliative Care, 4<sup>th</sup> Edition;
2. Endorse and adopt broad educational initiatives informing and empowering consumers and patients to the availability and value of palliative care;
3. Endorse and adopt educational initiatives to expand the workforce of providers qualified to deliver high-quality palliative care. This include physicians, advance practice providers, nurses, social workers, chaplains, pharmacists, as well as other professionals with skills applicable to the needs of palliative care patients;
4. Explore options in funding high-quality patient-centered interdisciplinary care to all MaineCare patients with life-limiting illness. This care can be provided in parallel to disease-modifying treatment. Features of the reimbursement model should include:
  - a. A focus on predominantly home-based supports and services that are delivered by an interdisciplinary team of physicians, advance practice providers, nurses, chaplains and social workers;
  - b. A focus on providing interventions that support comfort, quality of life and decision-making that supports patients goals and wishes for care;

*The Maine Hospice Council is a 501(c)3 non-profit organization. All donation are tax-deductible.*



**Maine Hospice Council and Center for End-of-Life Care**  
*Where Change Happens*

- c. Quality metrics that reflect the delivery of care that is high-quality, cost effective and in line with patient goals;
- d. Reimbursement to palliative care programs based on a value-based model, likely structured in per-member-per month (PMPM) or bundled payment models;
5. Consider the integration of palliative care into other value-based initiatives and care-structures as appropriate, such as Accountable Care Organizations, Patient Centered Medical Homes, and other care-delivery models that might exist. There are programs in Maine who will be participating in CMMI's Primary Care First/Serious Illness Program. Exploring lessons learned and linking a pilot to these providers will certainly prove helpful;
6. Consider organizing a 3-year pilot to explore the community-based palliative care model described in some resources provided, capturing important metrics such as quality added and cost savings;
7. Funding and support for the work of the Palliative Care and Quality of Life Interdisciplinary Advisory Council to organize, oversee and support the items described above.

The Palliative Care and Quality of Life Interdisciplinary Advisory Council appreciates the request from the Health and Human Services Committee to engage in dialogue regarding the future of palliative care, as both available and sustainable options in Maine. We look forward to continued discussion, in hopes of exploring solutions and opportunities.

Sincerely,

*Elizabeth Keene (KR)*

*Lauren Michalakes (KR)*

Elizabeth Keene, Co-Chair  
Vice President, Mission Integration  
St. Mary's Health System  
96 Campus Avenue #321  
Lewiston, ME 04240

Lauren Michalakes, MD, Co-Chair  
Palliative Care Physician and Consultant  
11 Salem Street  
Portland, ME 04102

*The Maine Hospice Council is a 501(c)3 non-profit organization. All donation are tax-deductible.*





**Maine Hospice Council and Center for End-of-Life Care**  
*Where Change Happens*

Reference

1. LD 782 An Act to Improve the Quality of Life of Persons with Serious Illness. (n.d.). Retrieved December 04, 2020, from [http://legislature.maine.gov/legis/bills/bills\\_127th/chapters/PUBLIC203.asp](http://legislature.maine.gov/legis/bills/bills_127th/chapters/PUBLIC203.asp)
2. Sanborn, L., & Purington, K. (2019). Palliative Care: A Primer for State Policymakers. Retrieved December 04, 2020, from <https://www.nashp.org/palliative-care-a-primer-for-state-policymakers/>
3. Office, U. (2015, May 08). Medicaid: A Small Share of Enrollees Consistently Accounted for a Large Share of Expenditures. Retrieved December 04, 2020, from <https://www.gao.gov/products/gao-15-460>Sawyer, B., & Claxton, G. (2019, January 16).
4. How do health expenditures vary across the population? Retrieved December 04, 2020, from <https://www.healthsystemtracker.org/chart-collection/health-expenditures-vary-across-population>
5. Frager, G. (2001). Improving End-of-Life Care. *Journal of Pain and Symptom Management*, 21(3), 249-250. doi:10.1016/s0885-3924(00)00270-0
6. Witkamp, F., Van Zuylen, L., Borsboom, G., Van der Rijt, C., & Van der Heide, A. (2015). Dying in the Hospital: What Happens and What Matters, According to Bereaved Relatives. *Journal of Pain and Symptom Management*, 49(2), 203-213.
7. Palliative Care Definition: What is Palliative Care. (n.d.). Retrieved December 04, 2020, from <https://www.capc.org/about/palliative-care/>
8. Morrison, R. S. (2008). Cost Savings Associated With US Hospital Palliative Care Consultation Programs. *Archives of Internal Medicine*, 168(16), 1783. doi:10.1001/archinte.168.16.1783
9. Temel, J., Al, E., Hospital, A., Meier, A., V. A. Simonovich and Others, Others, O., & J. H. Beigel and Others. (2010, August 19). Early Palliative Care for Patients with Metastatic Non-Small-Cell Lung Cancer: NEJM. Retrieved December 04, 2020, from <https://www.nejm.org/doi/full/10.1056/nejmoa1000678>
10. Morrison, S., Dietrich, J., Ludwig, S., Quill, T., Tangemen, J., & Meier, D. (2011). Palliative Care Consultation Cuts Hospital Costs for Medicaid Beneficiaries. *Health Affairs*, 30(3), 454-463.
11. Wagner, C., & Kassner, C. (n.d.). Prevalence of Palliative Care in Maine. Retrieved December 4, 2020, from [http://themha.org/policy-advocacy/Issues/Palliative-Care-Survey-\(2017\).aspx](http://themha.org/policy-advocacy/Issues/Palliative-Care-Survey-(2017).aspx)
12. Clinical Practice Guidelines for Quality Palliative Care. (n.d.). Retrieved December 4, 2020, from [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)
13. New York, N. (n.d.). New Public Opinion Research Reveals Palliative Care Still Relatively Unknown Among the General Public: Shows Education for Consumers and Physicians Necessary to Make a Difference. Retrieved December 04, 2020, from <https://www.capc.org/about/press-media/press-releases/2019-8-8/new-public-opinion-research-reveals-palliative-care-still-relatively-unknown-among-general-public-shows-education-consumers-and-physicians-necessary-make-difference/>
14. Rabow, M., Kvale, E., Barbour, L., Cassel, J. B., Cohen, S., Jackson, V., . . . Weissman, D. (2013). Moving Upstream: A Review of the Evidence of the Impact of Outpatient Palliative Care. *Journal of Palliative Medicine*, 16(12), 1540-1549. doi:10.1089/jpm.2013.0153
15. Lustbader, D., Mudra, M., Romano, C., Lukoski, E., Chang, A., Mittelberger, J., . . . Cooper, D. (2017). The Impact of a Home-Based Palliative Care program in an Accountable Care Organization. *Journal of Palliative Medicine*, 20(1), 23-28.

