



**Testimony of
Hospice and Palliative Care
Association of New York State**

To the Joint Health
Legislative Budget Hearing

On the subject of
2021-2022 Executive Budget
Proposals On Health Care
February 25, 2021

Submitted to:

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Introduction:

The Hospice and Palliative Care Association of New York State, otherwise known as HPCANYS, 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. We are grateful for this opportunity to present its members views on the Governor's budget proposals.

Hospice and Palliative Care providers have been on the frontline during the ongoing COVID-19 pandemic, and in addition cared for nearly 60,000 New Yorkers in 2020. Unfortunately, this means that approximately 120,000 New Yorkers died without this quality and compassionate care. Since its inception, hospice has been ahead of its time, focusing on delivering high-quality, holistic care to patients and families, with features that are only recently being adopted by the rest of the healthcare system. National attention is increasingly focused on patient-centered care, social determinants of care and improved care coordination, which have always been key tenets of hospice. National and state policies now aim to reduce unplanned hospital readmissions, excessive emergency visits, and overuse of services – all of which contribute to a sharp rise in healthcare costs and all of which have been shown to be dramatically reduced by hospice.

Hospice not only improves quality of life for the individual but also drives down health care costs caused by expensive treatments and frequent hospitalizations. In New York the current health care system and its related policies do not support access to these benefits as evidenced by New York ranking 50th out of all the states in the nation in hospice Medicare utilization. There are a variety of regulatory, reimbursement, and educational issues that can have an impact on access and all actions must have, at their core, the additional goal of decreasing the disparity that exists in quality end-of-life care for persons of color.

The Hospice Benefit guarantees comprehensive high-quality end-of-life care – at little or no cost – to New York's terminally ill beneficiaries and their families. Hospice care involves a team-oriented approach to expert medical care, pain management, emotional and spiritual support expressly tailored to the patient's needs and wishes. Hospice is an all-inclusive per diem rate that must not only provide for the interdisciplinary team visits but also must pay for all related medications, DME, and 24/7 nursing availability.

New Yorker's on Hospice die at home (personal residence or nursing home) 98% of the time. *Hospice has a 1-2% rehospitalization rate compared to the hospital 30-day unplanned all-cause readmissions of 16% in 2017.* According to a 2017 Kaiser Health News study, New York hospitals have one of the highest readmission rates in the nation with 90% of New York hospitals penalized by Medicare for their readmission rates. According to a study entitled "Hospice Use, Hospitalization, and Medicare Spending at the End of Life," published by [*The Journals of Gerontology*](#): hospice use of at least two weeks prior to death was associated with anywhere

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from one to five fewer days spent in hospital care for all Medicare patients. When you consider Medicaid only patients, and those who have both Medicare and Medicaid, the avoidable cost to the Medicaid system for care or coinsurance can be significant. When an individual is dually eligible the hospice benefit is always billed to Medicare, thus providing a savings to the state from costly aggressive treatment and/or the recurrent hospitalizations that comes with chronic advancing illness.

HPCANYS recognizes the severe and imposing budget gap related to the COVID-19 pandemic and the disproportionate reimbursement from the Federal government to date. Therefore, HPCANYS respectfully submits the following recommendations to the Executive Budget which could increase access to hospice, decrease overall healthcare expense, and perhaps more importantly provide information, education and support to the tens of thousands of New Yorkers that will be facing serious life limiting illnesses this year.

1. Create a Role/Responsibility at DOH as Hospice Palliative Care Expert/Liaison

Rationale: The lack of a Hospice Liaison within the Department of Health is perhaps the most readily identifiable no cost approach to improving hospice utilization. Hospice is a unique and highly regulated area of healthcare service, as it can be carried out in a variety of settings. It focuses on preventing, treating, and eliminating discomfort and pain related to physical, spiritual, and psychosocial distress. As such, it is unlike other forms of healthcare treatment, yet little consideration is given to the unique impact laws and regulations have on the hospice programs and patients. Time and again, hospice is overlooked and not considered in necessary and beneficial programs, nor is hospice excluded from burdensome unnecessary regulations. The new DOH “lead” will have the authority and jurisdiction to offer insight into all service lines as it relates to the impact on Hospice programs, their patients and their employees. This would include offering “best practices,” “carve-outs,” exemptions, and/or the creation of new beneficial programs that may include Hospice or palliative care services.

