LeadingAge represents not for profit and similarly mission minded providers of aging services, across the entire continuum of care. Our unique view on hospice issues emanates from our not-for-profit orientation and our emphasis on connections between housing, residential long-term care, and home and community-based services providers.

Below, we present a range of options to inform thinking about the future of the hospice benefit. This includes legislative proposals as well as ideas about ways to engage with CMS about things they could do to improve access to hospice and palliative care. This policy memo seeks to balance “big ideas” such as adding the ability to access concurrent treatments and adding levels of care to hospice with fixes that will make the current hospice benefit work better. We have shared and will continue to share these ideas with interested members of Congress and the Administration as part of our advocacy to improve access to hospice and end of life care. We also look forward to continuing the dialogue with members.

Allowing Concurrent Care with Guardrails

One often mentioned barrier to hospice care is the lack of the availability of concurrent care. LeadingAge members highlighted the challenges that they see with beneficiaries in need of hospice care who have to give up treatments that have a palliative effect. We believe Congress should focus on seeking a solution for hospices not being able to pay for a myriad of effective palliative treatments that are simply too expensive for a hospice, particularly smaller hospices, to cover effectively. Some of these palliative treatments may in fact extend life expectancy, but that does not mean the underlying illness will not ultimately cause death.

Example: A 75-year man in end stage heart failure is admitted to the hospital and given inotropic therapy by infusion. When he entered the hospital, he was basically non ambulatory – after the infusion, his ability to talk, walk, and breathe was much more limited than prior to his hospital admission. His underlying heart failure was not fixed – he is hospice eligible -- but the infusion was improving his quality of life and would likely allow him a higher quality of life for the time he has left. The cost of the infusion drug would be around $150/day; 33-40% of the hospice’s per diem would be spent on one medication.

A number of our members will admit the patient described in the example above; but others cannot afford to and there is not consistency across patients or disease states. There are examples like this one across conditions – including treatments that we often think of as “curative” like chemotherapy (which can be used to shrink a tumor to make a patient more comfortable). Patients with end state renal disease who still are on dialysis almost never receive hospice care because the cost of dialysis is too prohibitive.

The policy goal is that by making it possible for coverage of treatments that have a palliative effect while on hospice will extend the length of stay in hospice care and enable more people to access the benefit in a timely manner. For those who are electing a truly curative treatments (such as a third line
chemotherapy with the intent to cure the disease), we recommend that the billing remain the same while fixing issues with Part B palliative care to enable a more holistic experience (see palliative care section below).

LeadingAge recommends:

**MAKE PALLIATIVE CARE FINANCIALLY VAILABLE UNDER PART B**

A patient who wants to continue to pursue treatment aimed at “curing” their underlying illness deserves wraparound supportive services. Palliative care and hospice share a philosophical alignment because of the holistic nature to treat the patients’ medical, emotional, and psychosocial need. Many hospices offer palliative care because of the overlapping skillset. Palliative care services should be able to be offered both by hospices and by other providers. Our members across the continuum offer palliative care -- a supportive set of services related to diagnosis of a serious illness and the need for these supportive services – which can be provided inpatient, outpatient, or at home – fluctuate over the course of several years. Palliative care should be available as a distinct service from hospice. The main barriers reported by providers are the lack of adequate payment for palliative services and the lack of consistency across offerings (one palliative care program is one palliative care program).

LeadingAge recommends working to improve access to Part B palliative care through assigning adequate payment to an existing CMS comprehensive management and care coordination methodology. This structure could also be used for palliative care services are also found to be set up as a response to live discharge from hospice, with hospice teams focused on providing continuity of care for people with conditions that cause them to intermittently graduate from and return to hospice eligibility. Treatments aimed at “curing” an illness would still be offered in the same way they are now, but the ability to receive some level of supportive services would be more accessible.

LeadingAge recommends:

- Congress should authorize and appropriate money for an outside group to review literature and data and gather appropriate stakeholders to identify a core set of “outlier” treatments -- common treatments, by condition, that are frequent barriers to electing hospice. This work could be done by the National Academies of Science, Engineering, and Medicine.
- Two payment options
  - Bill these treatments via an outlier payment mechanism – billed to Part B or D or;
  - Increase the per diem to cover the cost of the treatment, managed by the hospice
    - Consider a hybrid that includes both options since smaller hospices might not be well positioned to manage these types of treatments.
  - Payment should account for the cost of increased staffing of complex patients (e.g., needing daily nursing visits to change an infusion pump).

