C-TAC
COALITION TO TRANSFORM ADVANCED CARE

May 30, 2023

Chiquita Brooks-LaSure, Administrator
Centers for Medicare & Medicaid Services
Department of Health and Human Services
Attention: CMS-4201-P
P.O. Box 8013
Baltimore, MD 21244

Dear Administrator Brooks-LaSure

Re: Medicare Program; FY 2024 Hospice Wage Index and Payment Rate Update, Hospice Conditions of Participation Updates, Hospice Quality Reporting Program Requirements, and Hospice Certifying Physician Provider Enrollment Requirements

On behalf of the Coalition to Transform Advanced Care (C-TAC), we appreciate the opportunity to provide comments on this proposed rule regarding its effect on those living with serious illness.

C-TAC is a national non-partisan, not-for-profit coalition dedicated to ensuring that all those living with serious illness, especially the sickest and most vulnerable, receive comprehensive, high- quality, person- and family-centered care that is consistent with their goals and values and honors their dignity. C-TAC is made up of over 200 national and regional organizations including patient and consumer advocacy groups, practitioners, health plans, faith-based and community organizations, and others who share a common vision of improving care for serious illness in the U.S.

C-TAC defines serious illness as a health condition that carries a high risk of mortality and either negatively impacts a person's daily function, or quality of life, or excessively strains their family caregivers. This definition has been widely adopted, including by the National Committee for Quality Assurance (NCQA) and the National Quality Forum (NQF).

A history of disenfranchisement has led to healthcare gaps across the country. Per a 2021 Commonwealth report on racial and ethnic health equity, communities of color live fewer years, on average, than white people, are more likely to die from treatable conditions, and are also at

higher risk for many chronic health conditions. For serious illness, the lack of access to health insurance and primary care mean many are diagnosed only at a late or end-stage of illness, when disease-modifying treatment is typically no longer effective. The COVID-19 pandemic has only made things worse, with average life expectancies among these groups falling more sharply compared to white people. Those from historically under-resourced communities who also have serious illness experience poorer care and access, making improving their care a health equity opportunity.

Misleading use of the term "palliative care"

We appreciate that CMS's definition of palliative care includes mention of its being appropriate "throughout the continuum of illness". We therefore disagree with the use of this term on page 34 as synonymous with "comfort care": *Hospice care changes the focus to comfort care (palliative care) for pain relief and symptom management instead of care to cure the patient's illness.* Hospice is that form of palliative care for the end of life but palliative care is not all or only end-of-life care. Per the CMS definition, palliative care can be delivered along with curative care, so this statement is misleading as it stands and should be changed.

We also note with alarm the increasing use in recent CMS proposed rules of the phrase "comfort care". This is a vague and euphemistic term that has no set definition and varies by practice setting. Therefore, we urge CMS to revise language in the final rule to change the statement that palliative care is comfort care, then drop that latter phrase, and only use "palliative care" when what is meant is care earlier in a serious illness. The terms hospice and end-of-life care are better ones to use for care at the end of life.

We are separately in discussions with CMS leadership about this issue as perpetuating the misconception that palliative care is only for dying people limits its access and appeal, which unfortunately denies many its multiple evidence-based benefits.

Request for Information (RFI) on Hospice Utilization; Non-Hospice Spending; Ownership Transparency; and Hospice Election Decision-Making

We appreciate the opportunity to comment on several aspects of this RFI and would say that, overall, CMS needs to keep in mind the great variability among hospice providers and that a "one size fits all" approach is problematic. We also would encourage CMS to use its existing oversight authority rather than adding further regulations since such additional regulations, combined with the enduring staffing and other challenges from the COVID-19 pandemic, are making it increasingly difficult for legitimate hospices to provide quality care.

Here are our responses to select RFI questions:

- Are there any enrollment policies for hospices that may be perceived as restrictive to those beneficiaries that may require higher cost end of life palliative care, such as blood transfusions, chemotherapy, radiation, or dialysis?

Yes, the historic requirement that people forego curative treatment for hospice services makes less and less sense in 2023. Now, as opposed to in the 1980's when the hospice benefit began, there are more treatments for those with serious illness that can both extend their lives meaningfully while also improving their quality of life. These include oncology treatments like palliative chemotherapy, radiation, or immunotherapy. Heart failure treatments such as inotropes can allow people to live more comfortably at home, versus the hospital, for their last weeks or months. The proposed rule's data show low enrollment for those with kidney failure who typically have to forego dialysis to receive hospice care. We therefore recommend CMS explore, to the extent statutorily possible, allowing transitional concurrent care with a separate and additional payment where hospice patients could continue these types of disease-modifying treatments for some period of time so as to increase hospice enrollment and mitigate against the 25% who get it for five days or less.

- Are there any enrollment policies for hospices that may be perceived as restrictive to those beneficiaries that may require higher intensity levels of hospice care?

  Yes. First, the current midnight rule that any continuous care must occur within a 24-hour period starting at midnight is problematic for those patients who may first need such care earlier in a day or the next. Possible solutions include viewing continuous care instead in terms of a set number of hours over a couple of days or even eliminating it and instituting a new "crises" category with an hourly payment that covers however much or little of such emergency end-of-life care as is needed.

