



February 22, 2022

Statement in Support
A8880 (Wallace) / S8205 (Hinchey)

An act to amend the Public Health Law, in relation to establishing a statewide advanced care planning campaign to promote public awareness of hospice and palliative care services

New York State has consistently ranked last in the nation in hospice and palliative care utilization metrics for over a decade. One of the most glaring issues leading to this chronic underutilization of vital health care services is a lack of public awareness and education regarding access and choice when confronted with a life-limiting illness. This gap in knowledge leaves many individuals unprepared should they become seriously ill or develop a life-limiting illness, leaving families struggling to ascertain their loved one's values and desires for end-of-life care. Unnecessary medical interventions and rehospitalizations could be avoided if individuals had the foresight to communicate their desires in advance. A statewide advanced care planning (ACP) campaign would promote public awareness and education about advanced care planning tools and the benefits and availability of hospice and palliative care services.

ACP is widely recognized as a way to support patient self-determination, facilitate decision making, and promote better care at the end of life. Although often thought of primarily for terminally ill patients or those with chronic medical conditions, ACP is valuable for everyone, regardless of age or current health status. Planning in advance for decisions about care in the event of a life-threatening illness or injury gives individuals the opportunity to reflect on and express the values they want to have govern their care, to articulate the factors that are important to them for quality of life, and to make clear any preferences they have with respect to specific interventions. Importantly, these discussions also give individuals the opportunity to identify who they would want to make decisions for them should they not have decision-making capacity.

Not only does ACP enable patients and their families to make informed health care decisions, it also supports the delivery of high quality care and more effective utilization of health care services. Studies have also shown that advance care planning improves quality of care and patient outcomes.

A public education campaign would also ensure more equitable distribution of hospice and palliative care services, as there are currently alarming disparities in historically underserved populations in the utilization of hospice and palliative care. Of the 30% of New Yorkers who utilized hospice for end-of-life care, only 9% were Black, 3% Hispanic, and 2% Asian. Public perception of hospice and palliative care in communities of color remains a roadblock to access, along with language barriers and culturally-based apprehension regarding the cessation of curative treatment.

As hospice and palliative care advocates, we are calling for lawmakers to address underlying issues that present barriers to end-of-life care for all New Yorkers. More sustained efforts must be made to reduce disparities in end-of-life care through efforts to better educate and promote the discussion of health care preferences. Every individual facing serious illness or caring for a loved one has a right to receive information about the services they are entitled to under Medicare, Medicaid, and most insurances. Let us do our part to advance conversations to restore and protect access and choice in health care.

An inclusive and culturally-competent public awareness campaign would help close disparities in care and ensure all New Yorkers have access to critical end-of-life services. Restoring and preserving health care rights of all New Yorkers with a life-limiting illness is paramount.

Therefore, the Association strongly supports the prompt passage and enactment of this legislation.

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The Hospice and Palliative Care Association of New York State (HPCANYS) is the only statewide association that exclusively represents the State's licensed hospice providers and palliative care providers, as well as individuals and organizations concerned with care for patients at the end of life. Hospice care is a team-oriented approach to expert medical care, pain management, emotional, and spiritual support expressly tailored to the patient's needs and wishes. Our vision is that all persons who are seriously ill receive a full spectrum of care to maximize their quality of life according to their own values, goals, and preferences.

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