Examples: From the onset of the pandemic in March 2020 the official communications from the Department of Health were lacking in direction and support to hospices. For example,

- **Supplies & Testing:** Hospice and palliative care providers faced widespread challenges in obtaining needed personal protective equipment (PPE) including appropriate masks, isolation gowns, face shields, and goggles as they were not considered essential personnel.
- **Vaccination:** Hospice workers were not eligible for the COVID19 vaccine until January 4th 2020, which was 4 weeks after the vaccination distribution began.

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- Access to Patients: Hospice providers continue to report facing difficulty seeing patients who are enrolled in hospice care who reside in nursing homes and other facilities because of conflicting and confusing guidance from the DOH on hospice as essential workers vs. visitors.

Other examples:

- The lack of consideration in Opioid and other drug bills on hospice and palliative care patients negate the patient’s pain management needs and end of life circumstances already being managed by qualified medical professionals.
- There remains confusion between hospices and MLTCPs related to admission practices and responsibility for payment for aide level services. The billing guidance issued in the past provided contradictory information, and the enrollment process which is still unclear, remains an impediment to hospice selection.

2. *Universal Use of Hospice Residential Beds*

Rationale: New York Public Health Law, Article 40, declares hospice programs to be a socially and financially beneficial alternative to conventional curative care for those afflicted by terminal illness. Although the vast majority of hospice care is provided in the home, there are occasional critical needs for inpatient care and for this reason there are 3 types of hospice physical facilities available. *Hospice Residence Bed Designation:* Hospice facilities can offer care, in a bed with the character and physical structure certified as hospice in-patient residential beds for individuals who are terminally ill to receive end-of-life services and supports in a home-like setting. A place in which to live your final weeks when home is not an option. These programs are paid for by private funds, charity care, and New York State Medicaid at 94% of the Long-Term Care/ Nursing Home rate. There are facilities with *General Inpatient Bed Designation:* Hospice programs built and staffed to provide General Inpatient/(GIP), which provides “hospital level” care paid by the patient’s insurance at a predetermined rate. These stays are generally very short in duration and if the patient stabilizes may return home. Even with a patient who could benefit from a longer stay in the GIP facility under residential care, due to family circumstances and the inability to provide care in the home, the hospice is not allowed under state law to use this bed for residential care. This necessitates a long term care bed placement in a nursing home, often paid for under Medicaid. The third facility type is a *Combined Facility Designation:* When a facility has the ability to have both types of beds, hospice programs are currently limited in the percentage of beds that can be dually certified for either residential level of care or inpatient level of care at 50%. “Swing beds, as they are called, provide the opportunity to offer a higher level of care to patients and avoid hospitalization, or offer a lower level of care thus avoiding nursing home placement. These beds must be built to construction standards for inpatient level of care and comply with Federal regulations ranging from staffing levels to pharmaceutical

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administration. Current law allows facilities to “swing” up to 50% of residential beds to GIP beds after submitting a CON request.

The 50% allowance imposed on hospice programs that separates residential beds from general inpatient beds violates these fundamental principles and goals of end-of-life care. This artificial separation hinders good patient care and prohibits the hospices from having the flexibility to meet the patients’ needs and operate in an efficient manner.

Already a part of Executive Order 202.1, the artificial separation of residential beds from general inpatient beds is removed allowing for increased utilization and improved transitions of care.

There has been no evidence to suggest any negative impact financially or otherwise on the 100% “swing” capability within a hospice facility. Instead, the options avail themselves to quicker discharges from hospitals allowing care to be delivered at the right time in the right setting.

We are requesting the ability for qualified hospice residential beds to be used as hospice inpatient beds and vice-versa 100% of the time to be made permanent allowing the reimbursement to follow the patient not the patient to follow the reimbursement.

3. Allow Emergency Medicaid for Hospice

Rationale: NYS's Medicaid for the Treatment of an Emergency Medical Condition helps eligible, undocumented and temporary immigrant New Yorkers pay for medical costs when an individual needs immediate medical attention for an Emergency Medical Condition. The term "Emergency Medical Condition" is defined as a medical condition (including emergency labor and delivery) that manifests itself by acute symptoms of sufficient severity (including severe pain) such that the absence of immediate medical attention could reasonably be expected to result in:

- Placing the patient's health in serious jeopardy;
- Serious impairment to bodily function; or
- Serious dysfunction of any bodily organ or part.