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ADD TO THE HOSPICE LEVELS OF CARE TO ALLOW FOR BETTER HOSPICE CARE

The hospice benefit is designed around four levels of care each of which are assigned a per diem payment – routine home care (RHC), continuous home care (CHC), respite care, and general inpatient care (GIP). In this reform package, LeadingAge recommends that Congress create two new levels of care – a “room and board” level and home respite care. LeadingAge also recommends that Congress modify or instruct CMS to alter the existing levels of care to make them work better for beneficiaries.

Increase access to inpatient hospice care because of the lack of ability or desire to die at home

Dying at home is more complex than it has ever been and puts a huge burden on family caregivers. There is a huge equity lens to consider as well – ranging from the availability of a family caregiver to enable dying at home to having a home to cultural preferences around place of death. Hospitals often refer patients to nursing homes for skilled care because a patient needs a bed and a Part A skilled stay in a nursing home is the only option available.

LeadingAge recommends:

✓ Congress creates a hospice “room and board” level of care that allows for patients to die outside their homes without qualifying for GIP or inpatient respite care.
  o This level of care needs to be flexible enough that it could be used in a hospice residence or inpatient unit but also be used by a hospice to pay for other existing beds for patients that are properly licensed (e.g. nursing homes, assisted living facility, hospital).
  o This additional level would allow individuals without informal caregiver support to access adequate care, as well as helping individuals who do not have a home.
  o Many cultures have preferences to die in a health setting over the home, this new payment level would honor those cultural preferences and potential remove barriers to hospice use and access.

Allow Respite Care to Occur at Home

LeadingAge recommends:

✓ Congress instruct CMS to allow for respite care to occur at home under the respite level of care.
  o A variety of types of professionals to provide the respite care in accordance with the plan of care. For example, respite care could be provided an aide, nurse, or spiritual professional depending on the plan of care, but it might also be a paid individual who stays with the beneficiary while the caregiver runs errands, etc.

AMEND THE CURRENT LEVELS OF CARE TO ENSURE APPROPRIATE ACCESS AND UTILIZATION

General Inpatient Care (GIP)

GIP is a critical component of hospice care and one that needs to be both better defined and more aligned with patient preferences. Regulators and hospices do not have a mutual understanding of GIP
eligibility. Often, a hospice provider will admit someone to GIP that they view as having medically necessity – in an acute pain crisis, for example. The goal of GIP is to stabilize that crisis. Hospice providers today are caught in a Catch-22 – if they do this job well, the patient will be stabilized (e.g. pain controlled) but if the hospice keeps them for even a short period of time after some level of stabilization has been documented, their claims may be rejected for not meeting medical necessity. This problem has reached a point where a hospice may get paid for days 1 and 3 of a GIP stay but not for days 2 and 4—this never happens with ICU care.

LeadingAge recommends:

✓ Congress needs to clarify minimum standards and the intent around the general inpatient level of care and instruct CMS to issue clarifying guidance accordingly for all its contractors and surveyors.
  o While CMS could do this on its own, the lack of a cohesive approach to this level of care indicates that direction from Congress on its intent would help fix issues with this critical part of the benefit.

Continuous Home Care
Continuous home care (CHC) is one of the four levels of hospice care required by Medicare. CHC is primarily nursing care and can be provided to individuals who live at home or in a long-term care facility that does not provide skilled care (e.g., an assisted living center). CHC cannot be provided in a hospital, skilled nursing, or inpatient hospice unit.

The definition of CHC is that the beneficiary receives at least 8 and up to 24 hours of care during a day that is defined as midnight to midnight. If someone’s need for CHC begins at 4:30pm on Friday and the “day” ends at midnight Saturday, the hospice cannot count those Friday hours towards the CHC calculation therefore decreasing access to this level of care.

LeadingAge recommends:

✓ Congress should instruct CMS to fix this issue with CHC so it becomes more accessible to patients and families.
  o They could authorize CHC to be billed within any 24-window (from documentation of onset of need for CHC)
  o Alternatively, CMS could create a modifier to indicate some hours utilized on a second day.

ELIGIBILITY FOR HOSPICE – PROGNOSIS
LeadingAge members are mixed on what to do regarding the prognosis standard. On the one hand, some professionals noted that access to health care benefits based on terminality when diseases do not have a linear trajectory was a mistake from the outset. Others feel very comfortable with the standard and do not see value in a more complex analysis akin to what we see in home health or nursing home settings. It was also noted, regarding clinical tools, that a policymaker could probably ask doctors what their favorite clinical tools are and get a wide variety of answers. The local coverage determinations in hospice are not validated and have not been updated in decades. There is also a lack of knowledge, at
this time, of what the Hospice Outcomes and Patient Evaluation (HOPE) assessment tool will look like. We know one of the goals of the HOPE tool is to provide additional clinical data to inform payment reform, but we are years away from having that data in hand.

