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Steve Smith, MS CAE FAAMSE

June 27, 2025

Michael E. Chernew, Ph.D. Chair Medicare Payment Advisory Commission 425 I Street NW, Suite 701 Washington, DC 20001

Re: Addressing Challenges with the Medicare Hospice Benefit

Dear Chair Chernew:

On behalf of the more than 5,200 members of the American Academy of Hospice and Palliative Medicine (AAHPM), we would like to thank the Medicare Payment Advisory Commission (MedPAC) for examining the issue of care delivery for patients who have elected the Medicare hospice benefit, and in particular their ability to access specialized and/or high-intensity palliative care services, in its April 2025 public meeting. These are among the nation's most frail and vulnerable patients, and it is imperative that they have the ability to live out their last days with dignity, in a manner that honors their care needs, goals, and preferences.

AAHPM is the professional organization for physicians specializing in Hospice and Palliative Medicine. Our membership also includes nurses, social workers, spiritual care providers, and other health professionals deeply committed to improving quality of life for the expanding population of patients facing serious illness as well as their families and caregivers. Together, we strive to advance the field and ensure that patients across all communities and geographies have access to highquality palliative and hospice care.

AAHPM appreciates the Commission's interest in supporting access to specialized services for hospice patients, including those with cancer and end-stage renal disease (ESRD). In particular, we applaud the Commission's focus on supporting patients' ability to exercise patientcentered shared decision making, including to pursue specialized services that may be either palliative or life sustaining, or both, as desired by the patient. Such a patient-centered approach is central to the way hospice care should be delivered. Unfortunately, there are numerous challenges that hospices face in furnishing specialized services for their patients. Moreover, these challenges are exacerbated by fundamental limitations of the hospice benefit itself, underscoring the need for broader reforms. We provide additional detail on these dynamics in our comments below.

# Challenges with and Recommendations for Furnishing High-Intensity Palliative Care Services

AAHPM agrees that hospice patients should be able to access medically necessary palliative care services in a manner that is consistent with their needs and goals and that maximizes their quality of life. However, hospices' ability to furnish high-intensity palliative care services is impeded by a variety of factors, several of which were addressed in the Commission's April discussion. These include:

- Prohibitive costs and financial risk. In too many cases particularly for small hospices and nonprofit hospices – the costs associated with providing higher-intensity services are prohibitive. Hospices take on full coverage and payment risk for providing services related to hospice beneficiaries' terminal illness. However, many hospices serve relatively small patient populations, which does not allow hospices to spread risk. Additionally, the Medicare hospice benefit does not have any payment policies that protect against outlier costs. As a result, one expensive drug or treatment could decimate a small hospice's budget. Hospices must therefore carefully balance patients' palliative care needs and preferences against their own cost management requirements when developing beneficiaries' palliative care treatment plans.
- **Expensive new therapies.** Further exacerbating the challenges that hospices face is the lack of mechanisms within the hospice payment structure to accommodate the addition of expensive new therapies – most of which were not even available when the hospice Medicare benefit was established – that are in no way curative but may help maintain quality of life. Additionally, some Part D drugs that historically had been used as part of curative treatment regimens have transitioned over time to be used as palliative treatments. Hospices had not been responsible for covering such drugs in the past, but the shift to palliative applications has contributed to hospices' increased payment responsibility without commensurate changes to hospice payment. Examples of these costly medications include tetrabenazine, which is palliative for Huntington's disease. A 30-day supply can run anywhere from \$5,000 to \$11,000. Metastatic lung cancer patients now often take erlotinib for palliation, which can cost between \$6,200 and \$,8400 per month. Patients taking one of these may also require a number of other expensive drugs. As a result, patients with a life expectancy that would make them eligible for hospice may not access this supportive care because Medicare hospice payment does not allow some organizations to provide all the medications these patients require to control their symptoms and still remain financially viable.
- Staffing challenges. In addition to financial constraints, staffing challenges limit hospices' ability to furnish advanced therapies, as this requires a sufficiently robust clinical staff to dedicate the time and resources for such therapies. As it is, many hospices are struggling with attracting and retaining sufficient staff to provide even routine hospice services. Moreover, hospices would require both physicians and nurses with the education and experience to safely manage patients

on such therapies, including to address any complications that may arise. Without sufficient resources to support the required level of staffing, hospices will continue to struggle to furnish the services for patients with complex palliative care needs.

• **Contracting challenges.** Finally, we call attention to the fact that many therapies require the participation of other non-hospice providers to furnish the therapies. Partnerships with such providers are particularly necessary given the specialized expertise that some advanced therapies may require. At the same time, hospices often experience difficulties partnering or contracting with such providers. While some hospices have entered into successful partnerships to furnish advanced palliative therapies, many others face difficulty in identifying partners that are willing and/or able to contract for the provision of therapies at reimbursement rates hospices can afford.

