



**Testimony of  
Hospice and Palliative Care Association of New York State  
at the Joint Legislative Budget Hearing**

February 5, 2019

**Introduction**

The Hospice and Palliative Care Association of New York State (HPCANYS) appreciates the opportunity to provide comments on the State Fiscal Year 2019-20 proposed Executive Budget. Hospice and Palliative care are the gold standard for person centered care. Hospice is provided to the patient and their loved ones as they face their own mortality, focusing on quality of the days left. Palliative care is for patients facing serious illness, focusing on symptom management and clarification of treatment goals. They exemplify the State's Triple AIM.

Although New York State has 44 exemplary hospice programs providing compassion, support and dignity at the end of life, only 29.9% of New Yorkers know about and avail themselves of their services. New York State has done very little over the years to promote and advance end of life care for its citizens. Today we ask you to invest both in the hospice and palliative care programs, and to advance end of life care for all citizens facing death in New York State.

We recognize and appreciate that the State has a responsibility to assure that healthcare funding is provided in the most effective manner. However, we are also keenly aware of the fiscal challenges faced by hospice providers as they attempt to adjust their budgets to accommodate reductions in funding. At the federal level, Hospice Medicare reimbursement has been significantly cut through phase-out of the Budget Neutrality Adjustment Factor (BNAF), productivity cuts, and sequestration. On top of that, hospices have had to find ways to budget for additional costs without additional funding to pay for new federal requirements, including non-

billable physician or nurse practitioner visits in the patient's home, Hospice Information Set reporting, and reporting of additional claims data.

### **About Hospice and Palliative Care**

Hospice and palliative care offer appropriate, high quality, cost-effective care to patients and their families, and Hospice is one of Medicare's most cost-effective programs:

- A study by B.A. McNamara, published in the Journal of Palliative Medicine, found that “Proactive care in the form of timely community-based palliative care assists in preventing vulnerable people at the end of life from being exposed to the stressful ED environment.” (McNamara, B.A., et al. (2013) ‘Early Admission to Community-Based Palliative Care Reduces Use In Emergency Days before Death.’ *Journal of Palliative Medicine* Vol. 16, (7) pg. 774-779)
- “Dying in America,” a report from the Institute of Medicine, focuses extensively on the needs of individuals with serious and chronic illnesses. It states: “People who meet the hospice eligibility criteria deserve access to services designed to meet their end-of-life needs.” <http://www.iom.edu/Reports/2014/Dying-In-America-Improving-Quality-and-Honoring-Individual-Preferences-Near-the-End-of-Life.aspx>
- This recognition of hospice and palliative care is important considering that in 2008, Medicare paid \$50 billion just for doctor and hospital bills during the last two months of patients' lives. As much as 20 to 30 percent of these medical expenditures may have no impact on improving the quality, or length of a patient's life. It is likely that the costs incurred and negative outcomes experienced by the Medicaid decedent population are even higher. The relative lack of access to coordinated and subspecialty care, often experienced by Medicaid patients, has historically lead to higher rates of hospital and intensive care unit use at the end of life. Ira Byock. The Cost of Dying, 60 Minutes, Nov. 22, 2009

The Hospice and Palliative Care Association of New York State represents the state's certified hospice providers and palliative care providers, as well as individuals and organizations concerned with care for patients at the end of life. Hospice serves patients at the end of life and provides pain and symptom management, addresses social, emotional and spiritual needs and

provides care and support to the bereaved. Hospice services are provided in the home, nursing home, and inpatient facilities. Hospice is a Medicare benefit for individuals who have a terminal illness of six months or less if the disease runs its normal course and 12 months when the patient has Medicaid.

Palliative care extends the principles of hospice care to a broader population that could benefit from receiving this type of care earlier in their illness or disease process. Palliative care seeks to address not only physical pain, but also emotional, social and spiritual pain to achieve the best possible quality of life for patients and their families. A number of hospice programs have added palliative care to their names to reflect the range of care and services they provide, as hospice care and palliative care share the same core values and philosophies.

The Hospice and Palliative Care Association of New York State respectfully offers the following recommendations to the Executive Budget which we believe would increase access to hospice care while also ensuring hospices can effectively provide care to those in need.

