



WRITTEN TESTIMONY OF:
**Hospice and Palliative Care Association of New York State
(HPCANYS)**

Jeanne Chirico, President/CEO

PRESENTED TO:
The Joint Health Legislative Budget Hearing

ON THE SUBJECT OF:
**FY 2026 Executive Budget Proposals on Health Care:
Recommendations and Priority Inclusions**

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SUBMITTED TO:
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SUMMARY

The Hospice and Palliative Care Association of New York State (HPCANYS) is the leading association representing New York State's hospice and palliative care programs, allied organizations and individuals that are interested in the development and growth of quality, comprehensive care for all confronted with serious illness and their families. HPCANYS works collaboratively with hospice and palliative care providers, policymakers, community organizations and other stakeholders to ensure access to quality and compassionate care for all New Yorkers with a life-limiting illness.

Underscoring the Association's advocacy and education is a commitment to health equity, patient-centered care and personal autonomy. HPCANYS promotes policies and practices to ensure access to quality serious-illness care for all individuals in alignment with their health care goals and wishes, while providing support to families, caregivers and communities.

As the only statewide association exclusively representing New York State's hospice and palliative care industry and its workforce, HPCANYS is uniquely positioned to identify barriers to care, challenges to sustainability, and to propose achievable and measurable solutions.

HPCANYS offers the following requests for your consideration to be prioritized on behalf of all New Yorkers with serious or life-limiting illnesses:

Hospice and Palliative Care Workforce Parity and Innovation Initiative

Budget Request: \$20 million dollars of the proposed MCO tax funds or other funding source deemed appropriate to allocate specifically for hospice and palliative care workforce initiatives.

Advance Care Planning: Development and Implementation of Statewide Campaign

Budget Request: \$3 million for the development and implementation of the statewide Advance Care Planning Campaign that was signed into law by Governor Hochul as Chapter 406 of the Laws of 2022.

The Association respectfully implores the committee members to prioritize funding for the hospice workforce and the establishment of a statewide advanced care planning campaign in the upcoming budget. By doing so, New York State can reaffirm its commitment to high-quality, patient-centered care, ensuring that all individuals facing terminal illnesses receive the support and dignity they deserve during their final days. Together, let us continue to work toward building a sustainable and equitable healthcare infrastructure to address the needs of New York State.

INTRODUCTION

Thank you to Chair Krueger, Chair Pretlow, and members of the Committees for this opportunity to provide comments and present recommendations from the Hospice and Palliative Care Association of New York State (HPCANYS) on the FY 2026 Budget.

My name is Jeanne Chirco, and I am privileged to present this testimony on behalf of the hospice and palliative care community in New York State.

Hospice is an essential part of the health care continuum. It is a team-oriented approach to end-of-life care that offers expert medical care, pain management, and emotional and spiritual support expressly tailored to the patient's needs and wishes. Hospice has long addressed social determinants of health, caregiver wellness, and family participation in the plan of care. Hospice promotes informed decision making throughout the serious illness journey.

The Executive Chamber, Legislature, and Department of Health have repeatedly stated their commitment to improving and strengthening the State's hospice and palliative care infrastructure. The support and advocacy the Legislature has provided for the hospice and palliative care industry over the past several years is greatly appreciated and has provided the industry with momentum to continue making strides for community-based hospice and palliative care services. However, the hospice health care infrastructure is not receiving the investments needed to assure adequate access and utilization of hospice services. As a result, New York state's hospice utilization rate remains extremely low, impacting where people receive end-of-life care and the cost of that care. New York, according to recent Center to Advance Palliative Care (CAPC) assessment, is the 2nd most expensive state to receive end-of-life care. Increased hospice utilization could thus save the state significant Medicaid dollars.

I am here to ask the Legislature to invest in two critical areas that require immediate funding: first, to infuse the hospice and palliative care workforce with desperately needed support; and, second, to fund the implementation of the statewide advanced care planning campaign which encourages and educates New Yorkers on informed decision-making throughout their life. I implore each of you and your colleagues in the Legislature to recognize that we are at a critical and pivotal moment in our state's history, with a rapidly aging population, depleted workforce, and the diversion of healthcare resources to other interests. I look forward to your consideration and acceptance of the two proactive proposals I am presenting on behalf of the hospice and palliative care community in New York State.