Given the above challenges, we appreciate that the Commission is considering options to improve access to high-intensity palliative care services for hospice patients, including potential payment reforms. *As the Commission undertakes this work, we recommend that the Commission adhere to the following principles, which we believe will support the delivery of seamless patient-centered care:* 

- Patients should be free to choose the mix of services they receive based on their individual needs, goals, and preferences;
- Delivery of high-intensity palliative care services should involve both the hospice and non-hospice service provider working together to implement a plan of care; and
- Neither the hospice provider nor non-hospice providers furnishing the high-intensity services should be financially disadvantaged for providing the care.

We envision that furnishing new payments to hospices – in addition to what hospices currently receive – could achieve the desired outcomes. Payments would have to align with the costs of furnishing the high-intensity palliative care services, including costs that hospices incur in coordinating with community providers and managing patients' care. Alternatively, a separate approach – under which Medicare pays providers of such services or treatments directly, rather than requiring hospices to coordinate and pay for services out of the payments they receive – could also address challenges that hospices experience, thereby facilitating access to high-intensity palliative services for hospice beneficiaries.

## Need for Broader Hospice Reform

While ensuring hospice patients' access to specialized palliative care services is imperative, we also highlight that there are additional challenges with the Medicare hospice benefit that underscore the need for broader reforms. These challenges limit patients' ability or willingness to elect hospice, despite the many benefits hospice care offers for patients near the end of life.

Perhaps most notable is the requirement that patients must waive access to all other Medicare services related to the terminal condition. As a result, beneficiaries and their families face a difficult choice. Too often, the desire to continue disease-directed care or certain intensive palliative treatments outside the usual scope of hospice care results in late referrals to hospice. For some, the need to make this choice means never electing hospice. Demonstrated racial and ethnic disparities in hospice use are particularly concerning. For example, <u>studies show</u> that for Black patients, a history of discrimination, structural inequities, and substandard service delivery has resulted in a lack of trust in the medical system associated with a reduced willingness to forgo life-sustaining care and lower enrollment in hospice. As a

result of this benefit requirement, then, many patients do not access hospice services until the last days or hours of life – or not at all – depriving them and their families/caregivers of the supportive care to which they are entitled.

In addition to requirement to forego active treatment, it is worth noting that the population of terminally ill patients enrolled under the Medicare hospice benefit today is very different than in 1983 when the benefit was established, and the care needs for these patients have also evolved. Forty years ago, hospices were largely caring for cancer patients who had fewer treatment options than they do today and for whom the course of illness was relatively certain. Today, patients with Alzheimer's disease and related dementias (ADRD) represent a growing portion of hospice enrollees, and while studies confirm these patients can derive significant <u>benefits</u> from hospice care, their disease trajectory is less predictable, and they are more likely to have longer stays. Unfortunately, current policies are based on a traditional understanding of the hospice patient population, including requirements for a terminal prognosis. As a result, patients who may benefit from hospice care may not be eligible to receive these services.

We also highlight that many aspects of the hospice benefit contribute to exacerbating disparities in care. For example, the hospice benefit was designed with the assumption that a patient has caregivers at home available to provide around-the-clock support to their loved one. However, the realities of today's family structures and work arrangements mean such at-home care is often unavailable. Families may find it difficult to fill in the gaps for a loved one enrolled in hospice, resulting in poorer care and outcomes, and patients without family nearby or otherwise socially isolated simply may not elect the benefit. (One <u>analysis</u> of Medicare data showed that older adults with cancer receiving 40+ hours of unpaid care per week were twice as likely to receive hospice care at the end of life compared to those who received fewer than six hours per week.) Likewise, the payment structure of the hospice benefit is also thought to limit access in rural areas, where hospice availability in is influenced by the lower Medicare payments made to rural providers compared to urban hospice providers. Rural hospice providers face increased costs due to travel distances and greater difficulties in maintaining staff, remaining capitalized, and overcoming economic disadvantages. This all contributes to reduced access to hospice care in rural settings.

AAHPM believes that Medicare beneficiaries in the later stages of serious illness deserve hospice care that meets their needs and provides the services that matter most to them. *To that end, AAHPM supports reforms to the hospice benefit that reduce access barriers and support patient well-being, and we have developed the following principles to guide our engagement on potential reforms to the hospice benefit:* 

- Hospice eligibility should take the needs of seriously ill patients and their caregivers into account and not depend solely on estimated life expectancy
- Beneficiaries should have access to concurrent care and treatments while receiving hospice care
- Hospice care should be provided by a full interdisciplinary team that addresses physical, psychological, social, spiritual, and practical needs
- Hospice payment should be sufficient to support the quality and experience of care that beneficiaries deserve through the later stages of serious illness
- Hospice care should advance health equity and improve access, support, and outcomes for beneficiaries in underserved and low-resource communities

Based on these principles, AAHPM has developed preliminary, high-level recommendations for reforming the Medicare hospice benefit, including recommendations addressing beneficiary eligibility criteria, care team requirements, covered services, payment, and quality measurement and accountability. While we recognize that these recommendations may be beyond the scope of the Commission's engagement on

this issue, we nonetheless share them for your consideration and potential application in future work (see Attachment A).