**Criminal History Record Checks:** Effective April 1, 2018, hospice workers who provide direct care or supervision of patients are subject to a criminal history record check (CHRC) as a condition of employment with all hospices licensed and certified under Article 40 of the Public Health Law. Title 10 NYCRR Part 402 is being amended to reflect that hospices request criminal history record checks for any prospective unlicensed individual employed by, or used by, the organization who provides direct care or supervision to a patient or resident or who has access to the patient or resident, their living quarters, or their property. Volunteers, students and professionals licensed by the State Education Department are not subject to the CHRC requirement.

When the law was enacted to require hospices to perform CHRCs, hospices were also added to the list of providers that would be reimbursed for the additional cost associated with the requirement of performing the Criminal History Record Checks. DOH has not created a mechanism for hospices to be reimbursed for this mandated cost. Alternative funding reimbursement must not be an addition to the Medicaid rate because of the minimal Medicaid

hospice volume. HPCANYS requests that the legislature direct DOH to create a mechanism for payment of these funds to hospice programs. And require payment of funds to all eligible provides within 45 days of receipt and approval of the invoice.

**Advance Care Planning:** New York State has a long-standing history of ensuring access to health care for all who reside in New York State. Key elements to ensuring this access include educating the public and involving them in their health care decisions. Governor Cuomo continued this commitment to access to healthcare in his 2018 State of the State when he stated the following to expand advanced care planning:

*Expand Advanced Care Planning: Advanced Care Planning (ACP) not only empowers older adults to participate in the decision-making process of their treatment, but also details their wishes for care if they were unable to speak for themselves. Governor Cuomo will initiate a statewide ACP campaign, to include, public outreach and education, engagement and encouragement of New Yorkers of all ages to complete ACP documents and a re-design of the Department of Health's ACP website to include additional functionality and resources. The State will also fully participate in National Health Care Decision Day.*

Yet currently NY ranks 47 out of 50 states and District of Columbia in 2016 for Medicare decedents who use hospice care at the time of their death. In NY, 29.9% of Medicare patients are on hospice at the time of their death compared to nearly 46.2% nationally. Clearly, more needs to be done to address increasing access to hospice.

Hospice Organizations provide end of life care focused on comfort while treating the body, the mind and the soul. Hospice promotes patient engagement and choice, we have been empowering the patient and family since our very humble beginnings in the early 1980's. The basic tenant of hospice care is to have the patient lead the team, based on their personal goals and values and needs. Hospice does this so well that 84% of respondents in the federally published Consumer Assessment of Healthcare Providers and Systems (CAHPS) surveys will say that they recommend hospice care to others compared to 72% when asked the same question about hospitals.

Even though Hospice promotes quality and dignity during your final days too few people

in NY are choosing hospice care. There are many factors that contribute to this problem. Too few people know what hospice is and how they or their families could benefit from this patient centered care. Socioeconomic and cultural factors impact on knowledge of and the ability to choose hospice care. Medical providers are still ill equipped to determine prognosis and to have the meaningful yet difficult conversations about end of life care. The impact can be measured in terms both financial and human perspectives. From the financial perspective, 28% of total Medicare spend is on the patients during the last 6 months of life. The human toll is greater with patients dying in pain leaving their families affected for years to come both financially and emotionally.

Research by the Massachusetts Coalition for Advanced Illness Care has shown that among the population who feel that their loved one's wishes were honored at the end of life, 60% of the time, the family initiated the conversation and not the medical team.

In an effort to promote access to hospice care for all New Yorkers facing a terminal illness, we propose the State of NY fund a public education campaign for **\$5 Million over the next 2 years**. Empowering the public with the knowledge of their choices, so that they can choose what is right *for them*, is a powerful tool. Public education on end of life care, hospice and the value of advance care planning will help many New Yorkers get the care they want.

**Emergency Medicaid:** The Hospice and Palliative Care Association of New York State requests the inclusion of hospice in Emergency Medicaid. New York State's Medicaid for the Treatment of an Emergency Medical Condition, also called Emergency Medicaid, helps eligible, undocumented and temporary immigrant New Yorkers pay for medical costs when an individual needs immediate medical attention for a serious health issue. Serious health issues include conditions like a heart attack or severe pain that could lead to a dangerous health outcome without medical help. Hospice provides care to seriously ill and terminal patients who may qualify for Emergency Medicaid. However, currently hospice is not a covered service. Therefore, the only option available for an individual eligible for Emergency Medicaid who is terminally ill would be in a hospital setting. Most people want to go home, or to a hospice

residence. Hospice care would both improve the quality of the remaining days, and provide a more appropriate environment for the patient while also saving Medicaid dollars.