  Then, we feel there is ambivalence at CMS regarding General Inpatient Care (GIP). On the one hand, data in this proposed rule shows how few patients receive this level of care. On the other, hospice providers are under great pressure to minimize its use due to concerns about Medicare audits. It is my own clinical experience that many hospital physicians do not understand the criteria for GIP admission and so mistakenly offer this option to families of their dying patients even when such patients do not meet GIP admission criteria. This becomes a problem when such patients arrive at the inpatient hospice unit as one of the first conversations the interdisciplinary team there needs to have with them is that they cannot stay on GIP status and, if the family cannot care for them at home, can only stay at the inpatient unit under routine home care status where the family then has to cover the room and board. (At my Baltimore hospice inpatient unit, this is $300 per day, an unaffordable amount for most families.)

  Finally, we feel that the current hospice benefit's emphasis on care at home is challenging for patients who may not have families or whose families cannot take time away from work or other responsibilities to provide the needed care for them. Many hospices develop ways to provide care at home for patients without caregivers to honor the patient's goal to stay at home and die there. When other options are not available, many families of dying hospital patients feel they have no choice but to choose "rehab" in the nursing home setting instead of hospice. This care provides at least a few days of

the nursing care needed in a skilled setting without requiring the family to pay for room and board. This requirement for family participation therefore reduces access to hospice among under-resourced groups who lack the financial or other resources to provide home-based end-of-life care for their loved ones.

What continued education efforts do hospices take to understand the distinction between curative treatment and complex palliative treatment for services such as chemotherapy, radiation, dialysis, and blood transfusions as it relates to beneficiary eligibility under the hospice benefit?

Related to our comments above, the distinction between curative treatment (a term that was always incorrect regarding those with terminal illness as cure is no longer possible) and complex palliative treatment is going away and it seems hospices make determinations about which of such treatments they can cover based on cost rather than the now old-fashioned curative vs palliative intent distinction.

Additionally, the use of the term "palliative" here is again confusing. The use of that term for such treatments suggests that these are appropriate for hospice patients if they reduce physical suffering or improve quality of life. As such, they should be covered along with other medications and treatments hospice routinely offers. However, a hospice cannot absorb the costs of such treatments without a separate payment. Hospices report that they have patients with monthly medication regimens costing $5,000 to $11,000 and the cost of some chemotherapy or palliative radiation of $8,000 or more per treatment. Those types of costs cannot be covered by even large hospice organizations for an unlimited number of patients who may need them.

We therefore recommend that CMS explore payment options in addition to the hospice daily rate so that such treatments can be offered and paid for. Again, we recommend CMS explore, to the extent statutorily possible, allowing transitional concurrent care with separate payment for concurrent care where hospice patients could continue these types of disease-modifying treatments for some period of time while also receive hospice care. We know that the Medicare Care Choices Model was financially successful in this regard.

- What are reasons why non-hospice spending is growing for beneficiaries who elect hospice? What are ways to ensure that hospice is appropriately covering services under the benefit?

  The increase in non-hospice spending is the result of the combination of more disease-modifying treatments being appropriate for people at the end of life compounded by the lack of adequate communication and information systems to allow hospices to know when their patients are pursuing such non-hospice treatment.

Hospices cannot coordinate non-hospice care if they are unaware of it. And non-hospice providers such as specialists may also be unaware that their patients are enrolled in hospice. We recommend that CMS continue its interoperability efforts so that all providers can be aware of any additional medical care their patients are receiving. Hospice is not officially a total cost of care model so, if that is CMS' intent, the benefit and information systems need to be adjusted to facilitate that.

Interestingly, even if one were to add in the increased non-hospice spending, new national research shows hospice still provides significant cost savings. The research found the total costs of care for Medicare beneficiaries who used hospice was 3.1% lower than those who did not use hospice, and that earlier enrollment in hospice and longer lengths of stay likely reduce overall Medicare spending. The report calculates that this reduction in spending translates to an estimated $3.5 billion less in Medicare outlays for beneficiaries in their last year of life. Some of which would certainly pay for non-hospice care.

- What additional information should CMS or the hospice be required to provide the family/patient about what is and is not covered under the hospice benefit and how should that information be communicated?

  We have mixed feelings about requiring hospices to provide additional information about what is and isn't covered since that needs to occur on a patient-by-patient basis as the patient's disease progresses, rather than making enrollment materials even more detailed. At the same time, we acknowledge that there is patient, family, and clinician unawareness and confusion about what is and isn't covered and so would recommend that CMS try to address this with their information to patients, families, and, importantly, non-hospice health care providers.

- Should information about hospice staffing levels, frequency of hospice staff encounters, or utilization of higher LOC be provided to help patients and their caregivers make informed decisions about hospice selection?

  While patients and families should certainly have access to all the information needed to determine which hospice is best for them, the emergent nature of most hospice admissions makes it unlikely that families are thinking of these factors as they scramble to choose a hospice for their dying loved one. CMS's Hospice handbook could certainly do more to alert them to the importance of such factors. The current handbook has only three paragraphs about choosing a hospice provider and most of those focus on that the hospice be Medicare approved. There is no mention of other quality concerns like staffing, ownership status, or the lack of the full range of hospice levels of care. C-TAC and its members would be happy to work with CMS on how to revise the handbook to address these other important quality areas.

Thank you for the opportunity to comment on this proposed rule. If you have any questions, please contact Marian Grant, Senior Regulatory Advisor, C-TAC, at mgrant@thectac.org .

Sincerely,

Marian Grant

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