### Interaction of Hospice with Medicare Advantage

Commissioners raised several questions around the relationship between hospice services and the Medicare Advantage (MA) program. As discussed, the Medicare hospice benefit is carved out of the MA program, and hospice services for MA patients are paid separately under Medicare fee-for-service. However, at least one Commissioner noted support for integrating the hospice benefit into the MA program (i.e., "carving-in" the hospice benefit into MA).

AAHPM has deep concerns around the potential for MA plans to restrict access to hospice care under a carve-in arrangement, including through the imposition of provider network restrictions and prior authorization requirements. We are particularly concerned about the risk of such policies reducing patients' ability and willingness to access high-quality hospice care in a timely manner. If additional consideration of carve-in is pursued, we strongly believe that robust safeguards must be in place.

As the Commission is aware, patients who require hospice are at a particularly stressful and vulnerable point in their lives. The hospice benefit is intended to ease many of their stressors, including pain and other symptoms, thereby contributing to increased comfort and improved quality of life in their final days, weeks, or months. Rather than supporting patients' smooth transition to the hospice benefit, restrictions that MA plans might impose would increase burden for patients, families, and caregivers, restricting access to patients' preferred hospices and requiring patients to jump through administrative hoops to obtain prior authorization for services to which they are entitled. In many cases, the added difficulty could result in patients' death prior to hospice admission. Indeed, one Academy member recounted how 64 percent of her hospice's non-admissions – that is, patients who were referred to her hospice but not admitted – were not admitted because they died prior to a first hospice visit, despite an average referral-to-visit time of 24 hours. If more hurdles are placed in front of patients as they seek to elect hospice, as we fear might happen under an MA carve-in, the proportion of patients who desire hospice but cannot access this vital service could see a troubling rise.

While we understand that network restrictions and prior authorization requirements are customary tools that MA and other health plans implement to manage costs and utilization, we highlight that the application of these tools in the context of hospice care is not comparable to other services for which plans apply these tools. Hospice patients may be at imminent risk of death, with half of patients enrolled in hospice for 18 days or less in 2022, 25 percent of patients enrolled for 5 days or less, and 10 percent of patients enrolled for 2 days or less.<sup>1</sup> This means that, for a substantial proportion of these patients, time is of the essence, and ready access to hospice care must be prioritized. Too often, election of hospice occurs because patients and their families or caregivers are aware of imminent death, and they have a strong desire to choose where the patients will be located when they die – most often in their homes. Honoring their decision-making at this stage is, therefore, of the utmost importance, particularly given the outsized impact of hospice election decisions on the emotional, psychological, and spiritual well-being of patients and their families and caregivers. Unnecessary barriers to patient- or caregiver-directed hospice election decisions, as we expect would happen under an MA carve-in, would place these considerations

<sup>&</sup>lt;sup>1</sup> National Hospice and Palliative Care Organization. NHPCO Facts and Figures: 2024 Edition. September 2024. Accessed from <u>https://allianceforcareathome.org/wp-content/uploads/2024/09/Facts-Figures-2024\_FINAL.pdf</u> on June 7, 2025.

lower on the priority list, and increase the risk of negative – and even harmful – end-of-life experiences for affected beneficiaries.

We therefore believe that the utmost caution is required if Congress, the Centers for Medicare & Medicaid Services (CMS), or the Commission advance any efforts to integrate hospice into the MA program. Among the safeguards that must be in place include prohibitions on prior authorization requirements for innetwork hospice services, or any network restrictions on urgent or emergency out-of-network hospice services. Additionally, hospice service availability should be consistent with services that should be available under fee-for-service Medicare, including with respect to the quality and intensity of services that hospice beneficiaries receive. We provided additional specific recommendations regarding access to hospice services, network restrictions, and prior authorization for hospice care managed by MA plans in our response to CMS' Request for Information on for the Value-Based Insurance Design (VBID) Model (see Attachment B); while we recognize the MA VBID Model has since been terminated, our concerns and recommendations regarding a potential carve-in continue to apply.

## Conclusion

Thank you for considering our comments regarding Medicare hospice services. AAHPM would be pleased to serve as a resource to the Commission as it continues its focus on hospice care, not only as it relates to specialized services, but however the Commission's work unfolds. If you have any questions, please feel free to reach out to Wendy Chill, Director, Health Policy and Government Relations, at <u>wchill@aahpm.org</u> or (847) 375-6733.

Sincerely,

Kristinia Newport, MD, HMDC, FAAHPM Chief Medical Officer, American Academy of Hospice and Palliative Medicine