HOSPICE AND PALLIATIVE CARE WORKFORCE PARITY AND INNOVATION INITIATIVE

***BUDGET REQUEST: \$20 MILLION DOLLARS OF THE PROPOSED MCO TAX FUNDS OR OTHER
FUNDING SOURCE ALLOCATED SPECIFICALLY FOR HOSPICE AND PALLIATIVE CARE WORKFORCE***

As we navigate the landscape of healthcare delivery in New York, it is essential to acknowledge the indispensable role that hospice care plays in our healthcare ecosystem. However, the effectiveness of these services is profoundly dependent on a well-resourced workforce. The workforce crisis remains the single largest obstacle to improving hospice utilization. HPCANYS remains concerned about the impact the overall healthcare workforce shortage is having on hospice access and utilization in New York State. Without adequate state investment in the hospice workforce, providers will continue to struggle to offer competitive compensation, which is leading to high turnover rates and could lead to the inability to deliver compassionate care. Addressing these funding disparities is vital to ensuring the hospice workforce in New York can thrive and effectively meet the needs of patients and families during their most vulnerable times.

We cannot effectively enhance hospice care without a healthy and sustainable workforce. Therefore, the Association requests a specific allocation of \$20 million to hospice and palliative care for a Hospice and Palliative Care Workforce Initiative pilot from the Executive’s proposed MCO tax or other funding source deemed appropriate by the Legislature.

In December 2024, the State secured CMS approval to implement a new Managed Care Organization (MCO) tax to leverage additional Federal resources. The FY 2026 Executive Budget proposal reflects the intent to allocate “\$200 million for investment in nursing homes, assisted living programs, and hospice programs.” HPCANYS is appreciative of the Governor’s attempt to support New York State hospices. Unfortunately, there is a lack of clarity in not only how these dollars would be assigned to each service line, but even more perplexing how a tax based on Medicaid would be transferred to providers who are primarily reimbursed by Medicare. This is concerning since New York State has historically overlooked the inclusion of hospice in its workforce initiatives. Consequently, this has resulted in a significant workforce disparity that is particularly concerning given the rapidly aging population in our state and the ongoing efforts to increase hospice utilization rates.

Further, while the state has received millions of dollars to support its health care workforce, hospice providers received nothing – not one cent in the available funding that went to every other healthcare sector was provided to the hospice workforce. Currently, the hospice workforce faces unprecedented challenges, including retirement age nursing population with related high turnover rates, workforce shortages in social work, advance practitioners, and chaplains, as well as insufficient training resources to upscale the lack of training received during nursing and social work higher education. These factors threaten the ability of hospices to provide the high-quality care that patients and their families rightfully expect. Without targeted funding to support workforce development, we risk compromising the integrity of hospice services in our state. Investing in our hospice workforce is not merely a budgetary consideration; it is an ethical obligation that directly impacts patient outcomes, health equity, and overall quality of life for those at the end of their life’s journey.

As the demand for hospice services continues to rise due to an aging population and increasing chronic illness, the multifaceted workforce crisis affecting hospice providers and seriously ill individuals highlights the urgent need for strategic interventions to bolster workforce sustainability. The state must

work to ensure that all New Yorkers receive the compassionate and comprehensive care they deserve during life's final chapter.

The New York State Workforce Planning Guide highlights the growing concern for both nursing and social work capacity as trends in planning are not growing quickly enough to keep pace with need. 42.7% of RNs in New York State are 50-years-old or older, leading to a compounded effect as their retirement looms in the not-too-distant future. Further, an overwhelming number of students in clinical disciplines, including critical care nursing, do not feel prepared to provide end-of-life care. In a 2019 survey of critical care nurses, less than 40% of respondents reported being "highly competent" in any palliative care domain while 38% reported no palliative care education in the past 2 years. A survey of undergraduate nursing students in junior and senior year overwhelmingly showed they felt unprepared to offer family care at end-of-life.¹ Historically, hospice employers often required nurses to have two to three years of experience in acute care nursing before being hired. Unfortunately, in the current environment this strategy is no longer viable, and hospices need to find a way to train their own new recruits. When you consider the higher level of experience and the autonomy needed to provide care alone in a dying patient's home, unique attention is needed to build the end-of-life care workforce infrastructure.