This definition must be met, after sudden onset of the medical condition, at the time the medical service is provided, or it will **not** be considered an emergency medical condition and therefore, cannot be covered by Medicaid.

As hospice is not an “Emergency Service” under the current definition, and therefore not a covered service, the only option available for an individual eligible for Emergency Medicaid who is terminally ill is ongoing hospitalization, rather than at home or in 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 by avoiding readmission costs. Our proposal in 2019 showed a conservative estimate of \$1.5 to \$2 million savings based on admission and readmission avoidance of the Medicaid only population.

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4. Require DOH to create a payment mechanism for hospice in Assisted Living Programs

Rationale: On December 28, 2019, after being unanimously approved by the NYS Assembly and Senate, Governor Cuomo vetoed bill A.10459-A/S.8353-A, a bill which would have instructed the DOH find a way for Medicaid-eligible assisted living program (ALP) residents to access Hospice services while living in the ALP. Current Medicaid policy prevents terminally ill **Assisted Living Program (ALP)** residents from accessing hospice services, forcing ALP residents in need of hospice services to be transferred to the hospital, a nursing home or to another location in order to receive hospice end of life care. The reasoning provided by the Governor was that a duplication of payment would occur if both the ALP and Hospice were to bill for services for the same person at the same time.

The Governor stated *“it would authorize the commissioner of Health to modify the scope of personal care services under the hospice program without recognizing that such services must be provided in accordance with federal mandated hospice care which DOH does not have the authority to unilaterally change.”* Based on Federal regulations no such adjustment in Personal Care Aide service would be necessary. The Hospice Conditions of Participation: **L635** state

“Services under the Medicaid personal care benefit may be used to the extent that the hospice would routinely use the services of a hospice patient’s family in implementing a patient’s plan of care.”

The services provided by hospice would supplement the ALP services, focusing exclusively on the additional end of life care needs. The ALP would continue to provide all of the services required of the ALP and was provided prior to the need for hospice. The ALP is responsible for room and board, as well as, for all custodial and chronic assistance with Activities of Daily Living (ADLs) all day and every day. The Hospice’s involvement by regulation is limited to supplemental care related to the terminal diagnoses. However, the hospice would take fiscal responsibility for all related medications and DME costs, as well as any additional supports needed as the terminal illness progresses. This is similar to what is currently in existence for residents of nursing homes.

The Governor also stated that hospice services are already available to the individual without a change in locations. However making this happen would require decertifying a Medicaid eligible bed through the ALP to an Enhanced Assisted Residential Living Bed, or to an Assisted Living bed, neither of these options happen in a timely fashion, or without financial considerations to the owners of the ALP’s and are therefore not a true option for the dying individual given when the median hospice length of stay of 18 days.

We respectfully request a full review of the policy and financial implications of making hospice admission possible without changing certification levels. Medicare maximization is an established state policy and when the ALP was created in the early 1990’s, the rates, were set

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with the understanding that Medicare would be the payer for some of the services included in the rate. While the ALP's Medicaid rate includes coverage of skilled services (i.e. nursing) and equipment when Medicaid is responsible to pay, overwhelmingly Hospice services are billed to Medicare. (If in the unlikely event that the resident in the ALP does not have Medicare, the ALP would be responsible to pay for those services from its existing daily rate.) The DOH Budget Office should also take into consideration the cost savings associated with the location of death and the resultant decreased terminal hospitalization costs for the deceased ALP residents.

5. Abolish Skilled Nursing Facility Pass-Through

Rationale. The current hospice payment system does not create an incentive for nursing homes to contract with hospice programs. Under current Medicare regulations, when an SNF resident is admitted to hospice the nursing home must bill the hospice for room and board. The hospice is then required to bill the state for room and board and then reimburse the nursing home. This *pass-through* requirement decreases access to hospice because the delay in reimbursement causes cash flow issues to either the hospice or the SNF. OIG is also concerned that this process leads to double billing as there is no common working file to identify patients enrolled in hospice. NYS should work to obtain a waiver/ State Plan Amendment from CMS to pay the SNF directly when Hospice is involved. Several states have obtained such a waiver including the state of Virginia which could serve as a model.

When an SNF resident is enrolled in hospice the hospice is already “penalized” 5 % of the current Medicaid Room and Board rate. In order to keep the SNF's whole the hospices pay that 5%. By changing the flow of these payments back to the SNF the Association is **not** seeking to have the 5% returned to the Room and Board rate (maintain at 95%), we are seeking only to have the original room and board payment made directly to the SNF to avoid cash flow delays to the nursing homes, decrease accidental double billing of Medicaid, and alleviate the administrative burden on the hospices.