**Health Care Facility Transformation Program:** There is a proposal for the allocation of up to \$300 million of the \$525 million from SFY 2018-2019 funds to applications already submitted under Phase II of the program. Hospice organizations are not included in Phase I or in Phase II but are now included in Phase III. Transferring Phase III money will decrease the ability of the hospices, in great need of facility transformation money, to access those funds. We request that in Phase III, programs that were not allowed to apply in Phase II receive preference for selection in Phase III.

**Access to Palliative Care for all New Yorkers:** Palliative Care is specialized medical care for people with serious illness. This type of care is focused on providing relief from the symptoms and stress of a serious illness. The goal is to improve quality of life for both the patient and the family. Palliative care is provided by a specially-trained team of doctors, nurses and other specialists who work together with a patient's other doctors to provide an extra layer of support. It is appropriate at any age and at any stage in a serious illness, and it can be provided along with curative treatment. Palliative Care provides an added layer of support for patients and their families during a stressful time.

Research has shown that palliative care improves patient outcomes, increases the likelihood of completion of cancer treatments, improves patient satisfaction with care, and bends the cost curve by decreasing unnecessary futile care. In New York, however, there are only a limited number of palliative care programs – whether in the hospital or post-acute care – thus patient access to palliative care is also limited. This limited access can be at least partially attributed to the lack of payment available for the team of specialized clinicians who provide palliative care. Currently the only team member paid for this service is the physician.

New York State has received a “B” grade by the Center for the Advancement of Palliative Care for the availability of hospital based palliative care programs. And has only 34 post-acute care palliative care programs for the entire state.

In order to expand on the availability of palliative care services, we need to:

1. Conform the definition of palliative care throughout New York statutes.
2. Create and fund a study to create a palliative care benefit and payment structure for Medicaid recipients.

**Medicaid Managed Long-Term Care and Hospice:** In 2012, individuals enrolled in Medicaid Managed Long Term Care (“MLTCP”) no longer had to disenroll from MLTCP in order to access their hospice benefit. This change allowed for individuals with a terminal prognosis to continue to receive the important services offered by MLTCP while adding specialized end-of-life care offered by hospice. Unfortunately, patients enrolled in hospice cannot access services of MLTCP without first dis-enrolling from hospice. The MLTCP enrollment process requires the completion of a ‘conflict free assessment’. This process, depending on where you are in the state, will take anywhere from 1 day to 6 weeks. During this time, patients are left without hospice care.

Anecdotal information indicates that these patients who disenroll from hospice care in order to access the additional services offered under the MLTCP are likely to require a higher level of care during this waiting period - in emergency departments and even hospitalizations. If a patient is admitted to the hospital from the emergency room, they might be referred to hospice and transferred to a hospice inpatient bed for treatment of their uncontrolled symptoms. But, when the patient is ready for discharge back home, they are no longer eligible to for admission to an MLTCP unless they first revoke their hospice benefit. Even worse, the patient may die while waiting to be admitted to a MLTCP and before a referral to hospice is made. This current process penalizes individuals who are eligible for both MLTCP and hospice simply because they chose hospice first. We request that the state remove this barrier and allow individuals eligible for MLTCP who enroll in hospice first to be able to enroll in MLTCP without dis-enrolling from hospice.

## **Conclusion**

Today we ask you to invest both in the hospice and palliative care programs, and to advance end of life care for all citizens facing death in New York State because every New

Yorker needs to be assured that they will receive compassionate, supportive and comfort care at the end of life.

We ask you to support the hospice programs by assuring the following:

- Payment for Criminal History Record Checks
- Payment for hospice through Emergency Medicaid
- Not be disadvantaged by moving money to Phase 2 Health Care Facility Transformation Program

We ask you to support the citizens of New York by:

- Funding and implementing consumer education for Advance Care Planning
- Granting Medicaid beneficiaries Access to Palliative Care through a study commission on a palliative care benefit in Medicaid
- Stopping the disenrollment from hospice for New Yorkers applying for Medicaid Managed Long-Term Care

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