Accordingly, HPCANYS recommends financial support for the Hospice and Palliative Care Workforce Parity and Innovation Initiative. Through this initiative, funds would be provided to community-based palliative care and hospice providers for workforce development and innovation. This initiative would include:

- RN Mentorship programs that offer comprehensive curriculum using multimedia efforts including didactic education, intensive skills training in a simulated lab environment;
- Financial awards to support sending interested professionals through education and study to become certified in hospice and palliative care within their specific discipline through the Hospice and Palliative Credentialing Center (HPCC) or American Academy of Hospice and Palliative Medicine (AAHPM);
- Support for community-based hospice providers making a commitment to support Physician Fellowships in Hospice and Palliative Care which ultimately reduces the productivity of current hospice physicians mentoring and supervising the Fellows;
- Addressing the critical social worker shortage to ensure that patients and families receive the emotional and psychosocial support, care coordination and advocacy, bereavement support, and cultural awareness needed in quality end-of-life care.

The World Health Organization has proposed a need for palliative care education to upskill all health professionals. Recent research has documented a lack of end-of-life and palliative care education among health and social care professionals in non-palliative care settings. An institutional survey in 2019 illustrated that 38% of critical care nurses reported having received no education on palliative care in the previous 2 years. A U.S. study of social workers found similar results, only 45.3% of whom reported that they had attended a conference related to hospice/palliative care. Insufficient education leaves providers feeling less competent, often susceptible to experiencing "burnout" and emotional exhaustion, and higher moral distress.

In line with the research, The Master Plan on Aging LTCS End-Of-Life Workgroup made the following recommendation and statement:

¹ Wolf AT, White KR, Epstein EG, Enfield KB. Palliative Care and Moral Distress: An Institutional Survey of Critical Care Nurses. *Crit Care Nurse*. 2019 Oct; 39(5):38-49. doi: 10.4037/ccn2019645. PMID: 31575593

“Affirming that patients with a life-threatening illness have a human right to palliative care, society has a responsibility to ensure all people living with life-threatening illnesses are provided quality care, regardless of race, ethnicity, language, disease, age, economic circumstance, geographic location, health care provider, or care setting. Since individuals and families affected by end-of-life issues can be found in different settings and in different levels of the health care system, End-of-Life Care Education should be provided to all health care professionals including but not limited to physicians, nurses and allied health practitioners, discharge planners, and other social care professionals such as social workers regardless of professional specialty.”

Therefore, financial support from the requested budget allocation would also be used to encourage existing licensed professionals to pursue certification in hospice and palliative care.

For the above-referenced justification and others, the Association requests a specific allocation of \$20 million for hospice and palliative care workforce parity and innovation. While time constraints limit the depth of our discussion, our Association eagerly anticipates the opportunity to engage in a more detailed review of our recommendations and implementation strategies. It is important to recognize that the workforce crisis in hospice and palliative care has far-reaching implications, particularly for the individuals most in need of these time-sensitive specialized services and their dedicated caregivers.



ADVANCE CARE PLANNING: DEVELOPMENT & IMPLEMENTATION OF STATEWIDE CAMPAIGN

BUDGET REQUEST: \$3 MILLION FOR THE DEVELOPMENT & IMPLEMENTATION OF THE STATEWIDE ADVANCE CARE PLANNING CAMPAIGN, AS SIGNED INTO LAW BY THE GOVERNOR (CHAPTER 406 OF THE LAWS OF 2022)

The Master Plan on Aging Long-Term Services and Supports End of Life Workgroup identified a lack of education and awareness among professional providers and community members concerning culturally and linguistically competent quality end of life care. The workgroup called for funding allocation and resources to develop and coordinate a comprehensive plan that would implement the statewide public health education campaign on advanced care planning, created by Chapter 406 of the laws of 2022, utilizing plain language with consideration for translation for individuals whose primary language is not English.

Our Association urges this committee to consider the pressing need for a statewide advanced care planning campaign. Three years ago, the Legislature, the Executive, and the NYSDOH agreed with the Association's call for action and mandated the development and implementation of this initiative; however, it has yet to receive funding.

The NYSDOH Center for Hospice and Palliative Care requires \$3 million to effectively develop and implement this essential initiative, in alignment with the recommendations of the Master Plan for Aging Workgroups. Comprehensive advance care planning is vital for ensuring that patients' wishes are respected and that they receive care consistent with their values and preferences. A robust campaign would empower individuals to engage in meaningful conversations about their care preferences, ultimately reducing unnecessary hospitalizations and enhancing the quality of life for patients facing serious illnesses.