6. Provide Public Education on Advance Care Planning, Hospice and Palliative Care

Rationale:

COVID-19 and the resulting health care crisis has also created an opportunity for policymakers, health care providers, and communities to continue to come together to make sure that everyone has the resources they need to make plans and have hard conversations before a crisis hits. More individuals recognized that they were not prepared or educated about the options that exist to help keep them comfortable through an illness or how to make informed decisions about what treatments they may want to pursue. Advance Care Planning is not just about filling out a form known as an Advance Directive, it includes giving people the tools they need to advocate and educate themselves on the choices that exist for their personal situation and corresponding values. The population with the highest rates of Advance Directive completion are white,

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educated, middle income families, suggesting that those not in this category are not receiving the same level of participation, education, and choice in their health care decision making. Barriers to advance care planning include lack of awareness, denial of death and illness, confusion, and cultural differences for both the individual and the provider. These barriers are best addressed through outreach, education, and discussion. NYS should within its current budget make every effort to designate areas for inclusion of Advance Care Planning education and awareness. The timing is right for such an effort. We support empowering the public with the knowledge, so that they can choose what is right for them.

Suggested Actions:

- *Include Advance Care Planning conversations and education into the Public Health Corp training requirements*
- *Include Advance Care Planning, hospice and palliative care in the health disparities conversation*
- *Create links on NYS various websites to lead people to approved advance care planning educational and document tools.*
- *Support an initiative to create formal partnership, committee, or task force to establish NYS Public Campaign on health care communication and advance care planning.*

The cost savings for Medicaid Hospice patients compared to non-hospice dying patients is \$9,000 nationally. This information should show that advance care planning and the potential for informed choices made available to ALL New Yorkers is the right policy decision from both a moral and fiscal standpoint. On behalf of the hospice and palliative care members of New York State, I thank you for your consideration of these recommendations.

Respectfully Submitted,

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Hospice: A Model for Quality Health Care

- **Person-Centric, Holistic Care.** A plan of care is based on the patient's needs and wishes. This plan is re-visited bi-weekly by the patient and his or her interdisciplinary hospice team. Grief support is an important aspect of the services offered by hospice. After the death, the family is offered bereavement support for at least one year. Such follow-up is not available even in trauma response facilities, where families who have experienced tragedies are sent home with little or no support toward emotional recovery.
- **Comfort-Based.** Hospice puts an emphasis on managing pain and other quality of life symptoms. Quality of life is the guiding goal, and hospices address pain and discomfort on the physical, psychological, social, and spiritual levels using both medical and non-medical interventions, often more effective and cost-efficient than traditional curative healthcare models.
- **Interdisciplinary.** Hospice is required by Medicare to be delivered by an interdisciplinary team, which includes nurses, doctors, health aides, social workers trained volunteers and clergy, and may also include occupational, speech, and physical therapists, and dietitians. The patient and family are the center of the team.
- **“Home”-Based.** In the United States, hospice has evolved to a home-based model. Most hospice patients are cared for at home, where studies have shown most patient prefer to be cared for at the end-of-life. A patient's home may be wherever he or she is living - their private home, a nursing home, or an assisted living facility. When it is not possible for hospice patients to die in what is thought of as their traditional home, they can receive inpatient hospice care in special inpatient units or hospice-contracted beds in hospitals or nursing homes.
- **Efficient, high-quality healthcare.** Hospice patients are supported in a way that reduces emergency room visits and unplanned hospital admissions. While pain management is not a central focus in the health care system at large, hospice clinicians have considerable expertise in managing pain. Hospice contributes to better care, as its presence in nursing homes has been shown to correlate with better performance in pain management compared with nursing homes that do not partner with hospice providers.
- **Ongoing involvement.** Medicare requires that bereavement support be made available to hospice family members for up to a year after a death. Some hospices go even further by offering support groups to the whole community, sponsoring grief camps, and training grief professionals.
- **Cost Effective Care-** not only does hospice enjoy high levels of consumer satisfaction as measured by the publicly available CAHPS surveys on the Medicare Hospice Compare website, hospice care has been proven to bend the cost curve at end of life by the avoidance of the hospital level of care and other ineffective treatments.