*The Maine Hospice Council is a 501(c)3 non-profit organization. All donation are tax-deductible.*



**Maine Hospice Council and Center for End-of-Life Care**  
*Where Change Happens*

16. Donlon, R., Williams, N., & Purington, K. (n.d.). Report: Advancing Palliative Care for Adults with Serious Illness - A National Review of State Palliative Care Policies and Programs. Retrieved December 04, 2020, from <https://www.johnahartford.org/dissemination-center/view/report-advancing-palliative-care-for-adults-with-serious-illness-a-national>
17. Advancing Palliative Care for Adults with Serious Illness ... (n.d.). Retrieved December 4, 2020, from [https://www.nashp.org/wp-content/uploads/2018/12/NASHP\\_State-Palliative-Care-Scan\\_Appendix-B-New.pdf](https://www.nashp.org/wp-content/uploads/2018/12/NASHP_State-Palliative-Care-Scan_Appendix-B-New.pdf)
18. Services, D. (n.d.). Palliative Care and SB 1004. Retrieved December 04, 2020, from <https://www.dhcs.ca.gov/provgovpart/Pages/Palliative-Care-and-SB-1004.aspx>
19. Mullery, S., Sinclair, S., & Silvers, A. (2019). Palliative Care's Value in Value-Based Payment. Retrieved December 04, 2020, from <https://www.capc.org/blog/health-reform-qtly-quarter-health-reform-fall-2016/>
20. Hospice Benefits. (n.d.). Retrieved December 04, 2020, from <https://www.medicaid.gov/medicaid/benefits/hospice-benefits/index.html>
21. Medicare Hospice Benefits. (n.d.). Retrieved December 4, 2020, from <https://www.medicare.gov/Pubs/pdf/02154-Medicare-Hospice-Benefits.PDF>
22. C-Tac. (2019, June 05). CMMI Announces New Serious Illness Payment Model Based on C-TAC Proposal. Retrieved December 04, 2020, from <https://www.thectac.org/2019/04/cmmi-announces-new-serious-illness-payment-model-based-on-c-tac-proposal/>
23. Stuart, B., Mahler, E., & Koomson, P. (2019). A Large-Scale Advanced Illness Intervention Informs Medicare's New Serious Illness Payment Model. *Health Affairs*, 38(6), 950-956. doi:10.1377/hlthaff.2018.05517
24. Abbott, J., Johnson, D., & Wynia, M. (2020). Ensuring Adequate Palliative and Hospice Care During COVID-19 Surges. *Jama*, 324(14), 1393. doi:10.1001/jama.2020.16843
25. Shamon, S. (2020). Person- and Family-Centered Approach Offers Healing in Long-Term Care during the COVID-19 Crisis. *Journal of Palliative Medicine*. doi:10.1089/jpm.2020.0312

---

*The Maine Hospice Council is a 501(c)3 non-profit organization. All donation are tax-deductible.*