Whether someone is healthy and identifying a health care proxy in case of emergency, or facing an acute illness, a long-term chronic illness or a terminal illness, advance care planning can help alleviate unnecessary suffering, improve quality of life and provide better understanding of the decision-making challenges facing the individual and his or her caregivers. An advance care plan can be used at any stage of life and should be updated as circumstances change.

As COVID-19 highlighted, more individuals recognized that they were not prepared should they become seriously ill. Individuals need to be educated about the options that exist to help keep them comfortable through an illness, how to make informed decisions about what treatments they want to pursue, how to talk with your doctors, and what hospice and palliative care are and how to access them. We support empowering the public with the knowledge, so that they can choose what is right for them. Barriers to advance care planning include lack of awareness, denial of death and illness, confusion, and cultural differences. These barriers are best addressed through outreach, education, and discussion.

A myriad of issues limit access and widen the gap in health disparities including regulatory, reimbursement, and educational issues. Public perception of hospice and palliative care remains a roadblock to access. In communities of color, additional challenges include language barriers and culturally-based apprehension regarding cessation of curative treatment. Further, individuals from minority groups are often diagnosed with diseases at late stages and have worse outcomes, leading not only to higher mortality rates, but also affording them less engagement in advance care planning, leading to an under-utilization of hospice care. A coordinated and comprehensive effort is needed to help address

cultural and linguistic barriers to understanding the benefits of hospice and myths about what hospice is and what the benefit is not.

Culturally competent communication and education on advance care planning, hospice, and palliative care, delivered by leveraging the use of community partners and stakeholders will not only improve access and utilization to hospice and palliative care, but help close the gap in health equity. Despite the benefits offered by hospice and palliative medicine as care options, significant gaps in awareness and understanding remain, including who is eligible and when such care would be appropriate. This gap exists not only with the public, but also with the greater health care community.

There is a critical need to increase this awareness in both the public and in the overall health care system so more individuals are aware of and can access their care options. This financial investment is needed to create a comprehensive stakeholder coalition to develop a public campaign on effective health care communications and advance care planning. The initiative may include media, social media and material distribution, education of State employees, long-term care facilities, other care providers, and faith-based leaders.

CONCLUSION

Our recommendations and priority inclusions represent a well-reasoned, comprehensive yet cost-conscious set of proposals that will help advance and improve the quality, access, and delivery of serious illness care for all New Yorkers, especially the seriously ill and dying in our community and congregate care settings. Our 2025-2026 budget requests complement our ongoing advocacy priorities, the legislature's commitment to investing in this rapidly growing care space, save the state Medicaid dollars, and would decrease the out-of-pocket costs to families in an individual's final stage of a life-limiting illness.

The data overwhelming shows that hospice utilization results in significant savings to the state in health care expenditures. Utilization of the hospice Medicare benefit directly translates to savings of Medicaid dollars and family out-of-pocket spending at the end of life. The estimated one-month out-of-pocket savings associated with hospice is \$670, which represents roughly 20% of the monthly income of the lowest third of older adults in the United States. Further, the \$670 estimated savings represent an almost 75% reduction in out-of-pocket costs compared with older adults who did not receive hospice care. ²

Building on the historic progress made over the last two years within our state to care for the seriously ill and dying, HPCANYS looks forward to continuing our work with the Legislature, Executive Chamber, the Division of Budget, and the Department of Health to improve the utilization of hospice and palliative care services as the state continues to develop a sustainable health care infrastructure. The research and data points consistently show that when hospice is appropriately funded and regulated, hospice represents the best of health care. Moreover, our goals are aligned with the state's obligations to provide more cost-effective, coordinated, and quality care to New Yorkers at the end of life. Such goals must be met as the state moves forward with other end-of life care initiatives.

Thank you for your attention and consideration. I welcome any questions you may have, and the Hospice and Palliative Care Association and its members stand ready to support your efforts toward building an equitable and sustainable healthcare infrastructure.

² Aldridge MD, Moreno J, McKendrick K, Li L, Brody A, May P. Association Between Hospice Enrollment and Total Health Care Costs for Insurers and Families, 2002-2018. *JAMA Health Forum*. 2022;3(2):e215104. doi:10.1001/jamahealthforum.2021.5104