One theme that did come out in conversations about the prognosis standard is a desire that hospice eligibility be more translatable across settings and translated into the language of the referring providers. Specifically, as we move toward more accountable care arrangements – whether through Medicare Advantage or Medicare fee-for-service models like Accountable Care Organizations – hospice should be accounted for in risk scoring. Even the Value Based Insurance Design (VBID) model is not applying beneficiary specific risk adjustment to the hospice capitation payment – though it is being applied to the A/B capitation rate that plans are continuing for the first month that a member enrolls in hospice.

LeadingAge recommends:

- Hospices work with payers and partners that judge patients on a risk scoring system, Congress should instruct CMS to build a risk scoring system that takes into account those whose illness is advanced enough for hospice. This, in combination with the HOPE tool, could serve as the basis for a future transition away from the prognostication standard.
- Congress should instruct CMS to work with stakeholders to update the local coverage determinations.

**ADDITIONAL PAYMENT REFORMS**
LeadingAge recommends:

- Deepening the “U-Curve” to put more payment near the front of the benefit to help absorb the cost of short stay patients who are usually the most expensive.
- Studying a setting specific payment adjustment including settings where additional professional staff are available and also responsible for supporting the patient vs. home-based settings where informal caregivers provide unpaid support.
- Eliminate or modify the service intensity add on
  - A Service Intensity Add On is permitted for a social worker or nurse during the last seven days of life. LeadingAge members agree this concept is great, in theory. One challenge with it is the general challenge with prognosis – even at the very end, it can be difficult to tell when the last 7 days will be – a hospice can easily be off by a day or two. We recommend that this could be a place to move money around in the benefit – potentially upfront to help with very short length of stay patients.
  - If it remains, count more professionals count toward the SIA: LPN/LVNs, aides, and spiritual care professionals. These professionals should also be instructed to count in the visits in the last days of life quality measure along with physicians.
NURSING HOMES AND HOSPICE
In discussion around the critical overlap between nursing homes and hospice, one point that came up repeatedly was responsibility. In the current, punitive regulatory world in which nursing homes exist, risking a survey citation because they do not have control over the care a hospice might be providing is a barrier to collaboration. Specific work needs to be done to clarify roles and responsibility for residents who elect hospice – both from a clinical perspective and from an oversight perspective. Neither provider should be freed from responsibility for the patient, but more clarity might increase access and collaboration.

LeadingAge recommends:

✓ Congress should instruct CMS to employ a technical expert panel and/or negotiated rulemaking with hospice and nursing home stakeholders to amend hospice and nursing home survey regulations to ensure that the appropriate entity is responsible, both clinically and from an oversight perspective, for the hospice patient who is also a nursing home resident.

INTEROPERABILITY
LeadingAge believes that federal financial support is necessary to ensure nationwide interoperability of health IT and data exchange and sharing across the care continuum, including technological functionality to improve quality of care, patient safety, and infection control during this pandemic and beyond. Interoperable health IT technology is foundational and a key enabler of data collection and reporting and other models to come.

EDUCATION FOR THE HEALTH CARE SYSTEM AT LARGE TO PROMOTE HOSPICE AND PALLIATIVE CARE
One facet of access is continuing to provide resources and incentives for education for all health and long-term care providers on the benefits of hospice and palliative care. Training in death, dying, the benefits of hospice, the differences between hospice and palliative care, and goals of care conversation skills should be incentivized.

The Palliative Care Education and Training Act (PCHETA) is one example of legislation that focuses on training. But the incentives should go further and should not be punitive – we do not want to promote any further negative associations with this area.

This lack of understanding of the benefits of hospice and how to have a goals of care conversation is pervasive across the health care workforce. For example, we hear from members that when hospice providers contract for aide services (from an agency) or when a hospice patient also receives personal care services (e.g. via a Medicaid waiver), there is often a gap in end of life care knowledge and training.
LeadingAge recommends:

- Congress should
  - Require hospice and palliative care training as part of all alternative payment models;
  - Require training in goals of care conversations, hospice basics, and difference between hospice/palliative care in medical schools, nursing schools, social work schools, etc;
  - Integrate competency in goals of care conversations into quality measurement across all appropriate Medicare and Medicaid settings; and
  - Include requirement for training in hospice and goals of care conversations in training for certified nursing assistants, home health aides, and other care partners.

**Bereavement**

Bereavement care is a critical component of the hospice benefit and high-quality bereavement care should be rewarded.

LeadingAge recommends:

- Congress should authorize study mechanisms to pay for high quality bereavement care, both as part of hospice and in the community,
- Follow up with AHRQ on status of study of bereavement consensus standards funded in Consolidated Appropriations Act, 2023

Please contact Mollie Gurian, VP of Home Based and HCBS Policy at mgurian@Leadingage.org with any questions or comments.